

THE ENCULTURATION OF A HEARING FAMILY
WITH A DEAF CHILD: WE ARE ALL LEARNING TO SIGN

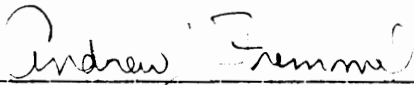
by

Claire M. Waldron

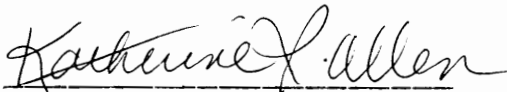
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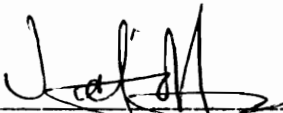
APPROVED:




Andrew J. Stremmel, Ph.D.
Chair



Katherine R. Allen, Ph.D.



Victoria Fu, Ph.D.



Judith Shrum, Ph.D.



Deborah Seyfried, Ph.D.

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by

Claire M. Waldron

Andrew J. Stremmel, Committee Chair

**Department of Family and Child Development
Virginia Polytechnic Institute and State University**

(ABSTRACT)

This study explored the sign language learning experiences and contexts of a hearing family who decided to learn and use American Sign Language (ASL) with their young deaf child. Multiple informants, including family members and professional participants, and multiple methods of data collection and analysis provided accounts of experiences that were examined within the frameworks of family ecology (Bronfenbrenner, 1986) and Vygotskian theory (Vygotsky; 1962, 1978) about language learning in the zone of proximal development.

Previous research regarding sign language learning has looked at language learning within the deaf child, but has not investigated

the language learning context of family members who are hearing.

This study identified a densely connected network of formal and informal service providers that both facilitated and constrained the sign language learning of the child and her family. Even these motivated parents encountered a system of service delivery that essentially ignored the profoundly social process of language learning for both the deaf child who was learning a first language and the family members who were trying to learn a second one. Most of the child's communication-related care in the first year was focused on her hearing loss. Despite the mobilization of effort in response to the child's profound hearing loss, very little of the advice given by most professionals concerned the child's language learning, and even less advice concerned how the family should and could learn sign language.

The persons most influential in helping the family decide how to communicate with the child included the hearing daughter of deaf parents whom the family met through their church, a speech-language pathologist who provided early intervention services in the home, and a preschool teacher for hearing impaired children. While the child's parents, an aunt, and her grandparents have taken a sign language class, other family members rely on the child's mother to

provide them with the language needed for communication with the child during their infrequent visits.

Strategies for improving family sign language learning, including applications from second language learning research and immersion programs, are discussed.

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The Enculturation of a Hearing Family with a Deaf Child: We are all Learning to Sign

Deafness is a paradoxical and complex condition. Damage to just one of the senses, hearing, housed in the tiny and inaccessible cochlea in the bony protection of the skull, can have a devastating impact on human development if special and unusual measures are not taken (Moores, 1987; Nerbonne & Schow, 1989; Rodda & Grove, 1987).

Patterns of occurrence of deafness create paradoxes for deaf children and their families. Deafness can threaten a child's first cultural belongingness, because it can create two cultures within one biologic family. Deaf children face a peculiar social "situatedness," because approximately 90% of them are born to hearing families who have no knowledge of deafness or deaf people (Jensema, 1977; Moores, 1987; Rawlings & Schein, 1987). The threat to belongingness is illustrated by the following case.

In June, 1995, in New Hanover County, North Carolina, the care, custody, and control of a 15 year old deaf girl was awarded to an intervenor who sought custody of the child due to "a material and substantial change in circumstances since the entry of the previous

court order giving custody” to the natural parents (Estes v. Kinney, 1995). The intervenor to whom custody was granted was the woman who served as the deaf child’s sign language interpreter. The case was reported on national television news programs and in newspapers (Deaf girl happier, 1995; Deaf youth, 1995). According to the presiding judge (S. Holt, personal communication, August 25, 1995), several significant issues of neglect, including the natural father’s alcohol abuse and the natural parents’ lack of stable housing, figured into the decision. However, the parents’ inability to communicate with the child using sign language was viewed as a central issue in this custody case; i.e., the custody of two hearing siblings was not contested even though they had been subjected to similar patterns of neglect. The following communication related circumstances were found by the court to be substantial and affecting the welfare of the minor child:

1. The main method of communication of the child, deaf since birth, was American Sign Language. Less than 5% of her communication is accomplished through sound or lipreading. Although both parents had been encouraged and given many opportunities over the years to learn sign language at no cost to them, neither parent ever learned to sign.

2. The child was sexually molested by her stepfather. The child's mother was not able to understand the daughter when she attempted to communicate the incident to her.
3. The child's basic needs, specifically including food, clothing, shelter, medical care, and communication of essential information (e.g., an explanation of menstruation) was provided by others, not by her parents.
4. The child expressed feelings of loneliness and exclusion when residing with her father due to her deafness.
5. The intervenor has the ability to effectively communicate with the minor child and has two daughters who can also sign and communicate with the child.
6. The mother took no action to see that a school interpreter was provided when the child enrolled in public schools.
7. The father testified that he had no desire to use a telecommunication device to communicate by phone with the child.
8. The father could not effectively and extensively communicate with the child without the assistance of others.
9. The father could articulate desires for the future of

his hearing children, but not for his deaf child. He testified that he had never talked to her about what she wants to do when she grows up or her dreams for the future because he cannot sign.

10. The Court found that the father would not be able to help the child deal with any issues that might arise as a result of being molested.

11. The father had been unable to detect that his interpretation of name-calling and joke-telling had not been interpreted in the same way by the child.

12. The father threatened to “ship the child off to a deaf school” even though he knew she had been unhappy there.

Society's views about child welfare evolve in complex political, historical, and economic contexts (Fineman, 1989; Kaplan, 1992; Mintz & Kellogg, 1988; Smart & Sevenhuijsen, 1989). Although the family is still viewed as the institution most responsible for a child's welfare, the definition of a child's well being and the evolving role that the family plays in contributing to that well being are being scrutinized by family scholars (Belsky, 1991; Booth, 1991; Maccoby & Martin, 1983; Sprey, 1991). During the 20th century, many traditional roles of the American family, such as caring for the aged

and educating the young, have shifted to public institutions (Mintz & Kellogg, 1988). However, according to Mintz and Kellogg, the role of the contemporary family has narrowed, and families now concentrate on socializing children and providing emotional support and affection.

The decision in Estes v. Kinney (1995) echoes these expectations regarding the roles of families. This decision recognizes that one of a child's basic needs is communication within the family, and that a child's parents have a responsibility for meeting that need. Additionally, the decision recognizes the futility of fulfilling these responsibilities without a common communication system between parents and children. This decision lent a sense of urgency to this study of family communication choices made by hearing parents of a deaf child.

Initially, the purpose of this study was to find out why hearing parents of deaf children do not learn to use sign language, when their children depend on sign language for social communication and learning. In much qualitative research, the initial question is dynamic, and becomes modified, refined and clarified in the process of collecting and analyzing data (Hammersly & Atkinson, 1983; Johnson, 1992; Miles & Huberman, 1994, Strauss & Corbin, 1990,

1994). In this study, preliminary data collection and analysis caused the research question to be not merely modified and clarified, but completely transposed. Rather than ask why parents do not learn sign language, I had the opportunity to ask why a hearing family does decide to learn sign language to communicate with a young deaf child and to ask about their sign language learning experiences once they made the decision to do so.

The evolution of the research problem addressed in this study will be described following a description of the nature of deafness and the history of responses to it.

The Paradoxical Nature of Deafness

The nature of deafness itself is paradoxical, because it can be viewed as two completely different states of being. First, the historical or traditional view describes deafness as a pathology or disorder of hearing, the most severe end of a continuum of hearing impairment (American Speech-Language-Hearing Association [ASHA], 1982; Wilcox & Corwin, 1990). When viewed as a pathologic condition, deafness is constructed as a general threat to human actualization and as a specific threat to full participation in the majority hearing society.

The second view, more recently emerging, is that deafness is not a pathological condition, but a socio-cultural condition or a signifier of cultural identity, a characteristic that marks cultural membership (Lane, 1984; Moores & Meadow-Orlans, 1990; Padden, 1989; Padden & Humphries, 1989; Wilcox, 1989). This view recognizes that deaf people are different from hearing people, but hold an equally valid view of the world (Wilcox & Corwin, 1990).

Which of these contradictory views is valid? How is it that deafness can be devastating, but need not be? How is it that some people view deafness as a threat to participation in the mainstream, while others view it as an interesting cultural difference? If deafness can be defined so paradoxically, what is the best way to respond to deafness?

Any individual's understanding of deafness and answers to questions such as these are likely to reflect that individual's location in a particular socio-historical and cultural context (Bruner, 1990; Van Cleve, 1993; Vygotsky, 1962, 1978, 1981; Wertsch, 1985a; Wertsch & Minnick, 1991). This study began as an inquiry concerning the language-learning context of deaf children of hearing parents. I wanted to learn more about the paradoxical reactions of some parents to the deafness of a child.

Definition of Deafness

The discussion that follows is intended to define critical terms concerning the nature of deafness and the needs of deaf children and their families who are in the process of learning language.

It may seem obvious that deafness refers to a loss of hearing. However, deaf people, professionals, and hearing lay persons may have different views about the meaning of the term itself. Like Padden and Humphries (1988), I will use the lowercase deaf to refer to the audiological condition of not hearing, and the uppercase Deaf to refer to culturally deaf people who share a language such as American Sign Language. Padden and Humphries point out that Deaf people and both Deaf and deaf. My personal experience is that hearing lay people understand deaf to mean many things, from no hearing at all, to a term that is interchangeable with hearing loss. I find that many lay people use the word death when they mean deaf, as in “I have a death cousin who uses sign language.”

For purposes of this inquiry, deafness is a very specifically defined degree of hearing loss with particular communicative consequences. Hearing impairment can refer to any hearing loss that affects communication or education (Quigley & Paul, 1984), and

millions of Americans, or 6.6% of the population, could be classified as hearing-impaired (Marschark, 1993; Rodda & Grove, 1987).

However, deafness is more narrowly defined according to two criteria: (a) the degree of hearing loss established as a result of audiometric assessment, and (b) the impact that the hearing loss has on a person's ability to process linguistic information auditorily (Nelson, 1993; Northern & Downs, 1991).

Audiometric definition. Audiometric definitions of deafness typically use an unaided pure tone threshold average of 90 dB HL in the better ear as a borderline between being hard of hearing and deaf (Paul & Quigley, 1994; Ross, Brackett, & Maxon, 1991). Many hearing specialists are reluctant to define an audiometric cut-off point between being hard of hearing and deaf, because unaided audiometric threshold configuration alone does not always predict communicative impact or outcome (Northern & Downs, 1991; Roeser & Downs, 1995; Seyfried & Waldron, 1993). With appropriate amplification, some children who meet the audiometric criteria for deafness can have access to sufficient speech information to learn language through the auditory channel (Schow & Nerbonne, 1989).

Functional definition. More importantly, from the traditional perspective, deafness is defined functionally, with specific

reference to its consequences for communication. The simple and traditional definition that “the essential feature of deafness is a physical condition of not being able to hear” (Wilcox & Corwin, 1990, p. 63) fails to make the point that deafness differs qualitatively as well as quantitatively from lesser degrees of hearing loss. Deafness defined qualitatively means hearing that is nonfunctional for ordinary purposes of life (Myklebust, 1960), or hearing that is so disabled as to preclude the ability to hear and understand speech through the ear alone (Moores, 1987; Schein, 1987). Paul and Quigley (1990) defined deafness as a “condition of a person with a severe to profound hearing impairment in the better unaided ear who is dependent on vision for language and communication, even with the use of amplification systems” (p. 266). The American Speech-Language-Hearing Association (ASHA) differentiates deafness from other degrees of hearing loss, defining it as “a hearing disorder which impedes an individual’s communicative performance to the extent that the primary sensory avenue for communication may be other than the auditory channel” (ASHA, 1982, p. 950).

The impact of deafness depends not only on degree of hearing loss and impact on communication learning, but also on its

occurrence chronologically. Children who experience severe to profound hearing loss prelinguistically, that is, before they learn speech and language, are at the highest risk developmentally (Paul & Quigley, 1990). Generally, children whose hearing loss occurs before the age of 2 to 3 years are considered prelinguistically deaf, although the notion that children have basically “acquired language” by age three is now viewed as overly simplistic (Bates & MacWhinney, 1987; Bench, 1992; Nelson, 1993). As Nelson points out, it is now widely accepted that language development occurs over the life span. Older children and adults who experience precipitous loss of hearing may experience some slow decline of speech, and difficulty understanding speech, but language that has been acquired is not lost, and speech remains essentially intact as a means of communicating to others (Seyfried, Hutchinson, & Smith, 1989).

Deaf children are not members of a homogeneous group, yet they share common problems (Marschark, 1993; Moores & Meadow-Orlans, 1990). Early childhood deafness is rare (Moores, 1987) and the small numbers of deaf children scattered throughout the population at large makes deafness research difficult (Moores & Meadow-Orlans, 1990). The study of deafness has revealed, just as for hearing children, that many complex variables account for the

differences in deaf children's developmental outcomes (Bronfenbrenner, 1979). A child's degree of hearing loss, intelligence, familial constellation, geographic location, socioeconomic status, parental education, the existence of concomitant developmental problems, attitudes, family involvement, educational placement and a host of other factors can affect a child's development (Marschark, 1993; Moores & Sweet, 1990; Thompson & Swisher, 1985).

Despite their differences, deaf children do share common problems. They are likely to be socially isolated, do poorly academically, and underachieve vocationally because their communication and language learning is so difficult (Charlson, Strong, & Gold, 1992; Foster, 1989; Moores, 1987; Paul & Quigley, 1990; Quigley & Paul, 1984; Rodda & Grove, 1987).

Deafness alters many fundamentals of the typical language learning environment. Because of their sensory deficit, deaf children of hearing parents may not have significant exposure to any language because the usual input, spoken language, is not accessible to them (Mayberry & Eichen, 1991; Mayberry, 1993). The language input to the deaf child of hearing parents can differ in quantity and quality, not just in the avenue or mode of input. Unlike hearing children who

have access to all the talk around them, including that which is directed to them and to others, deaf children with hearing parents miss interpersonal and adult problem-solving speech (Wilcox & Corwin, 1990). Deafness closes off the speech encoded language that is the means for communicating in hearing families. All language theorists, including Chomsky, Piaget, Skinner, and Vygotsky, agree that a child must be exposed to language in order to learn it (Ratner, 1993). However, deaf children are not exposed to the essential components of spoken language. They cannot hear human speech.

Why and how does not hearing threaten communication?

Bench's (1992) discussion of the interplay between speech perception, language, and cognition summarizes the communication problems of deaf children.

Depending on the degree and type of hearing loss, hearing-impaired children clearly have impaired speech perception. However, the problem does not stop here. Impaired speech perception leads to problems with language acquisition and cognition, which become evident in their communication. Then they encounter difficulties in learning to read and write, since literacy skills depend

on language and cognition. Their knowledge of affairs is reduced, also because of linguistic and cognitive factors. Such factors further deny them the normal range of the relevant metaskills. Again, hearing-impaired children come up against difficulties of a sociolinguistic kind. They have a lessened appreciation of the multifaceted nature of communication in a variety of settings. They also have difficulties in acquiring the usual pragmatic skills. (Bench, 1992, p.21-22)

These difficulties in communication between hearing people and deaf people begin early in the life of a deaf person and continue throughout life, affecting language development, academic achievement, social development and growth, and vocational attainment (Moore & Meadow-Orlans, 1990; Wood, 1992).

Historical Context

School context. In the twentieth century, until the mid 1970s, 85% of deaf children in the United States were educated in schools that used an oral only method of communication; i.e., a method that permitted absolutely no accompanying sign language or manual communication mode (Maestas & Moore & Moore, 1989; Mayberry & Wodlinger-Cohen, 1987). However, the educational and

communicative practices used with deaf children in schools have virtually reversed in the last 20 years (Moore, 1987; Nowell & Marshak, 1994). The extension of a free public education to all children, regardless of handicap (Public Law 94-142), dissatisfaction with the outcome of oral education and better understanding of the linguistic nature of sign language have resulted in a re-emergence of the use of sign language in schools (Mayberry & Wodlinger-Cohen, 1987; Stewart & Akamatsu, 1989).

Estimates vary regarding the current preponderance of teaching methods incorporating manual communication, but data obtained in the 1993-94 Annual Survey of Hearing-Impaired Children and Youth show that 84.08% of the 24,960 children with severe and profound losses were instructed using some form of sign language, either speech and sign (79.36 %) or sign only (4.5%). Only 3,447 children (13.8%) were educated using an oral only approach (Schildroth & Hotto, 1995).

Family context. While the language-learning context of deaf children in schools has reversed from an oral only approach to one using some form of sign language, research shows that this reversal is not mirrored in the family context for many deaf children. In the late 1960s to the mid 1970s, near the beginning of the movement to

use sign language in schools, several studies indicated that more than 80% of hearing parents did not know sign language beyond the use of a few iconic signs (Evans, 1975; Rainer, Altshuler, & Kallman, 1969). In a Canadian study, parents in 120 families of children who used primarily signs (not speech) for communication in schools were surveyed about the type of communication mode used at home (Malkin, Freeman, & Hastings, 1976; cited in Matkin & Matkin, 1985). No one signed in 27% of the families, both parents could sign in only 8% of the families, and, in 20% of the families studied, only one parent had taken a formal sign language course. A more recent survey was distributed to a national sample of 192 families of deaf adolescents (Kluwin & Gaustad, 1991). Families were asked to describe their primary communication mode. The results showed complex patterns of family structure and communication mode use. All family members (mother, father, and siblings) signed in only about one-third (35.42% or 68 of 192) of the families responding. Similarly, the same percentage of families (35.42%) reported that no family members signed. In families with both parents present in the home, 8.3% reported that just one parent signed. In 7.8% of the families responding, siblings were the only family members who signed.

How do such paradoxical situations arise? Why hasn't the language-learning context within the families of deaf children changed to reflect the language-learning context of school? Perhaps the answer to this question is that the response to deafness is historically contentious and paradoxical.

The Paradoxical Response to Deafness

Throughout history, even in Aristotle's time, deafness has been characterized as a threat to speech (Ling; 1976, 1990; Moores, 1987). More recently, given the explosion of knowledge about language acquisition that began in the 1950s and 1960s, deafness has also been understood to threaten language and literacy, particularly if it occurs before a child has heard or acquired spoken language (Ertig, 1992; Kretschmer & Kretschmer, 1990; Mayberry & Eichen, 1991; Paul & Quigley, 1990). Increased understanding about the role of communication in the development of language, cognition, and speech has forced professionals concerned with mitigating the effects of deafness to broaden their focus. Even those who hold diametrically opposed views about the best educational methods for deaf children agree that deafness can be disruptive to ordinary human communication (Calvert, 1984; Cornett, 1985; Ling, 1976;

Pollack, 1984; Rodda & Grove, 1987).

In this country, early efforts to educate deaf children were influenced by the religious paternalism of Yale-educated Connecticut gentry like Thomas Gallaudet (Valentine, 1993). Religion, paternalism, and views about societal class were closely tied to politics of the era, much as they are currently. Valentine (1993) pointed out that to men such as Gallaudet, “interference in the lives of others was proof of an individual’s love of virtue” (p. 61). It was assumed that the less fortunate (e.g., deaf people) would willingly defer to the advice and control of those select prominent few who were chosen by God.

In 19th century America, Darwinian concepts of evolution were applied to language theory, and the result was that sign languages came to be viewed as primitive, inferior to spoken languages, and “fit only for ‘savages’ and not for civilized human beings” (Baynton, 1993, p. 93). Baynton attributed the campaign that successfully replaced manualism with oralism, the educational practice that banned all sign communication, to these evolutionary concepts.

Unlike the view that deafness is a pathologic condition to be cured or fixed, an emerging perspective is that deafness is merely a cultural marker, a difference in how people understand and relate to

the world (Wilcox & Corwin, 1990). Rather than defining deafness as the lack of hearing, this view emphasizes the different sensory avenues and language used by deaf persons for communication. Rather than being described as not hearing, deaf people are described as seeing people, in contrast to hearing people (Bahan, 1989). The non-pathological view of deafness reflects broad and fundamental shifts in theories about human development, philosophic and religious beliefs, changing political and social agendas, and expanded linguistic knowledge about sign language acquisition and use (Baynton, 1993; Bonvillian, Orlansky, & Novack, 1983; Stewart and Akamatsu; 1988; Stokoe, 1960. 1971; Van Cleve, 1993; Wilcox & Corwin, 1990).

Educators and professionals may agree about the potentially devastating impact of deafness and the need for implementing special intervention, but the history of professional response to deafness is fraught with controversy and contradictions.

Roles and Responsibilities: Families and Institutions

The patterns of occurrence of deafness and its effects on human development have evoked a universal urgency to respond, to identify deafness as early as possible, and to intervene (Meadow-Orlans & Steinberg, 1993). The need for early intervention when

deafness has been identified is widely accepted, but paradoxically, little such agreement exists concerning how best to respond and intervene (Bench, 1992; Moores, 1987; Nelson, 1993; Rodda & Grove, 1987).

The intervention paradox is evident when a simple question is asked about the response of social institutions. Who is responsible for responding to a child's deafness? Is the family responsible? The medical establishment? The educational system? The government? Organized religion? The adult Deaf community? The question may be simple to pose, but even a brief historical review reveals surprising answers that are embedded in complex contexts.

A fundamental response to deafness since the sixteenth century has been to construct it as an educational issue (Moores, 1987). Prior to the 1960s, 20th century research focused on academic achievement of deaf children in the context of residential schools for the deaf, but did not investigate deaf children's development in the context of their families (Moores & Meadow-Orlans, 1990). Moores and Meadow-Orlans deplored the absence of family-oriented research:

In fact, educators have taken over for parents, whether at the parents' implicit or explicit request, or because

there seemed to be no educational alternatives. It is relatively recently that residential schools stopped accepting three-year old deaf children as live-in students. (p. 7)

Regardless of any intent to usurp familial authority, the educational system in the United States and elsewhere around the world has played a central role in responding to deafness (McCagg, 1993; Radutsky, 1993; Williams, 1993). However, deaf education is a philosophic and political hot potato. The heat is generated by disagreement about the merits of teaching methods.

Denial and Accommodation

At the heart of the controversy regarding teaching methods is the issue of communication mode. Communication mode can be thought of as the vehicle for transmitting meaning. Modes can include manual, oral, or written language; gestures; or facial expression (Lane & Molyneaux, 1992; Owens, 1992; Nelson, 1993). Specifically in this context, the debate concerns oral versus manual communication modes.

Oralism. Some educators have argued on behalf of oralism, a method that advocates teaching spoken and written English using only lipreading, speech, and use of residual hearing for

communication (Ling, 1984). Oralism, which emerged in the 19th century, became widely acclaimed after the 1880 Congress on the Deaf and Dumb in Milan, Italy (Rodda & Grove, 1987). At the Milan conference, oralists resolved that the pure oral method ought to be preferred because manual signing methods of education injured speech and the precision of ideas (Moores, 1987).

Baynton's (1993) chilling account of the influence of evolutionary theory on sign language as the preferred mode of instruction for deaf children demonstrates how complex value systems influence educational practice (Van Cleve, 1993).

According to Baynton, in the mid 19th century, sign language came to be viewed as lower on the evolutionary scale than speech, and thus associated in the public mind as the language of savages and half-civilized races. Alexander Graham Bell, America's best known oralist, was an extreme Darwinist who feared that intermarriage among deaf people would create a "defective deaf race" (Bahan, 1989; Baynton, 1993). To prevent the creation of a deaf race, Bell advocated closing deaf residential schools to prevent deaf people from meeting, marrying, and having more deaf children. According to Lane (1993), Bell advocated the banishment of sign language, the shunning of deaf teachers, and a model eugenics law that called for

the elimination of socially unfit classes from human stock via sterilization. Although Bell married a deaf woman himself, deaf people were included on his list of the socially unfit. While Baynton (1993) and Lane (1984) have suggested links between oralism and racism, others have objected to oralism on different grounds.

Oralism has been called a denial response to deafness (Rodda & Grove, 1987), because it denies that a sensory avenue has been cut off. Oralism denies that deaf children cannot hear for purposes of communication. In a different sense, and more importantly, oralism denies a deaf child essential human rights to relationships, communication, and accessible language (Johnson, Liddell, & Erting, 1989).

Manualism. In contrast to oralism, the other primary response to deafness can be termed manualism, because it involves communicating with the hands (Paul & Quigley, 1990; Plann, 1993). Throughout history, some educators and policy makers have accepted the sensory limitations of deafness and advocated a visual-manual communication mode, sign language. The prevailing communication mode used educationally in the United States today is Total Communication (TC), an educational philosophy based on manual or signed communication (Marschark, 1993). Unlike oralism which

denied deafness, TC recognizes the need to accommodate the deaf child's sensory differences.

TC was originally conceptualized and promoted in the early 1970s as a civil and human rights issue in response to decades of institutional suppression of deaf children's use of sign language (Johnson, 1989). According to Denton, the Superintendent of the Maryland School for the Deaf, the earliest written definition of TC was constructed to reflect the "right of a deaf child to learn to use all forms of communication available to develop language competence. This includes the full spectrum of language modes: child-devised gestures, speech, formal sign language, fingerspelling, speechreading, and reading and writing" (p. 17). In theory, TC was conceptualized as a multisensory approach that recognizes both manual and oral communication modes as legitimate for deaf children. In practice, however, TC means many different things to many different people, and currently has come to be synonymous with simultaneously signing and speaking English, but not using American Sign Language (Bahan, 1989; Johnson, 1989; Maxwell, 1990; Paul & Quigley, 1990).

Many different manual communication systems have been devised in an attempt to encode English. Adaptations of American

Sign Language signs are put in English word order with English morphologic markers (Easterbrooks, 1987; Gustason, Pfetzing, & Zawolkow,1972; Paul & Quigley, 1990). These systems are referred to as manually coded English (MCE). Many TC programs rely on simultaneous use of signed and spoken English.

Since the mid 1970s, sign language, particularly American Sign Language, has experienced a resurgence in the United States (Stewart & Akamatsu, 1989). American Sign Language (ASL) is a natural visual-spatial sign language whose structure and lexicon are derived in part from French Sign Language introduced in the United States in the early 19th century. ASL is used by an estimated 500,000 Americans as their primary means of communication (Easterbrooks, 1987; Stewart & Akamatsu, 1988). Intense sociolinguistic research, beginning with Stokoe's linguistic analyses in the early 1960s has refuted formerly held views that ASL is a broken or primitive form of English (Stokoe, 1960). The extensive research in the last two decades that legitimizes ASL as a full and complete language has been summarized by Stewart and Akamatsu (1989).

Choices

Deciding upon a mode of communication is one of the most

critical decisions that hearing parents face, since that decision determines how the deaf child will function within the family (Kluwin & Gaustad, 1991) and how the family will function within the larger community (Henderson & Hendershott, 1991). The selection process involves decisions about communication modes (oral or manual) as well as language (ASL or English). The nature of parent-child interaction, schooling, cultural identity, and the fundamental issues of participation in social life hinge on choice of communication mode (Nash & Nash, 1987). The quality of communication between parent and child is significantly related to a child's social maturity (Maccoby, 1992; Paul & Quigley, 1990). Given the paradoxes about deafness, intervention, educational methods, and communication mode choices, the confusion that parents experience is understandable.

From the moment they first suspect deafness, parents are faced with making critical decisions (Schwartz, 1987). They must sort through vast amounts of complex, often contradictory, and emotionally charged information presented by many different professionals who may have diametrically opposed opinions about what is best for the deaf child (Alpiner & McCarthy, 1987; Moses, 1985; Nash & Nash, 1987; Schlesinger, 1985).

In 20 years of clinical practice, I have followed the decision-making journeys of many parents of newly diagnosed deaf children. Their journeys have included visits to overwhelming numbers of health care and educational specialists. Those specialists can include pediatricians or family practitioners, audiologists, otologists, early interventionists, speech-language pathologists, social workers, hearing aid specialists, genetics experts, teachers, educational administrators, and psychologists, all within the span of a few short months. These parents and others like them have received advice and varying degrees of support from specialists, each other, from their families and friends, and even from strangers. They have spent time taking the child to hospitals, clinics, and schools for hearing evaluations, hearing aid fittings, speech-language assessment and treatment, educational and psychological assessments, and medical workups. A deaf child changes a family's ecology (Harvey & Dym; 1987). Families have had to decide how to prioritize and rearrange their lives and adjust their expectations for their child. They have had to decide how to use their time and energy, balancing their own needs with those of the child.

Some experts have urged parents to deny their child's sensory difference, to make their child as "hearing" as possible. Others,

equally well-intentioned, have advised them that using sign language is the only way to communicate with the child. Some experts only present an array of choices and defer any decision making to the parents (Schwartz, 1987; Tranchin et al.,1994). Regardless of philosophical orientation about best methods of educating a deaf child, most experts have stressed the importance of hearing aids and speech and language development and the critical role that parents play in the treatment process (Brown, Maxwell, & Browning, 1990; Watkins & Schow, 1989). How do parents make these decisions?

Research Questions

Original Purpose

Initially, the purpose of this study was to investigate the factors that are involved in hearing parents' choices of communication modes with their deaf children, from the perspective of the parents, not the experts. A particular theoretical standpoint appears to drive professionals' response to deafness (Mayberry & Wodlinger-Cohen, 1987), but there is virtually no literature that describes a theory of response to deafness from parents' point of view. Therefore, I proposed to use grounded theory methodology (Strauss & Corbin, 1990, 1994) to learn why parents would choose

not to sign with a deaf child.

The Situation at Hand

As part of my teaching load in the Fall, 1995, I was assigned the supervision of a clinical case of a 4 year old deaf girl, whom I will call Jena. Her family had decided during her first year of life to use sign language, specifically American Sign Language, as their primary mode of communication with her. Since two graduate students worked with Jena and her 2 year old brother, Mica (who is hearing), I was able to talk with the mother for several hours each week as we watched and participated in hour long sessions. As she began to describe their process of making the decision to use sign language communication with Jena, I began to realize that this child's family represented a negative case for my study, since her hearing parents had decided to use sign with her. Additionally, her case is what Miles and Huberman (1994) call an extreme case; that is, it was a case that provided "highly unusual manifestations of the phenomenon of interest" (p. 28). These unusual manifestations were as follows:

- 1) Jena is completely deaf, with no residual hearing. She does not respond to sound or spoken language with hearing aids or even more powerful FM systems. Communication, specifically

linguistic communication with Jena was possible via visual and tactile, but not auditory sensory systems. Therefore, the issue of depending on residual hearing for communicative purposes or depending on spoken communication is moot.

2) Jena's parents, who are hearing, decided before she was a year old and before the exact nature and extent of her hearing loss were determined, to communicate using American Sign Language rather than an oral method or sign systems that attempt to manually code English; and

3) The parents reported that the whole family, including 2 year old Mica, was learning to use sign language to communicate with her.

It became obvious to me that I was in the midst of what Fonow and Cook (1991) called an "already-given" situation, a highly unusual opportunity to study an otherwise hidden, ongoing event: the sign language learning process and contexts of the deaf child's whole hearing family, including her parents, younger sibling, grandparents, aunts, uncles, and cousins. Using the situation at hand meant transposing the research question.

The Revised and Refocused Research Question

The transposed research question concerns the sign language-

learning contexts of the family of a deaf child. Specifically, the question addressed in this study is “What are the sign language learning experiences and contexts of a hearing family when the parents of a deaf child decide to learn and use American Sign Language?”

Research Stance

According to Punch (1994), the contexts and constraints of politics influence the design and conduct of all social science research. Research concerning deafness is no exception. Historical reactions to deafness have been paradoxical and contradictory. Professionals and parents (mostly hearing people) who have sought to minimize the impact of deafness have agreed that their task is urgent, but they seem to agree on little else. They have been influenced by good intentions, misperceptions, linguistic snobbery, and religious zeal in the course of dramatic and bitter philosophic conflicts involving the education of deaf children and treatment of deaf people in society at large (Baynton, 1993; Lane, 1984; Van Cleve, 1993). Deaf people, like those in other minority groups, have struggled to control their own destinies and gain full participation in society (Wilcox, 1989); but they struggle against past and

prevailing contradictions imposed by the majority group, those who hear.

In the study of deafness, the consumer of research findings is rarely provided with explicit information about the person or persons conducting a study. Reading a study about deafness without knowing the values, perspective and agenda of the researcher(s) confounds the credibility, transferability, and confirmability of the results. Sometimes it is possible to infer what a researcher's perspective is by knowing the history of the institution with which the researcher is affiliated. For example, Central Institute for the Deaf in St. Louis, Missouri, associated with Washington University, has long been identified as an "oral only" program, while Gallaudet University in Washington, D.C., the first liberal arts post-secondary institution for deaf people, has been associated with a combined oral-manual approach and a more culturally sensitive view of deafness (Moores, 1987).

In both quantitative and qualitative inquiry, validity hinges on the measurement instrument. In qualitative research, the major instrument is the researcher (Guba & Lincoln, 1981; Patton, 1990). Given the bitterly dichotomous issues that have characterized deafness research and policy implementation, (Baynton, 1993; Lane,

1984; Van Cleve, 1993), validity is served by describing the researcher and the political contexts and constraints of a study, regardless of the methodology adopted.

The Socially Situated Researcher

Carmel and Monaghan (1991), in an introduction to ethnographic research in Deaf communities, stated that “Researchers must be very careful to contextualize all community work” (p. 416). The following section addresses the context of this study. The research problems addressed in this inquiry have emerged during the course of clinical interactions with parents of many deaf children in addition to Jena and with other professionals involved in their care.

Multiple roles. LaRossa and his colleagues (LaRossa, Bennett, & Gelles; 1981) warned that qualitative researchers must avoid interrogation or lapses into other roles, such as therapist or clinician during data gathering in unstructured interviews. However, in this situation, I was already functioning in the role of clinician and supervisor when I realized the opportunity to function as a researcher as well. Did this situation pose an ethical dilemma? Yes, it did. The nature of the dilemma and its resolution are discussed in more detail in Chapter III, Methodology. At this point, I argue that

conducting research as a clinician is not only ethical, but essential. Other researchers concur.

Miller and Crabtree (1994) see clinical research as the process of patients and clinicians conversing at the wall. They described a figurative wall that refers to the academic jargon and medical traditions that separate clinicians from patients, qualitative from quantitative research, academy from practice. There can also be a literal wall, a structure behind which patients reveal themselves and researchers hide. Miller and Crabtree imagine a clinical research space, a meeting at the wall,

where, in a language understandable by the existing clinical world, a space for more expansive imagination is created, tools for listening and seeing are shared, and transforming stories are enacted. (page 340-341)

Much of my professional experience has involved conversations near a wall like Miller and Crabtree's. I earned a Master's degree in Speech Pathology at the University of Missouri-Columbia in 1972, and worked in public schools in rural Vermont and inner city Miami, then in hospitals in Boston and Florida. Since 1977, I have been employed in university training programs in communication disorders, teaching and supervising the clinical practicum of

graduate and undergraduate students in both speech-language pathology and audiology. I have lived in the larger community where this study was conducted since 1988. In 1990, following two years of part-time, temporary work as a clinical supervisor and instructor in a university communication disorders program, I decided to accept a tenure-track position in that program with the understanding that I would complete a terminal degree. While I was beginning coursework toward a degree in child development, I also had to undertake an intensive, independent study of language development and language disorders. These were the content areas which I had agreed to teach.

Both fields of study led to a much richer understanding of the social and ecologic bases of child development in general, and language development in particular. Earlier in my career, I studied about language development in the child; but, studying Bronfenbrenner (1986), Bruner (1975, 1983, 1990), MacDonald (1989), Snow (1977, 1986), and Vygotsky (1962, 1978, 1981) broadened my understanding of the contextual complexities of development and intervention.

I also learned about a paradigm shift in the methods of conducting research. Observational studies began to emerge,

including ethnographies of communication, studies that targeted language-culture links, language sample analysis, studies that emphasized conversational discourse, and studies that linked literacy practices in homes and communities to language (Heath; 1982, 1983, 1989).

For most of my career, I have had unique opportunities to interview and talk with families of speech, language, and hearing disordered children. Until 1990, when I began to teach more than supervise, most of my time was spent observing diagnostic and therapy sessions conducted by students in a university clinic. I observed sessions from behind a one-way mirror in small, darkened rooms (near the wall) along with the parents and family members of clients. My interactions with many parents began during case history interviews in initial diagnostic sessions. I often participated in the interviews. Our relationships continued as we sat and discussed their children while we watched therapy through this glass wall. The children typically came to clinic for 3 hours each week, for 10 to 15 weeks in a semester. Some children were seen for 4 or 5 semesters of therapy. A conservative estimate of the time I spent with conversing with some families whose children were in therapy would be 40 hours (1 hour per week for 10 weeks for

4 semesters).

These observations reveal that I have spent a significant part of my career learning about parents' perceptions about their children's communication problems and skills, through semi-structured interviews based on case history forms and unstructured conversations over several years' time. I have learned about the figurative wall that separates parents from practitioners. Parents' understandings of their children's communication disorders and needs can vary, from completely in synchrony with professionals to diametrically opposed to professionals. Sometimes parents' understandings and meanings are nearly the same as those of professionals, but more often, they reflect different experience and knowledge about technical terminology and professional jargon. Their knowledge is also based on their ordinary daily routines and responsibilities as the parent of a communicatively handicapped child. My understanding of their perspective unfolded during these talks at the glass wall, and in the hallways and waiting rooms of the clinics, sometimes gradually, sometimes more rapidly, as if a light bulb had been flicked on in a very dark room.

Dissonant expectations. As a clinician, I encountered many families in which hearing parents were not able to communicate

with their deaf children. One father who only came to the clinic for one or two meetings in a year's time indicated that he had not yet learned to use much sign language with his deaf 4 year old son, because the boy only knew 3 or 4 signs and the father understood those. The father expected his son to lead their sign language development and seemed unaware of how delayed his son's language development was. Another mother could verbalize her understanding that her 2 year old son was deaf and could not hear speech, but her actions encoded a far different understanding. I never saw her use more than three or four single signs in an hour of playing with him. She never signed sentences or combinations of signs to him. She did not always make sure that she had her son's visual attention when she did sign. She placed him with a private babysitter who would treat him "just like a normal child." The sitter did not sign, so the child spent 8 hours each day in an environment where language was simply not available to him. The mother did not seem at all concerned about her communication with her son or the son's language development. In other families, I encountered deaf adults with hearing parents and hearing children who were closed off from communicating with everyone in the family because none of the hearing people signed. These situations were completely dissonant

with my expectations about parental roles and responsibilities.

Sign language background. Since the sign language learning of hearing adults is central to this study, it is important to describe my own sign language background. Carmel and Monaghan (1991), noting that ethnographies are the result of interactions between researchers and community members, felt that the nature of the relationships, including the sign language fluency of the researcher, should be described in full. Studies of deafness that describe the sign language learning and competence of the researcher are rare. Reports concerning the quality of language interaction in families with deaf children and hearing parents typically contain only terse descriptions of the investigators' sign language proficiency and background. For example, Bodner-Johnson's (1991) report concerning family conversation style said only that "Hearing graduate students at Gallaudet University who were proficient in sign language transcribed the tapes" (p. 503). Moeller and Luetke-Stahlman (1990) conducted a study of hearing parents' proficiency in using Manually Coded English with their deaf children. The two researchers who transcribed and coded the videotaped samples of interaction were described only as "each fluent in SEE 2." (p. 328).

I first studied sign language in 1975 during a week long class

taught in Boston by Racheal Mayberry, a speech-language pathologist, the daughter of deaf parents. Shortly after she taught this class, Mayberry began doctoral studies and has been an active researcher in the field of deafness (see Mayberry, 1993; Mayberry & Wodlinger-Cohen, 1987; Mayberry, Woodlinger-Cohen, & Goldin-Meadow, 1987; and Mayberry & Eichen, 1991). Mayberry herself does not mention her own language learning background in her research. During that week, I learned fingerspelling, and manually coded English (MCE) as well as some ASL. I learned a lot about the visibility of sign language from the way strangers stared at us when we went out to lunch and signed but did not talk. We were told that after this 5 day workshop, we probably had the signing skills of a 3 year old child.

I used my sign skills only sporadically until I participated in several summer public school programs for hearing impaired children in the late 1980s. I had to teach most of the university practicum students the fundamentals of fingerspelling and signing just before they started these practica working with deaf children. During those summer programs, I could sign to the children, yet I struggled to understand them if they signed very fast or used long sentences. I have taught one or two sections of a 3 credit university

sign language class most semesters since 1988. My approach to teaching sign language has been to stress the interactive aspects of signing and to emphasize the transmission and negotiation of meaning (Hadley, 1993; Johnson, 1992; Oller & Richard-Amato, 1983; 1994; Shrum & Glisan, 1994). I structure the class so that students are rewarded for being persistent communicators; that is, they are allowed and encouraged to ask for clarification until they are sure that they understand any message that any other signer sends. I encourage the students to sign in public so they overcome their inhibitions at using a new language. In the last several years, I have required the students to pick a child's book and read it in sign language to the entire class. I urge them to volunteer as readers for young deaf children in classrooms or libraries. I have not had training as an interpreter in either MCE or ASL, nor do I hold any level of certification at a national or state level for interpreting (Dahl & Wilcox, 1990).

As a sign language learner, I have struggled with the fear of looking foolish, the fear and the reality of being a novice, the fear of failing to communicate, and the fear of being marginalized by members of the Deaf community who really know how to sign. There have been times when I have failed to take the opportunity to strike

up a conversation with a person using sign language, for example, while waiting in line to register at a convention, because I was afraid of not communicating understandably with the person signing. I have felt the frustration of failing to comprehend the signed communications of very young children. My comprehension of signing is heavily dependent upon context, the speed of the other signer, and my own willingness to admit when I do not fully comprehend a message.

Cultural membership. Carol Padden's The Culture of Deaf People (1989) describes values and behaviors that characterize Deaf people. I am hearing, a member of the majority English speaking culture, but I shared some of those values. I value and accept American Sign Language, even though I am not yet fluent in it. I am more comfortable signing without speaking simultaneously. I am intently tuned in to the facial expressions of others and conscious of how I use my own face and body for communicating. I am aware of some of the pragmatics of communicating in sign that Padden mentions from reading and viewing sign language videotapes such as Signing Naturally (Smith, Lentz, & Mikos; 1988). I do not spend much social time with Deaf people outside of work, but being a graduate student, full time university instructor and clinical supervisor, wife

and mother of three children, I do not socialize much at all outside of work.

Perspective and Agenda

As a clinician interested in helping deaf children, I would describe my perspective and clinical agenda as “communication first, because it is the foundation for relationships; language second, because language is the key to literacy, abstract ideas, and access to the world outside of the here and now; and then speech, if it can be attained without threatening communication and language.” I believe that past infancy, communicative success between individuals depends on a shared, mutually intelligible language system. I believe strongly in a parent-centered approach to intervention with deaf children (Dunst, Lowe, & Bartholomew, 1990). As a scholar, I have studied and taught the development of language in both typical and atypical children long enough to appreciate the communicative bases for language, the intertwined development of language and cognition, and the critical role of language competence in literacy development and academic achievement. As both clinician and scholar, I have learned to appreciate the role of parents, caregivers, teachers, and older peers as scaffolders of language and transmitters of culture (Bruner, 1983; Snow, 1986;

Vygotsky, 1978).

To summarize my research stance, I view deafness paradoxically: deafness can be devastating and isolating, but it need not be if a deaf person has a viable communication system within their family and school, fully developed and flexible language capabilities, and full access to literacy. Defining deafness according to a traditional view is not at odds with my view that deafness can be viewed simply as a cultural difference. Deafness can be a pathologic condition when a deaf child's family or professionals ignores the child's unique communicative needs. Communication systems are available that recognize the communicative needs and promote cultural identity for the child who cannot hear and use spoken language (Wilcox & Corwin, 1990; Henderson & Hendershott, 1991). However, information about the process and experience of hearing parents and other family members as they learning those communication systems is not available.

Review of Literature

For centuries, deafness has been constructed as a developmental condition that threatens speech, language, cognition, academic achievement, social and emotional well-being, and vocational attainment (Stokoe, 1993). Research concerning deafness has typically focused on the developmental differences between deaf and hearing populations, and those differences have been attributed to deafness or located within the deaf person. For the most part, the research literature about deafness is a record of the politicized and polarized responses and reactions of educational and medical institutions (Moores, 1987; Van Cleve, 1993). The developmental context of deaf children did not receive much attention until recently (Meadow-Orlans, 1990).

Theoretical Model

Theoretical shifts that have redirected research efforts in academic disciplines such as psychology, sociology, and education are evident in recent studies of deafness as well. Developmental researchers have moved out of the mind of the developing child to investigate the context where development takes place

(Bronfenbrenner, 1979; 1986; Bruner, 1990; Vygotsky, 1962, 1978, 1981; Wertsch, 1985a). The contextualist theoretical models of Vygotsky and Bronfenbrenner provide part of the framework for the questions raised in this study. Vygotsky's theory is salient because of his emphasis on the role of more competent people in the development of children's higher mental functions (especially language). Bronfenbrenner's theoretical framework is salient because it recognizes the complexities and interactions of the multiple ecologies that influence development within family contexts over time.

Vygotsky

L.S. Vygotsky's socio-cultural theory of development has influenced research in deafness and the education of deaf children both directly and indirectly (Jamieson, 1994; Moores, 1987). Like Piaget (1954), Vygotsky viewed the developing child as an active participant in her own development, but Vygotsky was more explicit than Piaget (1954) about the role that adults play in the process (Stremmel, 1993; Stremmel & Fu, 1993; Wertsch, 1985b). Vygotsky's inescapable message was that even though children are active participants in their own development, they cannot develop higher mental functions by themselves (Stremmel, 1993; Stremmel & Fu,

1993; Wertsch, 1991). By higher mental processes, Vygotsky meant not only those that are uniquely human, but more specifically, he meant the mental functioning that is required for formal schooling (Wertsch & Youniss, 1987).

Two themes that appear throughout Vygotsky's work are particularly salient to this investigation. The first theme is expressed in his general genetic law of cultural development:

Any function in the child's cultural development appears twice, or on two planes. First, it appears on the social plane, and then on the psychological plane. First it appears between people as an interpsychological category, and then within the child as an intrapsychological category. This is equally true with regard to voluntary attention, logical memory, the formation of concepts, and the development of volition. Social relations or relations among people genetically underlie all higher functions and their relationships. (Vygotsky, 1981, p, 163)

The second salient theme from Vygotsky's (1962) work is his emphasis on the role of language in development. To Vygotsky, language was a symbol system for mediating, transforming, then internalizing experience. Spoken language first occurs as a social,

communicative function; that is, it occurs first in the intermental plane. A child hears the language spoken by adults during interactions. The developing child gradually begins to use private speech, or talking to herself, as a means of regulating her own behavior. Eventually, private speech is replaced by inner speech, and this process of internalization transforms a child's thinking process. Internalized language frees the child from the immediate context and assumes planning and future directed functions (Vygotsky, 1962).

Vygotsky felt that the transformation of language from a social, communicative function occurring first in the intermental plane between child and adult to an internalized, self-directed, and decontextualized function in the intramental plane provided a paradigm for the relationships between learning and development in general. In his own words,

Language arises initially as a means of communication between the child and the people in his environment.

Only subsequently, upon conversion to internal speech, does it come to organize the child's thought, that is, become an internal function. (Vygotsky, 1978, p. 89)

Vygotsky's influence can be seen in the increasing attention to

and understanding of the role of social interaction in the language and literacy acquisition of hearing children as well as deaf children (Bodner-Johnson, 1991; Ertig, 1992; Jamieson, 1994; Kretschmer & Kretschmer, 1990; Meadow-Orlans, 1990; Wood, 1990). The specific social contextual features of communication practices and language models of parents and teachers of deaf children have been investigated with increasing frequency since the 1960s (Bench, 1992; Goldin-Meadow & Mylander, 1984; Marschark, 1993; Moeller & Luetke-Stahlman, 1990; Schum, 1991).

According to Moores (1987), Vygotsky directly influenced the education of deaf children through his work at the Moscow Institute of Defectology. He was instrumental in the development of a deaf education movement labeled neo-oralism. Neo-oralism, implemented by parents and teachers who spoke and fingerspelled to deaf children at all times, emphasized the need to give deaf children tools of communication, especially expressive communication, at an early age. Another important goal of neo-oralism was to free children and their language from the immediate situation. Moores pointed out that the neo-oralists surprised many Soviet educators because the children they trained became more oral (i.e., had more understandable speech) than other children because they had a

language base and means of communication from an early age. They had the advantage of words to control and direct their actions.

Bronfenbrenner

Another contextualist, Uri Bronfenbrenner (1979, 1986), has conducted research investigating the external influences that affect child development. His work has influenced scholars to investigate the family ecology of deaf children (Bronfenbrenner, 1986; Brown, Maxwell, & Browning; 1990; Greenberg & Marvin, 1979; Hadadian & Rose, 1990; Harvey & Dym, 1987). Bronfenbrenner's research paradigm looks outside the individual at the external influences that affect how families and individuals within families function. His ecologic perspective advocates investigating the complex interactions of features such as social class differences, parental values, and evidence of developmental effects over time rather than conceptualize a simple linear paradigm or relationship between two processes. Bronfenbrenner (1986) described three examples of different environmental systems that can influence families: mesosystem models, exosystem models, and chronosystem models.

A mesosystem analytic model recognizes that events that occur in other settings can influence the developmental process within the family (the principal context for development), just as

the events within the family can affect development in other spheres, such as school (Bronfenbrenner, 1979). Mesosystem investigations would examine the relationships between families and hospitals, day care, children's peer groups, or schools.

An exosystem analytic model considers the effects of environments that are external to the child; for example, parents' world of work or parents' social world. Exosystem investigations have considered relationships between parental employment and family life, child development and parental support networks, and families and communities (Meadow-Orlans & Steinberg, 1993).

The chronosystem model makes possible the examination of developmental influences over time, as seen in the studies of the impact of significant life events and transitions on family processes (Meadow-Orlans, 1990).

Harvey and Dym (1987) applied Bronfenbrenner's ecological model to deafness. They discussed the interactions between multiple, hierarchially "nested" interrelated systemic levels that are relevant to the study of deaf people. In addition to the biological and psychological systems that are traditionally considered, they recommended that family and professional systems, informal networks, and cultural and political systems be considered in the

study of deafness. Noting that the family's behaviors, attitudes, and interactions with the deaf child have powerful influences on the child, Harvey and Dym also noted that the deaf child has a similarly powerful influence on virtually every aspect of family life, including the use of time and space, finances, travel patterns, communication patterns among all family members, and the family's image of itself.

In summary, a contextualist theoretical perspective provides part of the framework for the questions raised in this study. Contextualists have viewed human development in context, at a point in history, and across time. Contextualists advocate researching the process, not simply the product of development (Vygotsky, 1978; Bronfenbrenner, 1986). Additionally, this perspective is concerned with exploring the influences that are external to the child, but instrumental in shaping, directing, leading, or accounting for development.

Socio-cultural Context of Language-learning Children

Exploiting the Zone

Linguistic development in children is promoted when an adult or older peer exploits what Vygotsky (1978) has called the zone of proximal development (ZPD). The ZPD represents the distance

between a child's independent level of functioning or problem solving and the highest level of functioning that the child can achieve with the assistance of an adult or more capable peer. Bruner (1978) referred to the communicative assistance that adults provide to children as scaffolding. Scaffolding in the ZPD allows a child to use language that is more semantically complex and more decontextualized (Norris & Hoffman, 1993). According to Norris and Hoffman, adults "initially provide a relatively high degree of verbal structure that supports attempts made by the child to communicate an idea or to structure some level of discourse" (p. 176). Adults then gradually withdraw the verbal structure as the child internalizes the structure, in literal parallel to a work crew who takes down a scaffold that has allowed them to paint or lay bricks at a level they would not have reached on their own.

Specific adult scaffolding strategies that help move a child along in the ZPD toward internalization of language and independent mastery include (a) providing feedback to questions and comments, (b) providing semantically contingent remarks, (c) providing child with elaborations and extensions of utterances, and (d) modeling explicit and implicit meanings (Norris & Hoffman, 1993). In typical language learning contexts, the adult or older peer leads or pulls the

child along to higher levels of language usage (or mental functioning) in the ZPD by using a more sophisticated language system to engage the child in the negotiation and achievement of mutually understood meaning, or intersubjectivity (Bruner & Haste, 1987; Stremmel & Fu, 1993).

What is the nature of the intermental plane between deaf children and those who structure their context? The socio-cultural experiences of deaf children of hearing parents are likely to be qualitatively and quantitatively different from those of single culture families; i.e., families with hearing children with hearing parents and deaf children with deaf parents (Brown et al,1990; Jamieson, 1994; Meadow-Orlans, Greenberg, & Erting, 1990)

Hearing Children and Hearing Parents

A huge body of literature describes the socio-cultural context specific to language acquisition of hearing children with hearing parents. Research has investigated parental practices with both normal language learners and delayed or atypical language learners (Bruner, 1974/1975, 1975, 1983; Dale, Greenberg, & Crnic, 1987; Hart & Risley, 1992; Maccoby, 1992; MacDonald, 1989; Owens, 1992; Snow, 1977; Wood, 1988). Parental beliefs and practices concerning language acquisition vary widely across cultures and according to

the education and socioeconomic status of the parents (Crago, 1990; Heath, 1989; Schieffelin & Ochs, 1983).

The parent-child interaction that provides a scaffold for language learning is complex and reciprocal, and the affective behavior, timing, and focus of attention of both participants contribute to the interaction (Bronfenbrenner, 1986; Bruner, 1983; Dunst, Lowe, & Bartholomew, 1990). However, Maccoby (1992), in a historical review of the role of parents in the socialization of children, pointed out that the parent-child relationship is uniquely asymmetric: parents have more of the things children want: most notably power and competency. Parents must use their greater strength and power judiciously in order to promote children's development of self-regulating, pro-social behaviors. According to Maccoby, parents' interactions must be adapted to their children's capabilities and current states, tuned to the emotional needs of the child, and planned to extend the child's capabilities.

Research on parental language use and practices shows very consistently that the language used by parents makes a significant difference in a child's language acquisition (Hart & Risley, 1992; Rice, 1989; Ratner & Bruner, 1978; Snow, 1986). Parental communicative practices that facilitate language development

include the use of attention holding speech, talking while jointly attending to events and objects, and talking in frequently experienced situations (Adamson & Bakeman, 1985; Bakeman & Adamson, 1984; Bonvillian, Orlansky, & Novack, 1983; Sachs, 1993).

As children move from non-linguistic to linguistic communication, vocabulary acquisition is facilitated as adults continue to label objects and engage children in naming games (Pease, Berko-Gleason, & Pan, 1993). When adults match their attention to a child's focus of attention, they have achieved the foundation of meaning. When adults comment on the child's focus of interest, they have provided a symbolic means for representing the child's understanding.

Are specific parental linguistic-interactional practices more responsible than others for favorable outcomes in child development? Hart and Risley (1992) investigated that question by observing the unstructured, naturally occurring language learning of 40 children in their homes over 2 and 1/2 years. They sought to identify those aspects of parenting that were stable enough over time to be of importance to child outcome. Items from the HOME Inventory (Bradley & Caldwell, 1984) were selected to indicate parents' presence, interest, responsiveness, and restrictiveness.

Hart and Risley collected data regarding parents' and children's linguistic and communicative practices. They recorded the difference (called distance) between parents' mean length of utterance (MLU) and the mean length of the children's utterances; the number of different words addressed to the children; the parents' use of repetitions, expansions, and extensions; parents' use of questions; the amount of talking that parents did; and the effort parents made to encourage turn taking. Hart & Risley also examined how variation in these parental behaviors was related to child gender and birth order, family size and socioeconomic status (SES), and child IQ at 36 months.

Not surprising, the parents differed greatly on the measures of presence, interest, responsiveness and restrictiveness. Parents' utterances, on average, were longer than the child's by 2 and 1/2 morphemes. Some parents addressed less than 100 different vocabulary words per hour to the child, while others directed almost 500 different words in the same time frame. All parents talked to their children, but a seventeenfold difference was shown in the number of words addressed to the child per hour (from 200 to almost 4000 words). The amount of parent participation in each episode varied widely as well, with some parents engaging in 17

turns per episode, while others engaged in only 2 per episode.

Three parenting factors were derived from a principle-components analysis: amount of parent activity, parents' performance as social partners, and the contentive quality of the parents' utterances to their children. The amount of parent activity was strongly correlated with the existing SES of families. Hart and Risley stated that children from lower SES families received substantially less time and effort from their parents than children of higher SES families. The differences in amount of parenting per hour were strongly correlated with children's IQ measures. The social partner measures were found to be dependent on the child's social behavior, including the clarity and frequency of child initiations and the child's attentiveness to parent utterances, but these measures were only minimally related to child IQ measures.

The findings from this study concerning the quality of the content parents' utterances are important to the subsequent discussion of interaction between hearing parents and deaf children. Strong negative correlations were found between the parents' prohibitions of their children's activities and active listening, extending and expanding utterances, and encouraging the continuation of a conversational episode. In low SES families, a

substantial proportion of parental utterances were prohibitions, while prohibitions were rarely or never heard in higher SES families. Hart & Risley suggested that prohibitions have a toxic effect on child language outcome.

Deaf Children and Deaf Parents

The socio-cultural context of deaf children with deaf parents has been investigated with increasing frequency. Research findings have provided interesting insights about the cognitive and language learning capabilities of deaf children from these monocultural families (deVilliers, Bibeau, Ramos, & Gatty, 1993; Harris, Clibbens, Chasin, & Tibbits, 1989; Mayberry & Wodlinger-Cohen, 1987; Meadow-Orlans, Greenberg, & Ertig, 1984; Zwiebel, 1987).

Deaf children with deaf parents fare better than deaf children with hearing parents in academic achievement, impulse control, and linguistic competence (Balow & Brill, 1975; Harris, 1978; Marschark, 1993). Attachment behaviors of deaf children with deaf parents have been found to be comparable to those of hearing children (Meadow et al., 1984). Marschark (1993) has pointed out that deaf children with deaf parents have an advantage over deaf children with hearing parents in language acquisition through the one-word stage, but soon lose that advantage. Zwiebel (1987) found

that deaf children with deaf parents and siblings (DpDs) performed comparably to hearing subjects on tests of nonverbal intelligence and were superior to deaf subjects with hearing parents and deaf siblings and hearing parents and siblings. Zwiebel's study, completed with Israeli children, was conducted on a large number of children: 23 DpDs, 76 deaf subjects with hearing parents and deaf siblings, 144 deaf subjects with hearing parents and siblings, and 101 normal hearing children. Zwiebel concluded that a manual communication environment, not heredity, was responsible for the superior performance of the deaf children with deaf parents.

Why do deaf children with deaf parents fare better than those with hearing parents? Experts have not reached consensus, but they have speculated that early exposure to natural language in accessible modalities from the very beginning, a shared cultural view of the world, and parental acceptance of deafness are just a few of the complex factors to consider (Moore & Sweet, 1990). Marschark (1993) has speculated that the increased rates of touching, visual stimulation, and facial expression seen in deaf mother-deaf infant dyads can compensate for the absence of auditorily encoded language. Others theorize that the child's exposure to one or more varieties of ASL from a fluent signer

accounts for the difference (Moore & Sweet, 1990).

If more and better language facilitates the language acquisition of hearing children, then it is logical that the quality and quantity of language make a difference to deaf children as well.

Deaf Children and Hearing Parents

Outside the zone. Research concerning the socio-cultural context of deaf children with hearing parents shows that the language-encoded transactions that occur in the intermental plane between parents and their children are likely to be problematic and impoverished (Greenberg, Calderon, & Kushe', 1984; Meadow, Greenberg, Erting, & Carmichael, 1981; Moeller & Luetke-Stahlman, 1990; Swisher & Thompson, 1985; Wendell-Monnig & Lumley, 1980).

As indicated above, parental interactions must be adapted to children's capabilities and current states, but research shows that hearing parents have a difficult time adapting to the deaf child's unique sensory needs (Wood, 1991). Deaf children cannot benefit from overhearing the language that encodes some jointly focused events or object; the linguistic input they need is visual, and they cannot simultaneously focus their visual attention to the face of an interactive partner and a toy or action (Swisher, 1992; Wood, 1992).

A number of studies have shown consistently that hearing

parents of deaf children have difficulty providing linguistic scaffolding. They do not exploit the zone of proximal distance. They struggle to provide their deaf children with language that is increasingly more complex semantically and more decontextualized (Mayberry & Wodlinger-Cohen, 1987; Moeller & Luetke-Stahlman, 1990; Nienhuys, Horsborough, & Cross, 1985; Swisher & Thompson, 1985). In a study describing semantic, pragmatic, and syntactic characteristics of the simultaneous spoken and signed language input of hearing parents to deaf children, Moeller and Luetke-Stahlman (1990) transcribed and analyzed both the spoken and signed language used during play interactions. Parents varied in the extent to which they signed what they spoke, but were consistent in their deletion of morphologic markers, their failure to use possessive pronouns, and their failure to use complex utterances. For example, only 17 of 500 recorded utterances contained complex structures such as conjunctions and complex pronouns and main verbs. All five of the parents in this study had average utterance lengths that were significantly shorter than their children. In the sample of 500 parental utterances, only 2 instances of explicit vocabulary expansion were observed. In short, the parents of the deaf children did not use language to move a child along in the ZPD

toward internalization of language.

Swisher (1992) reported that hearing mothers of profoundly deaf children did not always take the children's dual visual processing requirement into account. Deaf children must look to gathering contextual information from the environment, and they must look at linguistic input. They cannot look at both simultaneously, and their mothers' difficulty with this processing need complicated their turntaking during book reading.

Wood (1991, 1992) has attributed the developmental and educational delays of deaf children not to the children themselves, but to the hearing adults who do not know how to communicate their knowledge, skill, and understanding to the children. Wood (1991) has asked "What effects does childhood deafness exert over the communication skills of hearing people?" (p. 249). He has characterized the adults' role in communication with deaf children, whether the communication takes place in speech or sign supported forms of English, as exerting "too much control" (p. 249). Using Hart and Risley's (1991) term, the interactions between deaf children and hearing parents can be described as toxic, because hearing parents exert more physical control, more prohibitions, more episodes of repair and fewer signs of approval. Wood pointed out that even in

hearing children, the long term effect of an excessively controlling style of parental interaction is a more passive, less motivated, and poorly self-regulated child. Wood's research has shown that when communicating with deaf children, many teachers and parents fail to use language that is complex, abstract, figurative, speculative, or imaginative, regardless of communication mode. These failures do not exploit the zone of proximal development. However, locating these failures in the parents, or in the intermental plane between parents and children may not be any more helpful than locating the problem of deafness in deaf children.

Inside the relationship. In hearing children who are learning language, a parent's being tuned to the emotional needs of a child and responding accordingly facilitates communication (Nelson, 1993). However, research shows that this aspect of communication development is also problematic for deaf children of hearing parents (Greenberg & Marvin, 1979; Lederberg, 1993; Lederberg & Mobley, 1990). Marschark (1993), in a review of early language and the attachment bond in deaf child-hearing mother dyads, summarized the evidence concerning hearing mothers by noting that, relative to mothers in like-hearing dyads, they are more likely to be intrusive, tense, and directive in their interactions. While Lederberg and

Mobley's (1990) study of early attachment behavior showed that secure attachment and maintenance of good mother-child relationships were not dependent on normal language development in a cohort of 41 hearing impaired children, a follow-up study completed when the same children were 3 years old showed that the deaf children were less interactive, compliant, creative, and showed less enjoyment in interactions with their mothers than they had in the first study (Ledeborg, Willis, & Frankel; 1991).

Marschark (1993) and Akamatsu (1994) both suggested that, like children, parents have difficulty continuing an interaction with a non-responsive or sporadically responsive child.

Quantity of input. Mayberry and Wodlinger-Cohen's (1987) research identified not just the kind of communication present in a deaf child's environment, but also the amount of communication that might take place. They refuted the notion that sign language could be used as a safety net later in a child's life if the child failed to acquire language through the oral mode. They pointed out that language must be learned early in life, regardless of the mode, in order to be learned well. They reported that students who received sign input from two adults in the home were more likely to develop better understanding of simultaneous sign and speech than were

students who received sign input from just one adult or none at all. Unfortunately, 54 percent of the deaf students in their study reported that only their mother produced signs with speech, while 23% of the group reported that no one in the family used sign when they spoke.

Quality of input. Henderson and Hendershott (1991) described the impact of deafness from a family systems and social interaction perspective. They pointed out that children who are without language cannot develop their sense of self, and are denied access to the typical familial interaction in which values and an understanding of family and cultural behaviors and customs are learned. Drawing on the literature which documents the educational, social, and communicative superiority of deaf children of deaf parents over the deaf children of hearing parents, they argued that linguistic function and symbolic interaction are pivotal elements in establishing family interaction. Because American Sign Language (ASL) is viewed as one of the defining characteristics of Deaf culture (Padden & Humphries, 1989), Henderson and Hendershott urged increased involvement of the Deaf community in providing training in ASL to hearing families so that symbolic interaction between hearing parents and deaf children can take place more naturally.

The empirical evidence concerning the socio-cultural context of deaf children is, not surprisingly, paradoxical. Concluding that deaf children of hearing parents have language learning experiences that are quantitatively and qualitatively different from hearing children is safe (Akamatsu, 1994; Dalglish, 1975; Paul & Quigley, 1990). As Nelson, Loncke, and Camarata (1992) pointed out, for deaf children as for hearing children, the nature of the language input used by parents and its accessibility to the child makes a difference in the child's acquisition of language. They stated that

the earlier the contact with first signing partners the better the chances of moderate to full mastery of sign language. There now appears little doubt that for many moderately to profoundly deaf children, the best guarantee for the child's acquisition of a complete internal language system is early and regular contact with highly fluent users of genuine sign language. (p.133)

Reflecting back. What do Deaf adults have to say about the socio-cultural context of deaf children? The consensus of deaf adults who were surveyed by Stewart (1983) was that deaf children should learn sign language from an early age and before speech, that language should be acquired bilingually (ASL and English), and that

deaf children should be able to obtain a bilingual education and converse with their teachers in either language. The deaf adults surveyed suggested that the key to language acquisition for a deaf child lies in its practicality for communication.

Intervention. Research shows that children are capable of producing signed language at very early ages (Bonvillian, Orlansky, & Novack, 1983). Comprehensive early intervention programs, such as the one described by Greenberg, Calderon, and Kusche (1984), have been shown to result in more advanced communication skills on the part of children who participated, compared with children in a comparison group. Mothers who participated in intervention, compared to non-participating mothers, were less controlling, more positive, and communicated more messages to their children that were received by their children. Research shows that hearing parents can learn to communicate with their children, using a language that is fully accessible to their children and that allows for satisfying negotiation of meaning (Bodner-Johnson, 1986, 1991; Luetke-Stahlman & Moeller, 1990). The problem is that not enough of them do. Although more parents are learning sign language now, most parents do not. In a recent survey of 105 deaf people whose primary communication mode was sign language, respondents indicated that

two-thirds of the fathers and nearly half of the mother could not communicate with their offspring in sign language (Meyers & Bartee, 1992).

Socio-cultural Context of Hearing Parents of Deaf Children

Context of Parent-Professional Interaction

Coping with a child's deafness depends on full awareness of the reality of the condition, its implications, and its irreversibility (Vernon & Ottinger, 1987). Unfortunately, many professionals involved in the diagnosis and treatment of deafness fail to communicate explicitly about the communication consequences of deafness and the implications of deafness for language development, literacy, parent-child communication, self-actualization, and cultural identity (Meadow-Orlans, 1987; Brown et al., 1990; Rodda & Grove, 1987). The subject matter involved is so complex that the experts themselves sometimes only grasp a piece of the reality of the implications.

Even when parents are given information, the research suggests that they are not able to understand and apply the input given them. For example, parents may understand hearing aid use and use sign language to communicate with their deaf children, but

they still may have difficulty providing the kind of every day language interaction experience recommended by interventionists (Brown, Maxwell, & Browning, 1990).

The research reveals a number of pertinent patterns regarding how parents feel about the help provided to them by experts and what parents understand about hearing loss and hearing aids and the implications of deafness. These patterns offer some indirect explanations for why some parents may chose communication modes that do not provide a child with sufficient language input and interaction.

Questionnaires have been used by a number of researchers to obtain input from parents regarding the counseling they have received in connection with their child's diagnosis of deafness (Kricos, 1993). One survey of parents' satisfaction with services provided by audiologists revealed the need for simplified explanations of complex terms and more written information about hearing impairment (Sweetow & Barrager, 1980). This same study also showed that parents needed more information about techniques for communication with the child as well as more frequent referrals for emotional and financial support.

Parents' satisfaction with a number of professionals involved

in providing services to hearing-impaired children was evaluated in a study by Haas and Crowley (1982). Pediatricians, the first professional consulted by 45% of the parents, were viewed as the least effective in giving parents information. Otologists (physicians who are ear specialists) also received poorer evaluations than deaf educators and audiologists. Parents singled out deaf educators as the most informative about implications of hearing loss.

In general, research shows that parents lack basic understanding of the nature of hearing loss and the implications of hearing loss (Brown et al., 1990; Williams & Darbyshire, 1982). For example, in Williams and Darbyshire's (1982) study, 84% of the parents felt that information presented at the time of diagnosis was not understandable. The overwhelming majority of parents (72%) did not understand what effects the hearing loss might have on their child and 64% of the parents were found not to have a realistic appreciation for the impact of a child's hearing loss on their own lives. Brown, et al. (1990) found that hearing parents were concerned and knowledgeable about hearing aids, but not consistent in gaining the children's attention, explaining situations to children to allay their fears, or setting up ground rules for activities.

Language Learning Contexts

Empirical studies concerning sign language learning or the use of sign language by typical hearing parents, grandparents, other family members, and friends of deaf children are scarce. Available studies do describe the frequency of sign communication of hearing mothers and deaf infants (Spencer, 1993), sign language learning of college students (Hoemann & Kreske, 1995; Lupton & Friscoe, 1992; McKee & McKee, 1992) or state employees who encounter deaf people in their jobs (Klee et al., 1994).

A few studies mention that parents attend sign language classes (Brown et al., 1990; Moeller & Luetke-Stahlman, 1990; Tranchin, 1994). Christensen (1986) described a program designed to improve the conceptual sign language skills of monolingual, Spanish-speaking parents of deaf children who were acquiring basic American signs in their schools. The training was presented via cable television in family's homes. Participating families agreed to view at least one televised 30 minute class once weekly for a 2 year period. The programs provided information in sign language, Spanish, and English. Improved competence in sign language and positive attitudinal changes were reported by the participants. Neither the content nor the teaching strategies of this program were described.

Several studies describe early intervention programs which

included a sign language instruction component (Greenberg, Calderon, & Kusche', 1984; Meadow-Orlans & Steinberg, 1993; Spencer, 1993). These studies focus on quality and frequency of mother-child interaction rather than parents' sign language learning experience. The parents in Spencer's (1993) study participated in programming using signing systems that were based on the structure of Spoken English. The study describes a 9 month portion of the program during which services are provided to families for 3 to 5 hours each week. Sign language instruction was provided along with information about child development and deafness, and play and language activities. Spencer's work offers a rare look at the zone of proximal development of hearing parents. The three mothers in this study who signed the most had the opportunity to sign with another adult (father or babysitter). The support of family members and others was also identified as important to the sign language use of mothers by both Spencer (1993) and Meadow-Orlans and Steinberg (1993).

Moeller (1989) described case studies that emphasized the formidable task of helping parents becoming proficient signers with their children. One parent's sign language learning was inhibited by her lack of acceptance of her child's need to sign, her embarrassment about being the only single parent in a parent

support group, and her lack of confidence in new signing skills. A parent-centered approach rather than a clinician-determined agenda improved services to this family. Moeller also described the need to help a family with conversational interactions even though they had acquired intermediate signing skills. Moeller's work described the family's learning manually coded English.

Swisher and Thompson (1985) also described the difficulties experienced by mothers learning manually coded English. They noted that these mothers are not immersed in a culture of signing adults, because at that time there was no culture of signing adults for whom manually coded English was a first language. With only an hour or two a week of teaching time from a single teacher, a husband who may not sign, other children and only a sign language dictionary, mothers were not progressing in their signing skills. The experience of these mothers was contrasted to an ideal language learning system for learning a foreign language:

In this situation, the learner would be immersed in the target language. She would have multiple sources from whom to learn new vocabulary, and she would be exposed to words in many different contexts and many different styles of speech. She would also need to produce the language in a number of

different situations in order to survive, for example, buying groceries, shopping, asking directions, and interacting socially with peers. Further, her desire to be integrated into the dominant society would provide strong motivation toward the development of native-language like production. (p. 214).

Choices and Attitudes of Hearing Parents

Kluwin and Gaustad (1991) examined why hearing families chose particular communication modes with their deaf children by analyzing responses to a questionnaire distributed to a national sample of families of deaf adolescents. They asked families to describe their primary communication mode as either (a) the use of speech to the deaf student, (b) the use of manual communication (sign) with the student, or (c) the use of some form of communication other than sign or speech with the student

Responses were obtained from 192 families. The results showed complex patterns of family structure and communication mode use. All family members (mother, father, and siblings) signed in only about one-third (35.42 % or 68 of 192) of the families responding. Similarly, the same percentage of families (35.42%) reported that no family members signed. In families with both parents present in the home, 8.3% reported that just one parent

signed. Siblings were the only family members who signed in 7.8% of those responding. Discriminant analyses of the variables influencing family members communication mode choices was completed. Statistically significant variables for mothers included the degree of the child's hearing loss, the mode of communication used in the child's preschool, and the mother's degree of education, with the degree of the child's hearing loss exerting the largest single influence. For fathers, the largest single influence was the mother's mode of communication, followed by the degree of the child's hearing loss and the mode used in the child's preschool. For siblings, mother's communication mode and degree of child's hearing loss exerted the most influence. Neither family ethnicity nor family income were significant statistical predictors of family communication mode choices.

Some studies have attempted to unravel parents' decision-making about communication modes by measuring their attitudes toward deafness and sign language (Hadadian and Rose, 1991; Weisel, Dromi, & Dor, 1990). Weisel et al., (1990) investigated the attitudes of 42 Israeli mothers of deaf children and correlated their responses with measures of the child's influences on the family's coping and adjustment, the family's sense of coherence, and The Family

Environment Scale. A Likert-type questionnaire was constructed to examine cognitive (what the mothers know or think about sign language), emotional (How the mothers feel about the need to use sign language), and behavioral (how willing and ready the mothers are to use sign language with their child) attitudes.

Their findings showed a relatively high correlation between SES and positive attitudes toward sign. Mothers whose children had more severe hearing loss and more handicapping conditions expressed more positive attitudes toward sign language. Mothers were less ready to adopt sign and had more negative attitudes toward sign if they evaluated their child's hearing loss as less severe. Weisel and colleagues concluded that professionals should provide mothers with accurate information about the severity of the child's hearing loss, particularly with regard to the limitations the child might experience with spoken communication. These authors also suggested a possible explanation for the more positive attitudes among the higher SES mothers; they felt that the mothers tended to perceive their children's conditions more accurately and adjust their communication accordingly. This study corroborated the findings of Kluwin and Gaustad (1991) regarding the influences of mothers' education and the severity of the child's hearing loss on

parents communication choices.

Hadadian and Rose (1991) included both fathers and mothers in their investigation of the relationship of parental attitudes toward deafness and their children's communication skills. Measures included the Attitude to Deafness Scale (Cowen, Bobrove, Rockway, & Stevenson, 1969), The Minnesota Child Development Inventory (MCDI) (Ireton & Thwing, 1974), and an interview form. The MCDI was adapted to accommodate the sign communication mode used by the children. All of the children in the study scored in the normal range of general development, but 29 of the 30 children had expressive language skills that were well below hearing children. Findings indicated that the more negative the fathers' attitudes toward deafness, the lower the child's language comprehension scores. One possible explanation offered for the finding was that the children had more contact with their mothers. Although the fathers and mothers reported similar attitudes toward deafness, the mothers described themselves as being more competent in sign language.

Qualitative Studies of Deafness

Qualitative studies of communication between deaf children and their families are beginning to be published. These studies offer

some insight into the perspective of families of deaf children.

Ethnography, phenomenology, grounded theory, case studies, and life history approaches are represented.

Wilcox and Corwin (1990) described the enculturation of a deaf Korean child who was adopted by American hearing parents. The child in this study had adoptive parents who were experts in communication and sign language. Her mother was a teacher of communicatively disordered children and her father had a Bachelor's degree in sign language interpreting. He was also knowledgeable about Korean and Deaf culture. The child BoMee learned to communicate using both ASL and signed versions of English. Her language learning occurred in a multicultural context, involving hearing and deaf people, Korean and American people, children and adults. This is one of the few studies that address the issue of the sign language proficiency of the hearing parents and the issue of what is communicated to a child. It is an article that describes an ideal socio-cultural environment, particularly an ideal language learning environment, for a deaf child.

Brown et al., (1990), whose description of babysitters' sign language learning was cited earlier, used grounded theory to focus on the relationships of hearing impaired children and their hearing

parents in public. Interviews, field notes, and participant observations were used to learn how the parents socialized their children and dealt with the reactions of others to their children. These researchers discussed the tensions inherent to participant observation: the tradeoffs of more intimate, but more intrusive relationships between the researcher and the participants, and the difficulty of staying neutral but showing interest and concern when the families shared their concerns and asked for advice about their children. The benefit to the researchers is added perspective. Being a participant observer “also put the researcher in the position of the mother, to the extent that she was a hearing woman going along on activities with a hearing impaired child” (p. 46).

Morgan-Redshaw, Wilgosh, and Bibby (1989) used a phenomenological method to study the parental experiences of 5 hearing mothers with deaf adolescent children. Three of the children were educated orally, and two were educated in total communication settings. Analysis of interviews revealed themes of personal growth of the mothers, frustrations from their inability to cure the child’s deafness, and both positive and negative experiences with professionals. Although mothers thought having fluent communication was “absolutely vital in developing meaningful

relationships” (p. 296), they believed that the mode of communication was of “secondary importance” (p. 296).

Thick description in qualitative research is a concrete and detailed account of the the events and people studied, generated by the discovery of “how people’s interaction with each other influences their understandings” (Maxwell, 1990, p.8). The book Deaf Like Me (Spradley & Spradley, 1978) is one the thickest descriptions of the processes of coping with deafness from the perspective of parents. Co-written by a deaf child’s father and her uncle, famous urban anthropologist James P. Spradley (see Spradley, 1979), it describes in detail a family’s coming to terms with their child’s deafness. The parents had no knowledge of deaf people or the implications of deafness until they happened to investigate the first tentative movements by parents of other deaf children toward the use of sign language in the public schools where they lived. Only when their daughter had learned three times as many words in a week via manual communication than she had learned to speak in 5 years did her family begin to understand the differences between speech and language and communication.

The parents portrayed in this book were well educated, concerned about literacy, and had the resources to be committed to

doing whatever was recommended to help their daughter. Unlike many fathers described in the current literature, Lynn's father was involved in the decision making about communication from the beginning. He described the visits to doctors, audiologists, and other experts from his own and from his wife's perspective. Deaf Like Me was published in 1978, and Lynn was educated at a time when oralism was the teaching method used with more than 80 % of deaf children. Her story predates the educational and civil rights movements that made language accessibility such an important issues for deaf children. Many family changes have occurred since Lynn Spradley grew up. A deaf child these days is much more likely to be educated via some form of manual communication now than when Lynn was entering school (Schildroth & Hotto, 1995).

Foster (1989) used ethnographic life history interviews to learn about the ways in which 25 deaf adults perceive, interpret, and organize their life experiences. Analysis of these interviews showed that recurring alienation over a lifetime of interacting with hearing people was a major area of shared experience. The informants shared stories about the impact of family members' choices of communication modes. Most of the informant' parents did not learn manual communication. If family members did use manual

communication, conversations at home were limited by parents' use of fingerspelling or a few basic signs that precluded any real conversations or sharing of information. The following excerpt illustrates the frustration and isolation experienced by the deaf informants in the context of their families:

They were pretty much limited and talked to themselves...For an example, like when we sit down and eat supper, I'd say "What did you say?" and they'd say "Wait a minute." And I'd wait and wait and wait. I'd say "Hey, what are you guys talking about?" They'd say "Wait a minute." And [then] they'd say "Well, what do you want?" You know, they should at least come back and finish the conversation, but they do that over and over and over, so I give up. So I just ignored it and eat. And I'd leave, I'd go out. Almost every day, I always leave. They'd say "Hey, why are you leaving us?" I'd say. "...'Cause you guys don't communicate with me-nothing. So what am I supposed to do?" So I'd go out and visit my deaf friends.Yeah, that's how it's been ever since I was a kid...they always left me out of everything. I needed that communication. You know, I needed to find out a little bit more of what was happening, and I learned from other deaf people. My Mom and Dad didn't teach

me, so the heck with them... (p. 229)

The family communication of the informants was limited by the lack of sign language skills; interaction during family meal times and holiday gatherings, usually traditional events during which intimacy and feelings of being connected are built, was especially difficult.

A second study by Charlson, Strong, and Gold (1992) examined the experiences of 23 high school students identified as "outstandingly successful" by their teachers. Content analysis was used to examine the nature of and sources of isolation among the students and their strategies for overcoming it. Even among these highly successful students, social, communicative, academic, or familial isolation was evident among most, and communication difficulty was identified as the the direct cause of or an exacerbating factor in their isolation. The students' most consistent message to their parents concerned the importance of good communication. The stories of two students stand out. Sonia, whose mother and stepfather speak Spanish but do not sign, lives in an isolated home environment, but wishes that her parents had learned to sign so that she could communicate her feelings and problems and get help from her parents to solve her problems. Sonia eats dinner

alone on the floor while watching captioned television, then reads or plays Nintendo. The videotaped interaction between Sonia and her mother was described as an argument about doing the dishes. Larry, another isolated teenager whose family does not use much sign language, seemed to know very little about his parents' personalities, opinions, insights, or emotions. While he was successful academically, he had problematic relationships with people, particularly in empathy and attachment.

The pervasive isolation and anger experienced by these deaf adults and teenagers makes a compelling case for pursuing the questions in this study. Although these studies gave deaf children a voice, the parents' stories and their communication abilities were not explored.

Research Gaps

While these studies offer beginning insights into the kind of choices parents make, they leave many questions unanswered. Kluwin and Gaustad's (1991) study looked primarily at family variables related to communication mode choices, but it failed to describe how the parents might have tried to learn sign language, or how well they might have signed.

The role of hearing fathers with deaf children is virtually

ignored by researchers. Boss (1987), writing about discovering the premise of family boundary ambiguity, said that, "a family that does not know who is in and who is outside the system will be highly stressed" (p. 154). The fathers she described were outside the system, psychologically absent despite being in an "intact" family, and angry. Similarly, the fathers of deaf children seem to be absent, if not from the families, then certainly from the literature. Fathers are under-represented in the literature in general. Computerized literature searches such as PsychLIT for journal articles concerning studies of parent-child communication between 1987 and 1994 revealed 377 articles concerning mother-child communication, but only 31 articles concerning father-child communication. A total of 1947 articles concerned mother-child relations, but only 439 concerned father-child relations. Sixteen citations were located that concerned deafness and mother-child communication, but no citations were available concerning deafness and father-child communication.

The sign language learning contexts and experiences of hearing grandparents, siblings, aunts, uncles, and cousins in the typical hearing family into which most deaf children are born are unexplored. The sign language contexts and experiences of child care

providers and family friends are not represented in the literature, except for Brown et al. (1991) offered this vivid example of the sign language training of one family's babysitter:

Although finding a babysitter did not appear to be a problem for these parents, they prefer strongly to use the same sitter all the time and they leave very specific instructions. Mrs. Cox uses a college student whose mother works for a government agency for the deaf. The first time she sat with Alice, Mrs. Cox taught her some special signs: "potty," "night, night" and "water." (p. 55)

The child Alice was 5 years old at the time of the study. Three signs seems an insufficient lexical base for even a short term relationship. These researchers also described the difficulties the families encountered in helping their children understand and participate in church.

A major research gap is that studies that do not address parents' experiences learning American Sign Language; most articles discuss parents' learning manually coded English systems.

Summary

In summary, despite dramatic paradigm shifts in the education

of deaf children in the last two decades, the sign language communicative abilities of many hearing parents are not keeping pace with their deaf children. In many families with deaf children, only one, or neither parent signs. Research shows that the parents are not using the type of communicative behaviors that facilitate language with their deaf children. Aside from noting that parents have taken a certain number of sign language classes, reports about hearing parents' use of sign language say little or nothing about who might have taught sign language to the parents, the language teaching strategies of the instructor, or the length of time the parents spend in learning to sign. Sign language learning contexts of siblings, other family members and friends are not discussed in research reports.

Research has identified some of the factors associated with parental communication choices, including mothers' education, the extent of the child's hearing loss, and the mode of communication used in the child's preschool. However, the literature concerning communication choices is typically positivistic, framed from the privileged perspective of the hearing researcher, and unclear about many of the actual language learning experiences and communication practices used by typical hearing parents with deaf children in

naturalistic environments. While research has begun to explore some aspects of parents' perspective about the experience of deafness in the family, the experiences of other family members and community members is ignored.

Interestingly, there are more explicit reports about efforts to teach sign language to chimpanzees and gorillas (Gardner & Gardner, 1975, 1980, 1984; Peng, 1978; Premack, 1971; Premack & Woodruff, 1978; Smith & Miller, 1966; Terrace, 1979, 1980) than efforts to teach sign language to the hearing families into which most deaf children are born.

Method

Object and Method of Inquiry

Case Study

This study is a qualitative inquiry about family communication when parents are hearing and a child is deaf. This study is both an intrinsic and an instrumental case study; intrinsic because I wanted a better understanding of how a deaf child's hearing family learns sign language, and instrumental because I sought insight into the issue of a hearing family's enculturation as sign language users (Stake, 1994, 1995).

Why is this process called enculturation? Padden (1989) described enculturation this way:

Certainly an all-important value of the culture [Deaf people] is respect for one of its major identifying features: American Sign Language. Not all Deaf individuals have native competence in ASL; that is, not all Deaf individuals have learned ASL from their parents as a first language. There are many individuals who become enculturated as Deaf persons and who bring with them a knowledge of some other language, usually English.

(p. 8)

Enculturation, then, involves both an experience (in this case, being

a parent, family member or friend of a deaf child) and a process (learning American Sign Language).

Qualitative research produces findings that are not arrived at by means of statistical procedures or other types of quantification (Strauss & Corbin, 1994). As in quantitative research, approaches, methods, and strategies are varied and should be chosen with the purpose of the research in mind (Tesch, 1990). Since case study is not a methodology, but a choice of object to be studied (Stake, 1994), decisions concerning methodology had to be based on the purpose of the study, the research question, and my own resources.

Grounded Theory

Ethnographically oriented approaches are widely used to study second language acquisition and teaching (Johnson, 1992).

Ethnographic research refers to social research that explores naturalistic phenomena, works with unstructured data, and investigates a case in detail (Atkinson & Hammersley, 1994), but according to Johnson (1992), studies are “not ethnographies unless they involve holistic study of cultural phenomena and cultural interpretations of behavior” (p. 134). Several features of this study are similar to ethnographies, including the exploration of naturalistic phenomena, unstructured data, and investigating a case

in detail. Unlike an ethnography, which would pose descriptive questions about values, beliefs, and practices of a cultural group, this study concerned how a family's experiences have changed over time (Morse, 1994). In qualitative research, terms such as methods and strategies, perspectives and paradigms often appear to be used interchangeably and are easily confused. However, Morse's discussion of different methods and strategies was useful in distinguishing between ethnographic and grounded theory strategies:

If the question concerns the *nature* of the phenomenon, then the answer is best obtained using ethnography. If the question concerns an experience and the phenomenon in question is a process, the method of choice for addressing the question is grounded theory. (p. 223)

This study concerns a family's experience, and language learning is a process that occurs over time. Therefore, grounded theory methodology (Strauss & Corbin, 1990, 1994) was used to answer questions about the processes and experiences of a hearing family learning sign language.

Grounded theory methodology is an inductive approach to exploring experiences and phenomena (Patton, 1990). Patton contrasts the deductive approaches of experimental designs which

specify hypothesized relationships at the beginning of a study, with inductive strategies which allow the “important analysis dimensions to emerge from patterns found in the cases under study without presupposing in advance what the important dimensions will be” (Patton, 1990, p. 44). According to Tesch (1990), grounded theory construction involves the collection of data that are relevant to a particular sociological problem, then the inspection of the data with the purpose of discovering theory or generating hypotheses. A grounded theory is one “that is inductively derived from the study of the phenomenon it represents” (Strauss & Corbin, 1990, p. 23). That is, findings are grounded in the real-world patterns that emerge from the data gathered (Glaser & Strauss, 1967).

The grounded theory approach is a qualitative research method that uses specific procedures for coding data and testing hypotheses generated in the course of an investigation (Strauss & Corbin, 1990, 1994). While the sources of data (interviews, documents, field observations) are similar to those in other qualitative methods, grounded theory methodology is unique in several important ways. Because this method is concerned with generating new theory or elaborating an existing one, data collection and theoretical analysis are intertwined processes that “strive toward *verification*”

(Strauss & Corbin, 1994, p. 274) of hypotheses from the very beginning and throughout a research project.

In grounded theory methodology, the researcher's first task is to identify provisional concepts or categories through a process of open coding of data (Strauss & Corbin, 1990; Tesch, 1990). According to Strauss and Corbin, the next step in coding, called axial coding, involves making connections between categories by identifying the conditions, contexts, action/ interactional strategies, and consequences associated with a phenomenon. Next, selective coding is completed. Selective coding is a process of selecting a core category, and systematically relating it to other categories. Process, or the linking of sequences of action/interaction, is an important part of a grounded theory study. Grounded theory methodology is characterized by the constant making of comparisons in the process of data analysis, and careful recording or memoing concerning the development of coding and analysis patterns (Strauss & Corbin, 1990, 1994).

Original Research Plan

Figure 1 is a graphic display or eco-map (Hartman, 1995) of the original family contexts that I had planned to investigate.

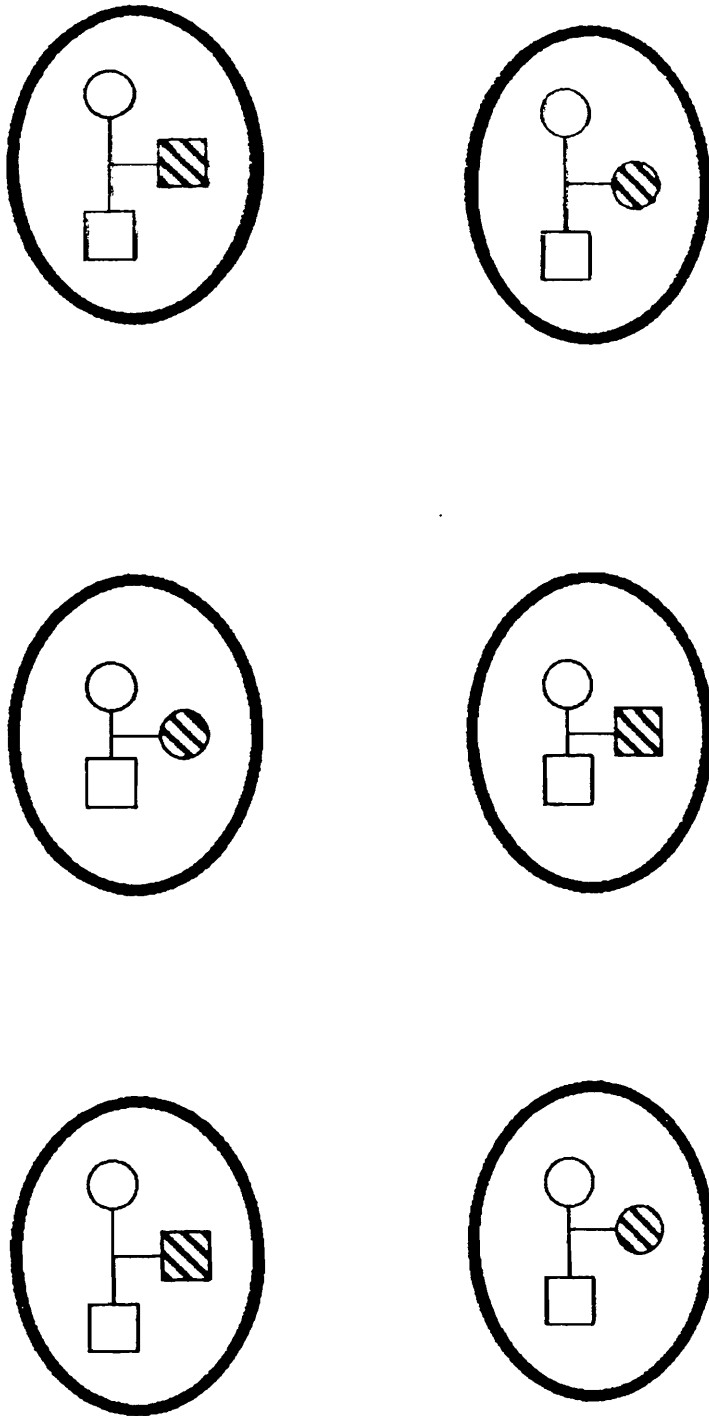


Figure 1 Original Eco-Map

Conjoint interviews would have focused on six sets of parents' and their understanding of communication modes. In the interest of participant confidentiality, I had planned not to interview families who lived locally or in contiguous counties, so I would not have been familiar with the range of educational possibilities, services and service providers. Although I had planned to gather and analyze data from documents provided by each of the six families, I had not planned to interview other family members or professionals who were involved in the child's case. Deaf children are included graphically in Figure 1, but only to indicate the sampling frame of the original design; i.e., hearing parents with a deaf child.

Identifying Participants/Gaining Access

Parents who do not use a communication mode that is used with their child at school could be viewed as non-cooperative by school personnel. It is also possible that these parents feel marginalized in their dealings with school personnel or the school as an institution. John Longwood, an advocate for deaf children whose perspective was sought in the process of gathering pilot data, expressed the belief that "They know they are not doing right" when asked why he thought parents might not learn sign. Therefore, I first attempted to solicit parent participation informally, without

contacting school systems, to avoid being associated with educators who may have already clashed with parents about their communication mode choice.

I began by mailing a packet containing a cover letter (Appendix A), copies of a brief written description of the study (Appendix B), and reply post card (Appendix C) for prospective parents to presidents of National Association of the Deaf (NAD) groups in Virginia, Maryland, The District of Columbia, West Virginia, and North Carolina. The circular contained only a general description of the types of parents (hearing parents with deaf children) being contacted, but it indicated that I was particularly interested in talking with parents who do not sign with their children.

Two weeks following the initial mailing, I communicated again with these NAD presidents. I mailed follow up letters to the individuals for whom no phone listing was available (Appendix D). I obtained the telephone number and address of a deaf advocacy group in Washington, D.C., and mailed the original request letter to the acting director. I telephoned the president of one state group who returned my call via the Virginia Relay System for the Deaf and hard of hearing. He suggested contacting participants through the schools.

This attempt to identify parents was not successful, so I corresponded in writing and by telephone with coordinators of 17 public school programs for the hearing impaired in Virginia and with the two state supported Virginia Schools for the Deaf and Blind (VSDB) in Staunton and Hampton. These programs were listed in the 1995 Reference Issue of the American Annals of the Deaf. After identifying the school official in charge of approving research projects, I sent cover letters (Appendix E), detailed proposals (Appendix F), and multiple copies of circulars and postal reply cards inviting parents' participation to those officials. My invitation to participate was subsequently published in the October 1995, Staunton VSDB parent newsletter. Despite the universal cooperation of school personnel, only three sets of parents responded to these preliminary sampling efforts. Two were parents of local adolescents who attend VSDB. After speaking with me and receiving my letter they expressed no further interest in participating.

Preliminary Data Analysis

Meanwhile, my clinical interactions with Jena, the deaf child described in the Introduction above, suggested that her family represented a negative case for my study, since her hearing parents

had decided to use sign with her. According to Patton (1990), a negative case is one that does not fit within a pattern, one that may be an exception to the rule. I had heard about Jena long before I ever saw her in the clinic, through the professional network. She was never identified by name, and I am not sure who told me about her, but I was struck by the situation because her parents had decided to sign with her at such an early stage in her life, and were resolved that she learn ASL. I interviewed Jena's parents and reviewed many of the documents describing her care. As I talked twice weekly with Jena's mother, read about how important sign language is for deaf children, and wrote in my journal, I began to see just how daunting the enculturation process was for this family who wanted to learn to use manual communication fluently.

Additionally, I began to reconsider the depth of the data I had planned to gather initially. All my years of conversing with client's families several times a week for years had taught me that it took time to understand a family's notions of deafness, language and communication. Each week's meeting with Jena and her family revealed a new layer of complexity, more details to consider, and new mesosystems and exosystems to explore (Bronfenbrenner, 1979, 1986). For example, as I was typing the transcript of my interview

with Jena's parents, I had problems inventing enough pseudonyms for all the family members and professionals who were a part of Jena's life.

Analytic procedures in qualitative methods are interwoven with data collection from the very start of a study (Miles & Huberman, 1994; Patton, 1990). In grounded theory methodology, early analysis usually takes the form of open coding of textual data (Strauss & Corbin, 1990). However, as this case study unfolded, I used another method of early summarizing and thinking about data to depict the complexities of Jena's cultural situatedness and guide further data collection. Graphic displays such as genograms and eco-maps have been used in medical and family therapy settings to represent complex family and social support relationships in a form that is more condensed than text alone (Hartman, 1995; Schilson, Braun, & Hudson, 1993). Therefore, I combined the genogram of three generations of Jena's family with a modified eco-map that included other people and institutions involved in her care. Figure 2 is the preliminary eco-map that resulted. Jena, her brother, mother, and father are represented by the small circles (representing females) and small squares (representing males) within the large heavily outlined circle in the center of the figure. Other family members

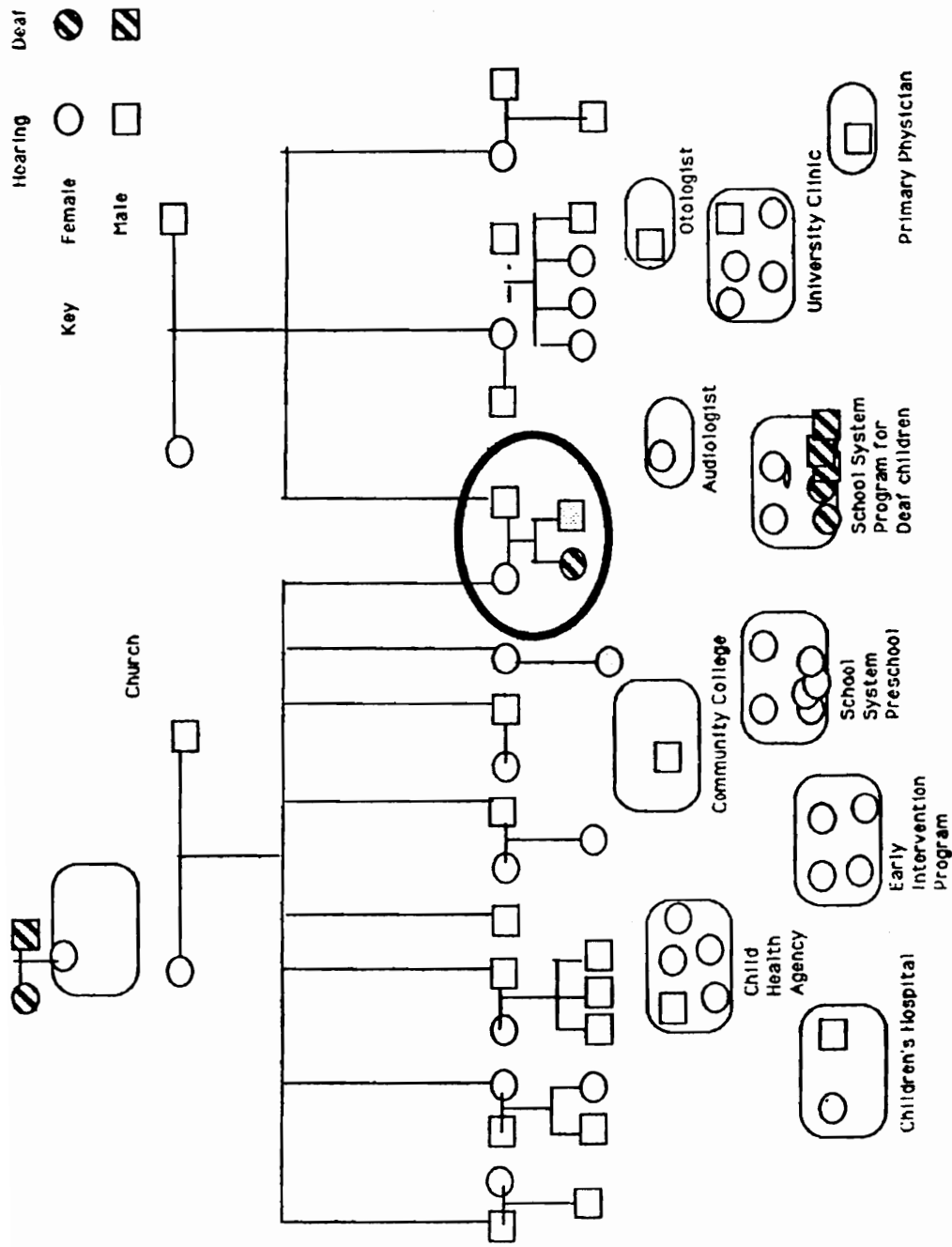


Figure 2 Early Analysis Eco-map

are represented on the genogram. The religious, educational, medical, and social support networks and institutions identified in the preliminary analysis are represented on the eco-map in the form of round-cornered rectangles. The people associated with those networks and institutions are depicted as circles or squares within the figure. In summary, this data display helped me identify some of the mesosystem influences that should be explored in this study (Bronfenbrenner, 1979, 1986). These preliminary analyses also showed that my original research question and design would have only allowed me to scratch the surface of the contexts that are relevant and important for any hearing family learning to communicate with a deaf child.

Revised Research Plan

The revised question addressed in this study was “What are the sign language learning experiences and contexts of a family when the hearing parents of a deaf child decide to learn and use American Sign Language?” Rather than collecting shallow and insufficient data from multiple cases, I decided to gather more in-depth data concerning this one extreme and intricate case. Although Jena is at the center of the eco-map model, this study focuses on

the sign language learning contexts and experiences of her family rather than her.

Participants

The names of all people, locations, and institutions described in this section have been changed in order to protect confidentiality. The following information concerning Jena and her family history was obtained from multiple sources 1) during interviews with Abby and Luke Byers, Jena's parents; 2) from a case history form completed by Abby Byers; and 3) from medical and speech and hearing reports provided by the Byers and collected in the course of the child's language treatment at a university speech and hearing clinic. The interviews with Abby and Luke involved both a formal tape recorded interview in their home, phone conversations during the period of the study, and during informal conversations during the twice weekly clinic visits between September, 1995, and April, 1996.

Byers family. Jena Byers was born on May 26, 1991, in Ashton General Hospital in Ashton, Ohio, to Abby and Luke Byers. Abby's pregnancy with Jena was her first. Jena was a full term infant who weighed 7 pounds, 5 ounces. Although Abby indicated that her

pregnancy with Jena was unremarkable, Jena had severe problems that were evident immediately at birth. Luke Byers described her birth this way:

Well, right when she was first born, I, right there in the delivery room, I was, I was saying to a nurse, I said, "Well, why's , why does she sound like that? Because she had this, she was all blue, and she had this real kind of gurgly, gravely voice, which now I realize it was because of her cleft palate. But you know, my gosh, to sound like that. ... Just kind of a little snarl, like a little growl or something. ...I thought she was really blue. I said, "Is she, you know, is that norm-?" They were saying you know, how she's, how that's normal when they are first born, to be a little blue, that once, you know, she gets the oxygen and everything, she would, it would kinda go away, but it, it didn't. Her feet, you know, and, and fingers, and feet were kinda purple on the bottoms. .. It was kinda purple around, around her lips. Blue, like a bluish purple around her lips.

Jena was taken to the intensive care unit, then rushed by ambulance to Homestead Children's Hospital (HCH) in Lakeport, a larger urban area, when she was only five hours old. She remained in the HCH intensive care unit for a week, and left the hospital after two additional weeks. Abby indicated that Jena had velo-cardio-facial (VCF) syndrome, a congenital malformation syndrome first identified by Shprintzen et al (1978). Jena's manifestations of this

syndrome included a cleft of the velum and tetralogy of Fallot.

Tetralogy of Fallot is a heart defect characterized by a ventricular septal defect, pulmonary stenosis, right ventricular hypertrophy, and some degree of overriding of the aorta (Kawabori, 1978; Shprintzen, Goldberg, Young, & Wolford, 1981). Although approximately 75% of the 60 cases with VCFS described by Gorlin, Cohen, & Levin (1990) had intermittent conductive hearing loss thought to be secondary to palatal clefts and serous otitis media, and one case had unilateral sensorineural hearing loss, none of the cases of VCFS had bilateral sensorineural hearing loss like Jena's. Jena had corrective heart surgery at Homestead Children's Hospital (HCH) in July of 1992; her palatal cleft was repaired at a hospital in Columbia, Virginia, in October of 1992.

Jena's hearing loss was first suspected in June, 1991 (chronological age: 3 weeks), when she failed an infant hearing screening procedure at HCH. A chronology of the diagnostic procedures that lead to the confirmation of Jena's deafness is provided in the following chapter (see Table 1).

Jena and her parents moved to Blueport, Virginia, in November 1991. Abby said that they moved here so she could be closer to her mother. She wanted her family's support, and she and Luke were both

between jobs.

Abigail (Abby) Byers, Jena's mother, was born on May 6, 1969. She is the fifth child of eight children (see Figure 2). She and Luke met at a small college in Ohio where she completed a bachelor's degree in social work. For most of the time period of this study, September, 1995, until April, 1996, Abby was employed part time with a state employment agency. Abby is pregnant, expecting their third child in the summer of 1996. Abby has an open, effusive, and warm manner. She laughs readily, displays affection to her children, and seems to be at peace with herself.

Luke Byers, Jena's father, was born on November 11, 1965. He is the second of three children (see Figure 2). Luke completed a degree in liberal arts and is an area specialist associate with an office supply company in Columbia, Virginia, a larger city located approximately 45 miles away from Blueport. I have had fewer opportunities to talk with Luke, since Abby usually brings Jena to the clinic. Luke is more reserved than Abby, and talks less, but he interacts frequently in a gentle, affectionate and firm manner with his children. He has signed frequently to Jena when I have been around them.

Mica Byers, Jena's brother, was born in July, 1993. Like his

mother and father, Mica is hearing.

Other family members are depicted in Figure 2. All are hearing.

Participants from outside the family. The professionals and others from outside the family who have been involved in Jena's case, and the institutions with which they are affiliated are described in the following chapter (see Table 2).

Data collection

Triangulation. Triangulation in qualitative research has come to have multiple meanings (Miles & Huberman, 1994). Many researchers use triangulation to describe tactics for gathering data from multiple sources (Denzin, 1978; Patton, 1990; Stake, 1995). Huberman and Miles (1994) describe triangulation as a mode of inquiry that has come to mean arriving at convergence among researchers, types of data, and theories. Strauss and Corbin (1994) argue that triangulation, or the systematic seeking of multiple perspectives during the research inquiry, is a strength of grounded theory methodology. Denzin (1978) listed several kinds of triangulation, including data triangulation, investigator triangulation, theory triangulation, and methodological triangulation. To Denzin's list, Janesick (1994) added interdisciplinary triangulation, a heuristic tool that uses art,

sociology, history, dance, architecture, and anthropology to “broaden our understanding of method and substance” (p. 214).

While this inquiry does not include dance or art, it does seek the perspective of lay people as well as professionals from various disciplines, and deliberately uses multiple methods of gathering data, multiple types of data, and multiple theories.

Interviews. Conversational interviewing, described by Patton (1990) as the most flexible and open-ended approach to interviewing, was used to collect participants’ descriptions of their experiences as family members or professionals involved with Jena, their perspectives about their own sign language learning, and their participation in Jena’s sign language learning process and that of her family. In contrast to structured or semi-structured interviews, where questions or general topics for discussion are predetermined, informal or unstructured interviewing allows the interviewer greater breadth and freedom to respond to the information that emerges from the perspective of the person being interviewed (Fontana & Frey, 1994; Miles & Huberman, 1994; Patton, 1990). According to Patton (1990), the “strength of the informal conversational approach is that it allows the interviewer/evaluator to be highly responsive to individual differences and situational

changes” (p. 282). However, this type of interviewing depends more on the skills of the interviewer and produces responses that may be more difficult to analyze (Patton, 1990).

Since the participants in this study played so many varied roles in Jena’s life, a highly individualized format was important. An open-ended strategy allowed the participants to tell their own stories from their own perspectives. In this regard, it is similar to ethnographic interviewing (Spradley, 1979; Westby, 1990) because both questions and answers were discovered from the people being interviewed. More traditional interviewing is characterized by questions predetermined by the interviewer. Like ethnographic interviews used by professionals to interact with families of children with special needs, the interviews in this inquiry had “the goal of helping the interviewer understand the social situations in which the families exist and how the families perceive, feel about, and understand these situations” (Westby, 1990, p. 105).

Abby and Luke were interviewed first. I asked them to “Tell me your story about being the parent of a deaf child.” I asked Jena’s grandparents to “Tell me something about your experience of being the grandparent of a deaf child, and then something about your sign language learning.” I asked other family members to tell me about

their experience being a member of a deaf child's family and about their sign language learning. The professionals were asked to describe their own role in helping the Byers family decide how to communicate with Jena and/or their role in the family's learning sign language. Because I saw Abby, Jena, and Mica twice weekly during Jena's clinical sessions, Abby and I had ongoing conversations. These conversations were summarized in my research journal.

The participants who live within an hour's drive from my home were interviewed in person, at a location of their choosing. Family members who were interviewed in person were typically interviewed in their homes, and professionals, with one exception, were interviewed at their workplace. Jennie Harris, the speech-language pathologist who provided early intervention services to Jena, is an independent private practitioner with a business office in her home, so she was interviewed at her home. Family members and others who lived more than an hour's drive were interviewed by telephone.

Interviews with Abby and Luke, Abby's sister Beth Solberg, Abby's parents, Jennie Harris, and Marlene Rogers were audiotape recorded using a Marantz PMD 201 tape recorder. For the Harris,

Rogers, Murphy, and Beth Solberg interviews, both they and I wore a Shure Sm11 lavalier microphone attached with an alligator clip to a lapel or to an area on a shirt that was within 12 inches of the speaker's mouth. The microphones were used so that each person's contribution was recorded with minimal interference from background noise. Each microphone was fed simultaneously into the tape recorder via a Shure M68 FCA mixer.

The interviews with Abby and Luke and with Abby's parents were recorded via the internal microphone on the Marantz. Abby and Luke needed to be free to respond to their two small, active children, answer the phone, and move around their home, so tethering them to the fixed position of the tape recorder was unrealistic. During the interview with Abby's parents, they expressed surprise and a little dismay that our conversation would be recorded, so I felt that hooking them up to microphones attached to long cords and fed through a cumbersome mixer would have been intrusive and counterproductive.

Verbatim transcriptions of the recorded interviews were completed using a word processing program on a Macintosh computer. The conventions for transcribing the interviews are contained in Appendix G.

Field notes. Field notes were developed and written following formal interviews, after Jena's sessions at the Speech and Hearing Clinic, after informal conversations with participants (in person or by telephone) that were not tape recorded, and following visits to schools and child health agencies. I had planned to record the interviews with several of the professionals in this study, but either their own negative reaction to being tape recorded or their stated time constraints led me to decide not to record, but just to take notes while they talked. The notes were typed usually on the same day, or a day following the interview or data gathering, using a word processing program on a Macintosh computer.

Documents and records. Some qualitative researchers distinguish between documents and records, with the distinction based either on the public vs. private nature of the content or the degree of contextualization required for interpretation (Hodder, 1994; Lincoln & Guba, 1985). For example, Hodder (1994) states that records include evidence of formal transactions (marriage certificates, contracts), while documents are prepared more for personal use (diaries, letters). In this case study, such a clear distinction may not be possible or even desirable. A more useful distinction for purposes of this study is categorizing the available

written texts as either 1) records that are written specifically concerning Jena , or 2) documents that are written concerning a general population of deaf children, their parents, or sign language learning possibilities. The Byers provided both records and documents pertaining to the diagnosis of Jena's hearing loss and recommendations regarding communication mode, treatment, educational alternatives, educational planning, and parenting.

The records included a series of audiograms, reports of audiological evaluations, speech-language evaluations, individualized family service plans, logs of clinical session and clinical treatment summaries, physicians' records that pertain to the diagnosis and treatment of Jena's hearing loss, and educational reports.

Documents provided by the Byers included booklets, pamphlets, fliers, handouts, charts, correspondence from deaf education programs, and parent newsletters. Other documents gathered included sign language studies curricula, and books. The documents provided do not constitute the entire list of readings that Abby and Luke have completed, but they do reflect some of the information that has been given to them by professionals.

Media. A parent-produced video documentary For a Deaf Son

(Tranchin, Tranchin, Martin, & Garcia, 1994) tells the story of a hearing family's search for answers for their deaf son. The documentary was narrated, produced and directed by the hearing father of a deaf boy, and co-written by the father and mother. The documentary chronicles the family's discovery that their son was deaf and describes their early decision to communicate orally, to raise their deaf son "in a hearing world." In addition to the first person narrative provided by the father and mother, other parents of deaf children and a number of professionals were interviewed regarding their choices and recommendations about communication modes. I was given the videotape by a colleague, an audiology professor who showed it to her graduate seminar in Deaf Culture.

In the initial stages of this study, I transcribed this documentary in order to analyze the data as a pilot study for several reasons. First, multiple perspectives about family communication with a deaf child were presented. The documentary provided a chronology of events, a linguistic and visual record of one hearing family's decision-making process concerning which communication mode to use with their son. Second, the first person perspectives of six other families (3 with hearing parents and deaf preschoolers; 1 deaf mother of a deaf preschooler; and 2 with hearing parents and

deaf adolescents) were also presented. The parents from these other families provided brief descriptions of their reasons for making their various communication mode choices for their children. Third, well-known professionals and both hearing and deaf educators of the deaf were interviewed about their widely differing recommendations concerning communication between hearing parents and deaf children. These professionals represented institutions on both sides of the oral-manual controversy.

Following the presentation of the documentary on the local Public Broadcasting station in March, 1996, I interviewed the producer, Rob Tranchin, by telephone. I asked him about his and his family's experience with sign language learning and included those comments in my field notes.

Reflexive research journal. Reflecting upon and about the research process is a critical component in qualitative studies (Fonow & Cook, 1990; Lather, 1987). The process of constantly examining and comparing data from the beginning of a study makes it important for researchers to record how and why they reformulate their ideas, examine the validity of their assumptions, and set up research projects that might help people change their own lives even as those projects intrude into the lives of the participants.

Beginning in July, 1995, I began to keep a reflexive research journal in a word processing program on my computer. I wrote notes about successes and failures in gaining access to participants, my struggles with other clinical cases involving hearing impaired children and deaf children, and my reactions to some of the interviews I had conducted. This journal proved to be a particularly useful place to verbalize the ever present but ever changing ethical dilemmas I encountered during this study. I also used the journal to record some of the developing personal interactions with Abby, Luke, other family members, and the professionals I interviewed. In addition, I found it useful to record the details of this story as it unfolded from week to week. It could be argued that events should be recorded as field notes. However, my reactions to some of the events were difficult to separate from the events themselves. For example, I wrote the following about the need for all the adults who are around Jena to sign and speak simultaneously:

I had given Maxine 2 copies of the article about BoMee. I had been worrying about all the language that Jena misses. It is hard enough to get her attention, and even if she were nosy enough to watch what we sign to each other, she misses all the spoken language that is not signed. It occurs to me now, even

as I speak, that maybe she doesn't watch us because we don't sign. I was reminded as I read this article that BoMee would ask her father to sign what her mother was saying to her (Mom used PSE), but wanted him to "say it the right way" meaning ASL! I asked Kristen if she had had the chance to give the article to Abby, and Abby said that she had already read that a while back. She said that the parents in the article were an "inspiration" to her, but that she doubted that she could ever sign that (much) (well) - which did she say?

Two hard copies of each transcript, my field notes, and the reflexive journal were printed. Similarly, two copies of each document and record were made. One copy of each type of data was used for preliminary coding by hand, and the second copy was stored as the archival copy of the data. All computer created data were saved both on my computer's hard disk and on floppy disks. The data created in word processing programs were then saved as text only source files in the HyperRESEARCH folder on the hard drive.

Data Analysis

Grounded theory methodology calls for data analysis to begin from the very outset of a study, since analysis directs the sampling of subsequent data (Strauss & Corbin, 1990). Coding procedures and

processes for analyzing qualitative data were adapted from Strauss and Corbin (1990).

Open coding by hand. Since HyperRESEARCH (Hesse-Biber, et al, 1991-1994), the computer-assisted program that I used for data analysis currently supports only textual source materials, I experimented with converting some of Jena's records and documents into text files in order to use its coding features. Many of Jena's records and documents that were in the form of typed text were scanned into a text-only file using using a MacIntosh Color One Optical Character Recognition scanner and OmniPage Professional (1994) software. This software, while interesting to use, had limitations for this project. OmniPage Professional does not convert graphs such as audiograms into text-only files, nor does it always recognize the print from documents that are not clear, dark copies. Those records and documents that were composed of sufficiently clear type to be recognizable by the scanning program were converted into text-only files on floppy disks and then transferred onto the hard drive of my computer. However, only about one-third of the records and documents were able to be scanned into text-only files. Many of the records scanned could not be scanned as a whole; for example, audiograms that accompanied reports could not be

scanned and converted into text. All the records that were scanned had to be proofread carefully and corrected. Since they were saved as text-only files, I was not able to use spelling or find functions that are available for most word processing programs. In addition, the scanning process itself was time consuming. University computer lab policies allowed only 5 pages to be scanned each day, and scanning those 5 pages took approximately 30 to 45 minutes of my time as well as the lab assistant's time. I was then able to locate a different lab setting which permitted me to do the scanning myself, but the scanning time was not reduced. Because the scanning was so time consuming, and because this attempt to create machine readable files produced only fragments of reports or documents, I elected to code the records and documents by hand.

I read through each document and record several times, highlighting significant phrases, making notes of themes and categories, and recording important events and happenings in their chronology. I typed the preliminary list of themes and categories using a word processing program, then converted that file into a text-only file that was then exported to the HyperRESEARCH program for coding and subsequent stages of analysis.

For each hard copy of the other textual data, I followed the

procedures for open coding described by Strauss and Corbin (1990). According to Strauss and Corbin, open coding is a process of “breaking down, examining, comparing, conceptualizing, and categorizing data” (p. 61). I read through each hard copy of each interview, my journal and field notes thoroughly one time, marking important segments of text with a highlighter pen, and writing codes notes in the margin near the highlighted text. I then referred to these notes as I began the more systematic procedures involved in the computer assisted coding described in the next section.

Computer assisted open coding. A HyperCard based software package for Macintosh computers was used for analyzing the data that were in the form of text. I experimented with analyzing pilot data using two different packages, HyperRESEARCH (Hesse-Biber, et al, 1991-1994) and Hypersoft (Dey, 1992). HyperRESEARCH proved to be the most user-friendly and the most logically related to the analysis procedures used in grounded theory methodology. Therefore, I used HyperRESEARCH to facilitate coding, searching, linking, retrieving, and displaying results.

The first step in coding using this program is to open a study using a typical pull-down menu. Once the study is opened and given a name, a case file is selected, then a source file is selected. Once the

source file appears on the computer monitor screen, any segment of text can be highlighted, then coded by either selecting an existing code from a Dialog Box, or creating a new code which is added to the list and then selected. Both the source file and the case card showing the text segments selected and the codes assigned appears on the screen simultaneously. Each new case created can be coded with the already generated list of codes or an entirely new set of codes. Codes can be renamed, deleted, and copied.

Data of varying lengths were coded. Rather than code line-by-line, I coded records and documents as whole. For the interviews, I coded blocks of text that tended to corresponded to a speaker's conversational turn; these blocks were usually paragraphs, or sentences within paragraphs. For the field notes and journal, I coded blocks of text that were either sentences or paragraphs. Open coding generated an initial code list of 216 codes (see Appendix H).

Axial coding. Axial coding involves a set of procedures that put data back together by specifying a category (phenomenon), then making connections between the category and its subcategories (Strauss & Corbin, 1990). These procedures use a coding paradigm that specifies the phenomenon of interest (in this case: FAMILY SIGN LANGUAGE LEARNING) and (a) the **conditions** that gave rise to it, (b)

the **context** in which it is embedded, (c) the **action/interaction strategies** by which it is carried out, and (d) the **consequences** of those strategies (Strauss & Corbin, 1990).

The initial categories generated during open coding were reanalyzed by asking questions about the relationship of each category to the phenomenon of SIGN LANGUAGE LEARNING. For example, diagnoses, events or experiences that led to the family's learning sign language were categorized as Causal Conditions. People and places involved in the family's SIGN LANGUAGE LEARNING were categorized as Contexts, while strategies that the family used for SIGN LANGUAGE LEARNING were categorized as either facilitating or constraining Intervening Conditions. Results of family SIGN LANGUAGE LEARNING were categorized as Positive Consequences, while results of a family's not learning sign were categorized as Negative Consequences. Hand sorting of each initial subcategory into these paradigmatic categories was followed by computer assisted recoding and verifying of these hypothesized relationships by re-reading the actual text and initial codes. Many of the provisional codes generated during open coding were either discarded, renamed, or collapsed together with similar codes. The resulting paradigm from axial coding is included in Appendix L.

Codes generated during this phase of analysis were not numbered, because the HyperRESEARCH program analyzes and sorts verbal codes.

Selective Coding. Selective coding involves identifying a story line and naming a core abstract category that encompasses the other categories developed in axial coding (Strauss & Corbin, 1990). In order to clarify the story line, monthly calendars (May, 1991-April, 1996) were used to locate critical events in chronological order. These calendars were generated and printed using Hypercard 2.0 v.2 (Takahashi, 1987-90). In this study, the core category is enculturation, since it incorporates processes, contexts, institutions, issues, events, theories, and very centrally, language learning. Bronfenbrenner's (1986) mesosystem, chronosystem, and exosystem models of environmental systems provide an organizational focus for the story line.

Ethical Considerations

Ethical dilemmas are not unique to qualitative research, but qualitative research within family contexts calls for particular sensitivity (LaRossa, Bennett, & Gelles, 1981; Lipson, 1994). A variety of ethical challenges and dilemmas face those who attempt to "get inside" hidden family settings (Allen & Baber, 1992; Boss,

1987; Daly, 1992b; Moon, Dillon, & Sprenkle, 1990). Special ethical challenges are involved if children are research subjects (Allen & Baber, 1992; Gorelick, 1991; Kashani, Orvaschel, Burk, & Reid, 1985; Langer, 1985).

Researchers who study families using qualitative methods do not always have clear prior assumptions about what risks might be posed. Qualitative researchers may not always know where an interview or natural observation might take them (LaRossa et al., 1981). Informed consent, the researchers' responsibility to the participants, balancing the risk-benefit equation, and clarifying the researcher's role as interventionist are important ethical issues that must be faced (Boss, 1987; Gilgun, 1992; Lipson, 1994; Moon et al., 1990).

Even seemingly straightforward data gathering procedures such as interviewing can create dilemmas. Interviewing couples together makes it more likely that fathers might participate (Daly, 1992a), but when more than one participant is interviewed at one time, it is more difficult to control what all the participants might say. Families under stress are more vulnerable and may be more likely to divulge information to researchers or each other than families who are not troubled.

Another ethical risk described in the qualitative literature concerns the potential discomfort, or anxiety, reduced self-esteem, or embarrassment that could come from the family “exposing itself” (LaRossa et al., 1981). The disclosure of one family member might invade the privacy of another. If unintended disclosure is a risk when couples are interviewed, then those risks are at least theoretically multiplied when siblings and parents of a couple are interviewed.

Though the ethical challenges in qualitative family research are well stated, and stated repeatedly, few solutions are offered. Some guidelines for ethical conduct of research can be found in institutional and professional codes of ethics (Gorlin, 1990; Lipson, 1994), and obviously, complying with these guidelines provides a measure of protection to vulnerable participants.

Confidentiality. Daly (1992a) suggested that confidentiality issues are best approached by taking a respectful stance to the participant’s privacy. He suggested that researchers could check with participants periodically about their comfort level, withdraw segments of data from the record if they threaten confidentiality, and actively encourage the participants not to talk about topics that make them appear anxious or stressed.

In this study, given the uniqueness of Jena’s history, ensuring

confidentiality of the participants was particularly challenging, but more so for the professionals than for Jena's parents. Abby and Luke were generous with their story. They have repeatedly stated that they feel that it is important for Jena's life to be meaningful, not just for herself, but on behalf of other children. Abby said that when her heart surgeon asked if Jena could be a subject in a study of an experimental heart drug, she felt that it would help Jena as well as other children. Similarly, they feel that if this part of her story can help other children in the same situation, it should be told.

In an effort to make the participation of others confidential, I have 1) changed names of participants, their cities, school districts, and medical institutions. I would not want to change data that concern parents' education, family constellation, or gender of the participants. These are factors that have been implicated as important in families' choices of communication mode (Kluwin & Gaustad, 1991, 1994).

Confidentiality of the tape-recordings, transcripts, documents, and field notes that were gathered were maximized by 1) replacing the participants' names with pseudonyms after the data analysis, 2) storing tapes, written transcripts, and documents in secure cabinets, and 3) storing electronic data on the hard drive of

my home computer (not connected to any network) or on floppy disks in a secure cabinet. Data were not stored on the hard drive of my computer at my office, since that computer is not completely secure and since I do not know how to hide or lock electronic files. It must be noted that using pseudonyms during most of the data analysis was not practical. At least 55 adults who were not members of Jena's family and 21 adults who were members of her family were identified as contributors to Jena's story. Changing the names of 76 adults would have made coding and keeping track of identities and connections an impossible task.

Informed consent. Participants other than Abby and Luke were provided with a description of the study that included a description of their expected participation (Appendix I). This description contained a statement about potential risks and benefits, as well as a statement concerning a participant's right to withdraw from participating at any time. Participants were asked to sign this statement of informed consent and keep a duplicate of the statement for themselves. Jena's parents were asked to sign a form giving me written consent to obtain information about her case before I spoke with any individuals about her case (Appendix J). When I revised the research questions to focus on Jena's case, I changed the informed

consent form slightly and included a letter to the parents that clarified the extent of their participation (Appendix K). I obtained the parents' signatures on the revised informed consent form.

Risk/benefit equation. In return for their participation in the study, the parents were offered a chance to tell their stories from their own perspectives and to offer suggestions to the professionals about their family communication needs. For other family members, I offered to send them information on sign language videotapes and books that they could ask local libraries to order. I also offered to Abby and Luke, as well as Abby's parents, to conduct a signing communication workshop or some less formal type of instruction to the teachers at the Sunday School that Jena attends.

Researcher's role. The role of the qualitative researcher is discussed in some detail in the literature concerning methodology and ethics (Boss, 1987; Collins, 1991; Denzin & Lincoln, 1994; Fonow & Cook, 1991; Lather, 1987; McCracken, 1988; Patton, 1990; Stake, 1995). We are sometimes cautioned about our role in the research process, or advised about the relationship between the researcher and the participants (Spradley, 1979; McCracken, 1988; Morse, 1994). Spradley advised the beginning that "most people find that strangers make better informants (p. 28)." McCracken (1988) described the

complexities of the issues concerning these relationships.

Who does the respondent think the investigator is? As sentient social actors, North American respondents use every available cue to categorize the investigator and the project.... If the investigator does not carefully control these cues, they will confound the nature of the respondent's participation in the interview and the data he or she provide. (McCracken, 1988, pp. 25-26)

Boss (1987), writing about the ethical issues in family research, said "We are not there to become friends or enemies. We are there *to gather* information and, perhaps, *to leave* some information (p. 149)." Stake (1995) described the multiple roles that case researchers might play. He said, in any one study, the researcher may play the role of teacher, advocate, evaluator, biographer, theorist, and interpreter. of theory (not a sign language interpreter). Here, I will not defend the roles that I played, because many of those roles were a given, part of my work assignment. I can state the roles that I played. The advantages and disadvantages of multiple roles in the research process will be discussed in subsequent chapters. First, I functioned as a clinician and clinical supervisor, then as a researcher, evaluator, theorist, and interpreter

of theory (not a sign language interpreter), and a professional colleague. Eventually, I hope to function as teacher and advocate, since the purpose of this study is to improve the language learning situation of hearing families with deaf children.

Findings

What happens when parents of a young deaf child decide to learn and use American Sign Language? The story of Jena Byers and her family is compelling testimony about the interaction of personal, familial, cultural, and bureaucratic response to deafness. It is the story of a battle for life and against time. It tells about the acceptance of reality, and the mobilization of effort to provide improved hearing, and to ensure a child's access to language, social appropriateness, acceptance, emotional attachment to her family, understanding of the world beyond the here and now, and enculturation in her own family and the deaf community. This story is not an indictment of any one person, philosophy, institution, or practice; but a retrospective look at the ecologic and contextual realities influencing the development of one child.

Conditions That Delayed Family Sign Language Learning

An Uncertain Beginning

When Jena was born, sign language was not the phenomenon of interest, but her survival was. Her parents learned that she had serious heart problems, a devastating experience that was

exacerbated by the way this unexpected news was delivered. Abby and Luke remembered pieces of the event differently. I had asked them when they were first aware that Jena had heart problems.

Abby: At, bir-, that was at birth.

Luke: That was, that's that's why she was rushed, to the, to Homestead Children's, because of her heart.

Abby: (interrupting) You see, we had a doctor then that gave us a real, we felt he was a terrible doctor because he ... told Luke about Jena being sick, separately from me. Came in, I had no one with me, had just delivered a baby, told me that she might have some kind of syndrome, they're going to run chromosomes, she might not be worth fixing. I thought, I thought she was gonna die overnight.

Luke: I don't think they said it like that, honey. You were

Abby: (interrupting) That's, that's what I remember.

Luke gently coached Abby in reconstructing this memory, saying that the physician had not said that she wasn't worth fixing. Abby amended her story somewhat, but the anger in her voice was unmistakable as she told that the impression she got was that was that her new baby could die in the next 24 hours, that she was very sick, that they were going to run chromosomes, and see what the expectancies for her life were, since it might not even be something

worth pursuing. Luke remembered being told in the delivery room that it was normal for babies to be a little bit blue when they were first born, so he took pictures, and then went with his mother and two sisters to find Jena in the nursery. She was not there, but in the intensive care unit.

Luke: I just thought, well, okay, ... maybe they took her down there for whatever reason, so then we walk down, they tell us where it was. We walk down to the intensive care unit. And that's, that's not good for that doctor, to first came out to tell us. I just kinda lost it right there. (laughs quietly).

Abby: And then he (the doctor) went out to them and said, "Somebody needs to be in there with the mother. (laughs)

Another physician explained that Jena needed to be transported to a facility in Lakeport. Luke and his father followed the ambulance to Homestead Children's Hospital, a 90 minute trip that took only 45 minutes by ambulance. Luke and his father waited several hours to be told what was happening. They learned about Jena's heart defect, then later about her palatal cleft.

At the time of this interview, I was interested in how professionals contributed to parents' decision making about communicating with their deaf children, so we talked a lot about

how professionals had communicated to them about their daughter's multiple problems. They said they reacted negatively to the audiologist who told them about her hearing loss, partly because they may not have wanted to hear the news, but partly because of the way the news was presented.

Abby: It was just the way she worded things. Because, like her cardiologist could say something really negative, but the way he worded it, he still gave us hope. She's just real matter of fact. And maybe we didn't feel like there was a lot of sympathy coming from her, so we got a real negative impression from her.

Similarly, the speech therapist at HCH used words like that "were a mile long," treated their questions chauvinistically, and seemed arrogant. The Byers reacted positively to the cardiologist, because he gave them hope, but not false hope. The timing and amount of information delivered seemed to be important as well.

Abby: (referring to the cardiologist) And you know, he doesn't lay it so, in all these **big** words, and in a way that you just feel overwhelmed with information. ...When they did her heart, they told us step by step, everything that was going to happen. They told us twice. And then, enough, so that afterwards, I could tell people exactly what they did. And, because the way they were so calm

about it, they, they took an interest in Jena, you know, the nurse came out in the middle of her surgery, told us what, where they were at, in the procedure, what was going on.

The Co-construction of Denial

Hearing centered practice. Jena's hearing loss was actually identified and diagnosed earlier than average. The average age that hearing loss is suspected is 12 months, but it is not confirmed until an average of 18 months (Elsmann, Matkin, & Sabo, 1987). Jena's loss was first suspected when she was three weeks because she failed infant hearing screening procedures while she was still in the Homestead Children's Hospital.

Some parents can pinpoint the exact day when their child's deafness is confirmed. In the video documentary For a Deaf Son (Tranchin, Trachin, Martin, & Garcia, 1994), Thomas Tranchin's mother recalled the event this way:

Laurie: I continued to have suspicions. He went and was examined and the lady stepped out of the booth and said "Honey, he wouldn't hear a train go by."

In Abby and Luke's case, their coming to accept the reality of Jena's deafness was an unfolding process, rather than an event. The process that delayed the acceptance of Jena's deafness was not just

a simple matter of denial on the part of her parents. The professionals who tested Jena's hearing, those who treated her middle ear disease, her parents, and Jena herself constructed a complex puzzle that obscured or at least confounded the true state of her hearing. Jena's heart problems and the middle ear disease related to her palatal cleft delayed the determination of an exact diagnosis of the type and severity of hearing loss that Jena had, and subsequently, the family's acceptance of Jena's deafness and their sign language learning. The early stages of the diagnostic process seem characterized by the sending and receiving of mixed messages between the professionals and the Byers.

Abby: And uhm, she had, um, A, is it an ABR, where they put her to sleep and they measured her brain wave. And they were flat. And, so basically at that point, you know, the audiologist counseled us, you know, told us that.. they thought.. you know... she had.....pretty profound loss and that, um, with hearing aids, it would probably improve her hearing about 30 percent.

Claire: Um-hum.

Abby: We didn't really believe 'em (laughs)

Claire: What didn't you believe?

Abby: I just, (laughs), we just couldn't believe she was deaf! (laughs).

Luke: Cuz they had said that the reason that she had a like a lot of fluid behind the ear and sometimes that'll cause you not to not be able to hear well when you have a lot of buildup back there, so we were just kinda thinking .. "Well, maybe that's how it was, once they drain it....you know.."

Abby: Once they, yeah, put tubes in her ears and get rid of the fluid buildup, then she'll, you know, then she'll be able to hear.

Table 1 summarizes some of the critical events concerning the diagnosis of Jena's hearing loss, and health and family related events involved in her sign language learning and that of her family. It shows that Jena had pressure equalizing tubes placed when she was 5 months old, but a month later, audiological evaluation still showed that she was not responding normally to sound. Abby and Luke continued to hope that Jena's hearing loss was not permanent.

Abby We felt like maybe once they fixed her cleft palate, fluid would quit building up in her ears, and things like that, so, she had her open heart surgery at 14 months. They couldn't fix her cleft palate until after that. So they fixed that about 18 months, and then, when there was no improvement at that time, you know, reality set in.

Abby's sister Beth Solberg, and Celeste and Lawrence Solberg,

Table 1

Chronology of Events

Date	Event/Procedure	Setting	Outcome
5-91	Jena's Birth Date	Ashton Hospital	
6-91	Initial hearing screening	Homestead Children's Hospital (HCH)	Failed screening
8-91	Auditory Brainstem Evoked Response (ABR)	HCH	No reliable responses at 99 decibels (dB) Hearing Level (HL)
8-91	Otologic examination	HCH	Bilateral middle ear effusions
8-91	Audiologic evaluation	HCH	Severe, bilateral possibly mixed hearing loss, need for amplification
9-91	Audiologic re-eval & Hearing Aid Selection	HCH	<u>Aided</u> Speech Reception Threshold 35 dB Hearing aids recommended Referral to early intervention
10-91	Pressure Equalizing (PE) tubes placed	HCH	
11-91	Byers move to Virginia		
11-91	Audiologic re-eval	Community Clinic	No consistent response to warble tones & narrow band noise, soundfield Speech Awareness Threshold 55 dB HL, ABR
4-92	Audiologic re-eval	Private practice in VA	Inconsistent, hard to test, Hearing aids recommended
4-92	Began Early intervention, SLP and family began using total communication with Jena		
5-92	Began wearing hearing aids		

Table 1 (cont.)

Chronology of Events

Date	Event/Procedure	Setting	Outcome
7-92	Heart Surgery performed	HCH	
8-92	Began rejecting hearing aids		
10-92	Cleft Palate surgically repaired	Columbia Memorial Hospital	
4-93	Audiologic re-eval	Private practice in VA	SAT 95 dB both ears NR to BC testing Aided thresholds 70 to 80 dB HL
4-93	Parents take sign class with Rachel Holder		
7-93	Mica born, family moves to new house		
10-93	Audiologic re-eval	Bangston University	No response to sound with hearing aids on
9-94	Begins preschool	University Lab School	
2-95	Audiologic re-eval	Bangston University	No response to FM system
4-95	Auditory Brainstem	Child Health Agency	No waveforms elicited Severe to profound loss
Summer 92	Language Tx sessions (8)	Bangston University	
9-95	Jena starts preschool	Columbia City School Program for Hearing Impaired	
Fall 1995	Abby & Beth take sign class	Southern Community College	
	Language Tx sessions (19)	Bangston University	

their parents, also reported similar stories of diagnostic uncertainty. They all reported thinking that Jena was not actually deaf and that once her middle ear disease was treated, she would be able to hear. Jena's contribution to the construction of denial is paradoxical. She often made her family think she might be responding to sound, but she totally rejected the hearing aids that seemed to hold such promise.

Beth: They said, "Once the tubes go in her ears, she'll probably be able to hear. So, we didn't learn sign, and Abby feels a lot of ..guilt for that now. And I was like "It's not her fault." Because they really gave us false hopes. They should've said, "Your child is deaf." You know, and "The tubes probably will help her." You know, like they did then later.

I asked Beth about when and how the family decided to sign with Jena.

Beth: Um, well, we found out that she was deaf and that she was gonna **be** deaf, ...then...Yeah, I mean it wasn't at birth, it was you know...If we would've known, like, she was **not** deaf when she was born. It was a few weeks later. And, so, if we would've known that she was going to remain .. that way, we would have started **right then**. But who's to know?

Abby's parents, Celeste and Lawrence Solberg, have similar memories about accepting Jena's deafness.

Celeste: Abby has shared too, how at first, we just, we really .. didn't want to accept that she couldn't hear. And there were indications in the way she responded, at least we felt there were, that said she could hear, that maybe something was wrong where sometimes she heard, and sometimes she didn't, and because of that I think we ..slow in starting the sign language ..process, because we didn't think we were going to need it.

Claire: Well, I can go back through her records and there are some audiograms that show some hearing, I think with the hearing aids, that suggest ..that she'd be able to hear speech just fine.

Lawrence: Yeah. So, um, I said, what it seemed like, is that there was a loose connection that sometimes connected. but, um, ..with ought- the test, they said that she's profoundly deaf. But anyway, so, that's how it, that's how we started dealing with it.

In Abby and Luke's case, as with the families described by Brown et al., (1990), getting Jena to wear hearing aids was viewed by professionals as vitally important, even though the encouraging results of hearing aid fittings when Jena was three months old were never duplicated. About a month after Jena's heart surgery in July of

1992, she started walking, and as soon as she started walking, the battle over her wearing hearing aids started in earnest. At first, Abby and Luke made it a practice that she would wear the aids when she was awake. However, Jena resisted.

Luke: She would take 'em apart, she would **hide** the pieces, so that we couldn't find 'em. (Laughs)

Abby: (Laughing) and to this day we still have a thousand pieces (laughs).

Luke: Oh. She would hide 'em, so, so, she wouldn't have to wear 'em.

Abby and Luke never noticed any difference in Jena's behavior or response to sound when she wore her aids, and they stopped making her wear them. They were chided by professionals for that decision, although hearing evaluation when Jena was 2 years old showed that her aided hearing was well outside the range for hearing human speech. I asked where the criticism had come from.

Abby: From professionals, the audiologists mainly.
Note: Shifts into deeper, serious voice register: "Don't you want your daughter to hear? Don't you want your daughter be able to talk" (laughs derisively)

Hearing, more than not hearing or communication or language, appeared to be the central issue of services provided in this early stage of intervention. While the bureaucracy responded quickly to the medical and hearing aspects of Jena's case, it did not respond quickly or efficiently to Jena's communicative or language learning needs or those of her family. Abby estimated that only about 20% of the advice that she had been given by professionals concerned Jena's language learning needs, and less than 5% concerned how the family might learn sign.

Similarly, in the case of Thomas Tranchin (Tranchin et al., 1994), the family received extensive advice about hearing, auditory training, and speech, but not language.

Laurie: We took him to Boston and had a whole battery of tests done on him. It lasted a week. And finally, at the end of all these tests, there was a little ray of hope. We found out he had high frequency hearing and that meant we'd be able to put hearing aids on him and he would acquire speech. And that seemed great. We thought that was what we wanted. And so we focused on hearing aids and speech therapy.

The paradox of hope. Another paradox that emerged in the early stages of this story is that the diagnosis of Jena's deafness seemed to leave a sense of hopelessness. In the process of emphasizing the

irreversible nature of the sensorineural hearing loss, do professionals leave parents without any hope?

Luke: And then, the cleft palate...was what they found out next, ..that was sorta, the same, ..well,.. sorta..the same time And, then, the hearing, that was, the **third** thing. Later. And I told Abby, I tell her all the time, I said "I wish, you know, the heart, the heart and the cleft and all that stuff, I can **deal** with, because I knew that could be **repaired**. You know, but the hearing, is..

Abby: Is harder.

Luke: It's, is really, there's really nothing you can do. Least, it seems, later, all indications right now is really nothing that they can do.

The video documentary made by Laurie and Rob Tranchin's echoes this paradox (Tranchin, Tranchin, Martin, & Garcia, 1994) The day that their son Thomas was classified as profoundly deaf, Laurie described her reaction by saying, "That was just so devastating for me. I was just stabbed with a knife. I got in the car. I cried all the way home." Her older son Matthew said, "It wasone ofthe saddest days of my life."

Many books written for parents of deaf children begin with parents' statements about pain, fear, and devastation. (Luterman &

Ross, 1991; Schwartz, 1987), rather than statements of hope. In fact, in the first chapter of the parent guide book When Your Child is Deaf, Luterman and Ross offer a litany of reactions that parents might feel when they find out that their child is deaf: numbness, shock, devastation, being overwhelmed, feeling inadequate, anxiety, confusion, desperation, confusion, overwhelming anxiety, loss of control, anger, loss of freedom, guilt, powerlessness, and impotence. They state that "Having a deaf child is limiting and causes feelings of anger and frustration" (p. 5). On the next page, in discussing why fathers might feel guilt, they state, "No hearing parent wants a deaf child." (p. 6). Such a litany does little to create or preserve hope; rather, it seems to suggest a state of being from which parents must be rescued.

The hearing evaluations that were completed before Jena was six months old suggested that there was good reason for hope. Although her unaided hearing loss was initially categorized as severe, her aided hearing thresholds would lead to the expectation that she could have heard human speech, though at a reduced level. Similarly, her bone conduction thresholds were at hearing levels that suggested that only part of her loss was irreversible. Within just two months, Jena's hearing thresholds dropped considerably. By

the time she was about 30 months old, her hearing had virtually dropped off the audiogram.

We will never know why, but several possibilities come to mind. First, the earliest set of results could be unreliable, meaning simply not repeatable with a different examiner and different equipment. The initial testing was completed by only one examiner and it may have been very difficult for one examiner to work the controls of the audiometer and monitor the infant client's behavioral responses at the same time. A second explanation is that Jena did have a progressive hearing loss that was reliably documented when she was three and four months old, but which worsened to the point that she did not respond to sound at the limits of an audiometer. It is possible that unknown conditions associated with Jena's congenital syndrome, including hypoxia associated with her heart condition, or medications could have contributed to the continued decline in her hearing.

From my point of view, what was missing from Jena's story was the combination of **bad news**, **good news** that the cardiologist seemed to be able to deliver. The hearing professionals do not have good news to deliver in the same sense that the cardiologist does. They cannot say that they can perform surgery to fix a sensorineural

hearing loss, but their good news is that deafness isn't fatal. The bad news can be constructed as something other than devastation and the other negative reactions offered by Luterman and Ross (1991).

John Longwood, the hearing son of deaf parents, is an advocate for deaf children. I interviewed him at the very beginning of this study because I had questions about gaining access to marginalized parents and their children. I had asked John about who influences parents of deaf children. John said that the parents are usually in a state of panic, so the first person with confidence, the first authoritative figure that they encounter is the one who influences them. He said that person was usually the doctor. Then, he said that the doctor usually referred the parents to a like-thinking audiologist and or speech-language pathologist. He thought that these professionals usually think along the same lines. He said the first thing he does is calm parents down. He reassures them that deafness, though permanent, isn't terminal. He said he tells them it's **a pain in the neck**. He describes his own family life, his middle class, well educated parents. He tells them how he went on family vacations, traveled all over with his family, and didn't miss out on normal family things at all.

In the Tranchin video, Rob Tranchin interviewed Alina Engleman, a profoundly deaf girl of about 12 years who attends a mainstream hearing school. Alina was brought up on Cued Speech (Cornett, 1985), a speechreading and speech training method that uses handshapes to help identify different sounds. Alina uses sign language, too.

Alina: A lot of people don't know much Cued Speech yet, and the only way for me to have a relationship with other deaf people like me is to learn sign language. And it's also easier to communicate using sign language because when you speak you sort of make an effort to speak and with sign language, you can just talk!

Alina, talking about being teased over her deafness, said, "It was a real pain!" She used the word pain to mean an irritation or annoyance, much like John Longwood does as he talks with parents. However, Rob Tranchin misunderstood her.

Rob: What should I tell my son when he grows up about being able to handle that kind of pain?

Alina: What?

Rob: What should I tell my son, Tommy, about ...helping him to handle that pain?

Alina: Well, just say “live with it.” (She shrugs). That’s life!”

Bureau-Centric Practice

Multiple service providers. The professionals who offered and dashed hopes were among an astonishing number of professionals to be involved in Jena’s care and to interact with her parents. Table 2 lists professionals who have been involved in the diagnosis and treatment of Jena’s hearing loss, and the agencies they represented (pseudonyms are used for all people and agencies). I am not included on the list, nor are all the nurses, and other hospital personnel who must have been involved in Jena’s care when she was hospitalized for her heart surgery, the repair of her palatal cleft, having pressure equalizing tubes place in her ears, and for pneumonia. None of the individuals who interacted with the Byers family about the financial aspects of all these procedures and hospitalizations are listed either.

These multiple mesosystems differ widely in the amount and type of influence, support, and time devoted to Jena’s care. In addition to the professionals and agencies listed in the table, other settings and individuals have played a role in Jena’s life. She has stayed with different babysitters, goes to Sunday School where

Table 2

Professionals involved with Jena by Agency

Name	Role
Homestead Children's Hospital (HCH)	
Martha LaRose	Audiologist
Martin Burnett	Physician
Scott Lyon	Physician
Bob Schwartz	Physician
Donna Nelson	Speech-Language Pathologist (SLP)
Craniofacial Clinic	
Special Education Director, City Schools	
Hearing Aid Dealer	
Chris Spencer	Director of the Program for Hearing Impaired
Community Speech and Hearing Clinic	
Sandra Arthur	Audiologist
Medical Private Practice #1	
Marlene Rogers	Audiologist
David Canfield	Otologist
Early Intervention Program	
Bonnie Lemmon	Physical Therapist
Mandy White	Infant Educator
Jennie Harris	SLP
Sophie Reid	Infant Educator
Kaye Howe	SLP
Mary Custis	Infant Educator
Gracie King	Program Coordinator
Medical Private Practice #2	
Matthew Frier	Audiologist
Pediatrics Practice	
Richard Baker	Physician
Adam Littrell	Physician
Peter Nunn	Physician

Table 2 (cont.)

Professionals involved with Jena by Agency

Name	Role
Church	
Rachel Holder	Sign Language Interpreter
Family Medicine Practice	
David Goren	Physician
Herbert Hanson	Physician
State Child Health Agency	
Will Sherman	Otologist
Yvonne Robeson	Audiologist
Lilith Greene	Education Consultant
Martha Miller	Nurse Coordinator
Stacy Atkinson	Secretary
Cassie Wright	SLP
Christine Roemer	SLP
George Rupp	Audiologist
Larry Mullens	Plastic Surgeon
Bob Carroll	Dentist
Southern Community College	
Lee Johnson	Sign language instructor
Bankston University Speech & Hearing Clinic (SHC)	
Denise Masters	Faculty Audiology Supervisor
Rob Anderson	Faculty Audiology Supervisor
Darla Stacy	Faculty Audiology Supervisor
Denise Andersen	Faculty SLP Supervisor
Sally Ernst	SLP Graduate Student
Shelley Oldham	SLP Graduate Student
Jessie Johnson	Audiology Graduate Student
Maxine Williams	SLP Graduate Student
Olivia Price	SLP Graduate Student
Ross Atkins	Audiology Graduate Student
Callie Wright	Audiology Graduate Student
Vickie D'Angela	Audiology Graduate Student

Table 2 (cont.)

Professionals involved with Jena by Agency

Name	Role
Hill County Public Schools	
Leigh Murphy	Preschool teacher of Hearing Impaired children
Carla Fuentes	Teacher
Margaret Cordes	Student Teacher
Leigh Schowalter	Director of Special Education
Brenda Andrews	Bus driver
Columbia School System	
Jeanne Nance	Teacher
Kathy Shelton	SLP
Amy Istre	SLP graduate student

there are several teachers, and has had at least two different bus drivers who transport her to school and back each day.

In addition to their interactions with Jena and her family, these mesosystems are linked and interact with each other in complex ways. The university students complete practicum assignments in the hospitals, private practices, and schools where they are supervised by the audiologists and speech-language pathologists employed in those settings. Audiologists in private practice contract with the Child Health Agency to provide hearing aids to children seen through the clinic. Hearing impaired children who attend public schools or are served by the early intervention program are frequently clients of the university speech and hearing clinic and the Child Health Agency. Findings revealed that this densely connected network of formal and informal service providers both facilitated and constrained the sign language learning of Jena and her family. The network provided care, but not cohesive, efficient, or comprehensive care. The bureaucracy had a system for hearing and audiological follow-up, but the plan for ensuring communication and language learning was not as systematic. While the speech-language pathologist who provided services through the early intervention program did initiate Total Communication with

Jena, the system did not address the family's sign language learning. I asked Leigh Murphy, a preschool teacher who worked with Jena, if there was a systematic way of teaching parents sign language through the school system, and she said "No." She thought that services were scattered. Abby and Luke indicated that their decisions concerning communication mode choice were largely influenced by Rachel Holder, a woman they knew through their church. Her role in the family's sign language learning is described below in the section titled Contexts.

Institutional Processes. Several themes about institutional processes emerged from this study that are worth naming, even if it is premature to draw any causal links between them and Jena's language learning situation, that of her family, or other families in similar circumstances. The first concerns the agenda for the development of the deaf child. One of the categories that emerged from my open coding of the interviews, field notes, documents and records, and my own journal was **the menu without consequences**. Parents of deaf children, including Abby and Luke, are offered an array of choices for communicating with a child who is newly identified as deaf (see Schwartz, 1987). These choices are presented as equally attractive entrees on the menu of life, and the

choices are, according to one of the professionals I interviewed for this study, “strictly up to the parents.” Like the exclusive restaurants which do not list prices for their attractive entrees, the people doing the presenting of choices rarely list the potential costs of the options they present, or, more importantly, any plan for knowing whether the option is working. Institutional policy reinforces the individual who feels compelled to offer such a menu. The official institutional policy of the Virginia Department for the Deaf and Hard of Hearing is one of **neutrality** concerning communication mode decisions (Brad Staton, personal communication). Some service providers were cautious or neutral in offering advice. Marlene Rogers was an audiologist who fit Jena with hearing aids.

Marlene: In their case, it was different because they knew she had a hearing loss before she came here, so, you know, they were past the point of denial and all that, so they, they came here mainly for the help. But I had given all that information, and, ..pretty much at that time, said,... “You know, these are the options. It's up to you what you want to do.”

Rob Tranchin, Thomas' father, described how educational choices were presented.

Rob: Time for preschool. We had a choice. We could put Thomas in a class where the teachers used speech supported by sign or a class which used speech only. We choose the speech only classroom. It seemed obvious. ... That's what we wanted. We wanted our child to be like us.

When I returned home from Brooklyn, it was time to evaluate Thomas's progress in school. Laurie and I had to decide if we wanted to keep him in the oral class or expose him to sign language. We were under a lot of pressure about Thomas and sometimes it made life around the house pretty tense.

Thomas' speech and language had improved, but not enough for either of us, and the evaluations at school were depressing. We wanted Thomas' school to help us make a decision about whether or not to introduce Thomas to sign. But the school would not make a recommendation. They said the decision was ours.

An examination of the diagnostic chronology that led to the confirmation of Jena's deafness explains part of the institutional caution that delayed her language learning and that of her family.

Time works relentlessly against deaf children. Regardless of the age when a child is identified as deaf, language learning time is lost. Even though the results of the hearing aid evaluation in September, 1991, suggested that Jena's hearing loss was aidable,

she did not have hearing aids until near her first birthday. She **did not hear** human speech for at least her first year of life, and there is no conclusive evidence that she ever heard human speech for any length of time even with the hearing aids.

Jena's loss was suspected before she was a month old, and confirmed by the time she was three months old. She was seen consistently for treatment of her middle ear disease, and she was referred for hearing aids at the time her loss was diagnosed. While the response to her hearing loss was timely, the response to her **language loss** was not. Her sign language learning was not really started until she was between 10 and 11 months old, and she did not have hearing aids fit until she was about one year old. Even when her language learning was initiated, there seems to have been more emphasis on Jena's language learning than her family's. The family picture was not entirely bleak, though. As indicated earlier, multiple and intertwined time-related factors either facilitated or delayed the family's sign language learning.

Conditions That Facilitated Family Sign Language Learning

Acceptance of Deafness

Abby described her family's coming to terms with Jena's

deafness as a gradual process with a conclusive end product, acceptance. She talked about acceptance in reference to their decision to begin using Total Communication with Jena.

Abby: I guess we just came to accept that this was, unless there was going to be divine intervention, this was how she was going to be. You have to come to a point where you say "Okay, his, these ears are not doing what they are supposed to do. We can't utilize anything with these ears, we can't make Jena hear. So, what can we do to help Jena be aware of sounds in her environment, if we can't amplify sound to any level to make her hear them?"

Addressing Communicative Needs: Child Centered Practice

An early intervention team evaluated Jena in April, 1992, and together with Abby and Luke, developed an Individualized Family Service Plan (IFSP). Jena began being seen for physical therapy once per week for 45 minutes per visit, for visits from the infant educator for one hour per week, and for speech-language therapy once per week for 45 minutes. Jennie Harris, the speech-language pathologist, recommended total communication, the use of signing, speech, lipreading, body language, and any other means of communicating. At first, though, Jennie's initial focus was on feeding.

Jennie: Yeah. That was the initial, um, .. primary purpose for me being in there. It was not the hearing loss, And not the language at all. It was "Let's gain some weight. This is a .. teeney-tiny child." We were in there before surgery. Because I do remember we did need to work on feeding. And that was real difficult, .. early on. She just, she was just a kid who didn't want to eat.

Jennie indicated that using total communication had always been her philosophy, especially with young infants, because young infants are not going to be able to choose (a communication system) right away anyway. She offered a simple, and rather startling solution to the dilemma facing parents who are trying to decide which method or mode of communication to use with a deaf child: **let the child choose.**

Jennie: So, And I guess, my feeling is early on, you've got to give .. the kids and the families .. every opportunity to communicate that there is. and whatever they, however they choose to communicate, ..they can choose that if they've had the options ... presented to them.

Once again, the manner in which the information was presented was important to the family.

Abby: It's just what you do, you know. She can't hear, she has-, and her-, see, the way Jennie said it to us, too, probably: "Jena needs a way to communicate right now. You know, maybe she'll be able to learn how to talk later, but so she's not frustrated **now**, we need to give her some way to communicate her feelings now until she can learn how to use her hearing, and use her voice. So, she gave us **hope** that this was the first step

Luke: Yeah, I know, it just seemed... (trails off, but agreed strongly with Abby nonverbally).

In contrast, throughout the Tranchin videotape, Thomas' communication needs are ignored. In one particularly vivid scene, Rob Tranchin described the emphasis placed on Thomas' talking ability.

Rob: We were told that Thomas was not a candidate for cochlear implant. Laurie and I still wanted him to talk. And that meant hours of speech therapy.

The next scene shows a speech-language pathologist (SLP) in one room of a sound-treated suite.

SLP: Thomas, listen. Buh-Buh-buh."

Thomas, who says very little that is understandable, turns to his father with an anguished look on his face.

Thomas: Daddy, Daddy. Daddy, buh-buh NO!

SLP: You heard it, Thomas! You were listening!

Thomas: No, Daddy, buh-buh no. Don't want it.

Family Culture of Inclusion

Repeatedly throughout this study, the Byers family talked about wanting Jena to fit in and to be part of their family as well as part of Deaf culture. They understood that they would have to accommodate to her. One of the most important contexts for the Byers family's sign language learning and enculturation was a serendipitous one, their church. As indicated below, the church offered many forms of support to the Byers. Through church, they met Rachel Holder, a hearing woman whose parents are deaf. Once Abby and Luke came to accept that Jena was going to be deaf, they formed many of their opinions about Jena, her deafness and how they were going to respond to it, with Rachel's help. Before Mica was born, Rachel would babysit for Jena, and spend time with her and just sign with her. She also taught Abby and Luke signs. Abby and Luke came to depend on Rachel for her feedback, for her opinions, and her guidance. Knowing that she had 2 deaf parents and that she worked with the deaf community all the time was reassuring to them.

Claire: Was there something about her that was calm, not scary?

Luke: Yeah. Yeah, she did lots, showed us a lot. I got a lot of good advice about deaf people, how the deaf culture, how they really.. were. And, would tell us about, like you said, how people perceive them ..to be, and things, and how it wasn't

Abby: (interrupting) stereotypes?

Luke: Really the way, you know, it happened.

Rachel introduced Abby and Luke to her parents, They said that Jena took to them immediately.

Abby: The impression that I've gotten from Rachel about ... just the impression I get from the deaf community is that there are so many parents who are unwilling to sign with their kids. And not only parents, but even if the family does it, the other family just..** it's almost like leprosy, you know, they just don't know what to do with that child, they don't know how to talk to that child, an- um, I, I've never gotten that. ** From any one in my family.

Abby: If that's the only choice, to send her to the School for the Deaf, we are moving there, and she's going to come home to our house every night. I heard, well, if that's what's best for her, then you need to let go of her. I mean, I could never let my baby go. I can't just let her go. She needs to be with her

family. I want her to have the values we have, I want to teach her, you know, want her to know we love her.

Luke: I heard on the news an example, like a 14 year old deaf girl who was, that kind, basically wanted to disown her father because he didn't want anything to do with her. So she wanted to live with this woman who, her teacher who would sign to her... I've thought about that, and that is sad. I thought, "Man, I wouldn't be able to ..talk to my daughter."

Abby: That's our main-, I guess our whole thing is, we want to be part of her life. I mean, so, it's never been an option.

The Tranchin family viewed accommodation differently.

Throughout the videotape, Laurie and Rob shared their disparate opinions about how to respond to Thomas' deafness. In this scene, they argued about changing the oral approach they have used.

Rob: We have a child who's ...different from us and we've gotta, you know, totally reevaluate...our... relationship to him and consider other relationships to the world that don't include hearing.

Laurie: You know what I'm thinking? I'm thinking.. okay..it's like having a child not born with with legs, but fins, and, and, all of a sudden, you're going "Oh, my gosh, we've gotta to live in water (said with rising volume, indignantly). This child doesn't belong here on land. This child needs to go somepla.....Is that

what you're saying? I mean, because that's, I mean, that's to me as dramatic a change. Where we have to do...go find him a deaf home? And put him in a deaf community? We don't live in a deaf community. We live in a **hearing** one, Robbie. That's **our** family. **We** are Tommy's family. **He** came to us.

Rob: Yeah, but we can come to him.

Laurie: Well, I'm not saying we can't, but I think we need to determine **when**, we need, he needs, to, he needs to be in a position to be able to say "This is what I want."

Contexts for Family Sign Language Learning

Church

One family member's interest in sign language actually predated Jena's birth. Jena's Aunt Beth became interested in learning to sign in grade school. She explained how she became interested at such a young age.

Beth: Well, there was a blind lady in the church with a seeing eye dog. And I, I would like, I liked that, but I really, for whatever reason, I thought, "You know, we can talk to her, and communicate to her in church, but what if sh-, they were deaf? They wouldn't understand." So, I went to the library, and I got some sign language books out, and I started learning, and Abby was helping me and Joanne, and we all three sat down and started learning it. But I just kept learning it, and I

learned the worship songs, and I started signing them in church, ** and then as I got older, I went to worship seminars where they had signing as a, incorporated into the worship, then I started interpreting for the worship, for my church.

Beth was interpreting songs and teaching the congregation some signing by the time she was in tenth grade. The church was started by Abby and Beth's father, Lawrence Solberg, who was the pastor. Beth was not the only person to have had an interest in deafness and deaf people before Jena was born. Abby's mother, Celeste Solberg, indicated that, before she met and married Lawrence, she had originally planned to go and teach at the school for the deaf associated with their church.

Church was the setting for the family's first formal class in sign language. Rachel taught their first sign class the fall semester of 1993. Abby, Luke, and Lawrence Solberg, Abby's father, all took the class. Celeste Solberg was not able to because she was studying for her Master's degree and had a class that same night. The last class meeting involved a silent dinner at a local restaurant with deaf people. Abby and Luke recalled being unable to understand the rapid signing of their deaf dinner companions.

Community College

Abby and her sister Beth began to take sign language classes through the interpreter training program at a nearby community college in the summer of 1995. Their instructor, Lee Johnson, told me that he learned to sign about 30 years ago. He was an electrical engineering and computer major in college, working at a television station that broadcast church services for deaf people. Lee got involved both through his church work and through his technical interest. Lee spent a lot of time immersed in the deaf community, went to the Deaf club, and told me that he was the first hearing person to be the vice-president of the local chapter of the Virginia Association for the Deaf. Lee was hired at a state school for the deaf, where he put together programs to help the dormitory parents, maintenance people, and others at the school learn sign language communication skills, because they did not know how to sign. He said he thought it was important to emphasize the need to communicate; if a kid had a bloody nose, it was not important to worry about English word endings. He used the Vista Signing Naturally Video series (Smith, Lentz, & Mikos; 1988). He completed a two week immersion program, building the class around vocabulary, emphasizing understanding first. Lee taught sign language classes

for the National Association for the Deaf, started a deaf ministry at a church in Tennessee, completed a degree in Sociology. and served as an interpreter for a term at a school of electronics. He was involved in forming an interpreter training consortium, and worked with others at Gallaudet University to train trainers of interpreters. Lee said he became a member of the Registry of Interpreters) when "it meant something."

I asked Lee about his recommendations regarding sign language learning for families like Jena's. He recommended that they attend community group meetings, such as the Hands Group that meets locally. He told about a family in a community two hours away who was learning sign through the videotapes broadcast to them locally. Lee felt that families could take the beginning and intermediate classes, that auditing is an option. He strongly recommends taking classes, saying that "you get what you pay for." For distance learning, for credit or not, a three-credit class costs \$154.95.

Family

Abby and Luke's family has been supportive and have made an effort to learn how to communicate with Jena. Beth Solberg currently works as a sign language interpreter for a teenager girl in a nearby county school where the girl attends classes with hearing

children. Her sign language learning is continuing.

Luke's mother, Eve Byers, took one sign language class at a community college. The class met two evenings a week and had about 10 people in the class. She did not get to go to all the classes because of her changing work schedule. No other people in the class had any deaf family members. Her instructor was a hearing man who works as an interpreter in the local school system. Eve said she would like to get into another class, a basic class. She would like to work harder on it. She said you tend to get lax. It worries her that she is getting older and it's going to be more difficult for her to learn. She said that Jena is so much better at signing now, that communication is a problem, since "she has by-passed us all." She depends on her other grandchildren (ages 10-16) to help her communicate with Jena. The oldest can just take the book and go through it, and learn things in an evening. Both Eve and Abby have said that Bud Byers, Luke's father, has had a terrible time accepting Jena's deafness. He doesn't see how this has happened. If they are out shopping, and he sees something that he thinks Jena should have, he wants to buy it, but Eve has to remind him that "it won't mean anything to her because she can't hear it." and he becomes upset, because he wants to do a lot for her.

Other family members depend on Abby and Beth to help them communicate with Jena. Luke's sister Paula, Abby's sister Joanne, and Abby's brothers Lawrence and Jack responded to my letter of inquiry. They all indicated that they wanted to take a class, but had not been able to. Lawrence said that expense was a factor when he and his wife had looked into taking a class when he was a graduate student. He also commented that one class that they had investigated at a community library was basically about fingerspelling. He said that "no one learns a language that way," especially a 4 year old child like Jena."

Several challenging tasks face Jena's family as they learn to communicate with her. One is a chronosystem problem: infrequent opportunity to use and practice signing with Jena or anyone else. The family gets together two or three times a year, for just short visits, and in between visits, there simply is no opportunity to keep up. Even Jena's grandparents who live in the same town struggle to keep up.

Celeste: Well, I think, I think we've both really been ..frustrated with that. Um, the girls were taking a sign class, and I watched the videos some, but uh, with us not using it all the time, and I mean, I don't know, but it's just, it's hard to remember it all. I'm able to do a little bit more than say horse

or cow now, but I still feel so limited in communicating with her.

They are also frustrated because Jena signs like a child, and their classes have taught them to sign with adults.

Lawrence: Like .. any child learning to speak, they don't speak clearly, and she didn't sign clearly. Like the sign for bear is like this (makes sign) and she would just go like that (makes a one-handed variation of the sign) with one hand.

Claire: (laughs) really fast.

Lawrence: and you were supposed to know what it was. And I'd catch just snatches of, of a sign. Okay. And it's just like, "Oh!" You're, you're kind of racing (laughs) to try to catch up and stay with her. And then, uh ..I think, I think like she said, not using it every day, you know it's like, "Okay, what was the sign for if?" You know, and you can't remember.

Celeste: When she was real little, all we knew were isolated signs. That was what she was doing. And it was always connected, like if we saw something on television, or saw something in a book, and one time she, the first time she did this, she had gone .. to her Grammy and Pappy's house, and she came back, and she came back, and she was telling me .. about the dog, and it was the first time she had communicated something that wasn't just what we were observing right now.

The other big challenge is that Jena has 8 cousins, a two year old brother, and another brother on the way. All these children, all under the age of 5 years, have struggled to communicate with each other to negotiate play, to interpret each other correctly, and to solve problems. One problem seems to be that they simply do not understand what deafness means. The family has patiently explained that Jena's ear's are broken, or that they don't work. They tell the cousins to talk with their hands, but these very young children, just in the process of learning language themselves, either speak more loudly or decide that Jena is "grumpy" or "stuck up" because she will not talk. One other recurring issue is the tension created by the children's tendency to solve their problems by hitting, fighting, scratching, and pushing. Family members have different ideas about how to react to that situation.

Lawrence: Then as she got older, she was so rough in her play, and I think it was because she could not hear .. the child complaining. And I think within the family, even, some people thought that she should .. ah, be treated like a normal child, and I said, "Well, that's true to a degree, but she does have special needs and you do have to consider that."

Claire: What do you think they meant by "treating her like a normal child?"

Lawrence: How, how she would, like if she hurts a child, then she would be corrected, um, in the same way that a hearing child would be corrected. And we said, well, you know, she doesn't understand the same thing. Yes, she, she can't just go around and hurt other children, but she doesn't understand the same way that a hearing child would understand.

Abby's sister Joanne spoke about this issue. Her three year old daughter Serena signs a little. She signs PLAY, EAT, DRINK, and now she knows SNAKE. Joanne has to take Serena aside and practice with her and teach her about the signs before they visit Jena. Joanne said several times that is is very frustrating for Serena because of the hitting that goes on between Jena and Serena. She says that Jena hits Serena, but doesn't get in trouble for it, but if Serena hits Jena, then Serena gets in trouble. She said that Serena is the type of child who will hit back if someone hits her. Communicating and just being around Jena has been stressful for them, because "Serena is always the bad one." Joanne said that she has been able to help Serena by telling her that she has to treat her Jena the same way she treats her younger brother: by gently showing her things first and using a lot of gestures.

School

When Jena was referred from the early intervention program to

the Hill County school system, Leigh Murphy, a preschool teacher for hearing impaired children began to play an important role in the family's sign language learning. Abby described Leigh's role as very influential.

When I asked her to describe her role in the family's sign language learning, Leigh said that Abby had run into Rachel Holder long before Leigh ever knew the family, and Rachel was a large influence. Leigh said Abby told Leigh that "We need to teach her ASL." Leigh said she told Abby that she wasn't fluent in ASL, that she would only be able to use a form of Pidgin Signed English (PSE).

Leigh saw Jena for home visits for a year before she started preschool at a university lab school. When Jena moved on to the preschool at a university lab school, Leigh went to school every day with Jena for the first half of the year, then she had a student teacher, Margaret Cordes, who was really good in sign language, who stayed with her the second half of the year. Leigh said that the lab school teacher, Carla Fuentes, was really good with her. Carla was really interested in trying to communicate with Jena, and made an effort to sign to her, even though she only used one or two signs at a time. Leigh continues to visit her at the school program for hearing impaired children in Columbia. Leigh is the teacher in Hill County

who is responsible for follow-up.

When I asked Leigh about what she thought was the best way to help parents learn sign in a case like this, Leigh felt that seeing Jena at home was very helpful. She said several times that Abby has the desire to learn sign language. Leigh said she helped Abby get the whole series of sign language videos about the deaf family going about their daily routine; the videos were obtained through the Parent Resource Center. She also helped them get a captioned TV. We came back to the subject of Rachel's influence. Leigh said she told Abby that Jena would have to learn Signed English anyway because she needed that for reading and writing.

We talked about the lack of a systematic plan for family sign language learning. There are classes at one of the middle schools for teaching the children sign language. Leigh teaches a 6 week course through the YMCA, and said that a typical class begins with 36 people and then dwindles down to about 6 by the end. I had this same experience when I attempted to teach through church. Leigh said that learning sign is hard.

Jena now attends preschool in a regional program in a public school in Columbia, the same city where Luke works. Abby and Luke felt that they had to convince the special education director in Hill

County that Jena should not be included in a regular classroom with hearing children and a sign language interpreter. They wanted her to have deaf friends, and teachers who were used to working with deaf children and who knew the adult deaf community. The program in Columbia offers a weekly sign language class for parents early on a weekday afternoon. The coordinator of this program feels strongly that parents of the children in the program must sign. If the children go home to a family that does not sign, the coordinator considers them to be multi-handicapped, not just deaf.

Intervening Conditions That Constrained Sign Language Learning

Bronfenbrenner (1986) said that the psychological development of children is affected by domains which the children rarely enter, such as the parents' world of work. He termed these domains exosystems; they include parents' support systems, their friends and the community. In the Byers' case, I learned that important exosystems were not external to Jena, because those systems directly affected the family's sign language learning. Many exosystems were really not separable from chronosystem issues. These systems overlap, are intertwined, and all have paradoxical contributions to the family's sign language learning. I nearly failed

to delve into this issue. Why I would overlook an issue (balancing family obligations with my own world of work) that requires my attention every single day, I do not know. It is important, so important that it probably deserves individual attention of its own in another study.

I did ask Abby today about work and what role work played in their sign language learning and Jena's. She had a lot to say about that. She said that it mostly affected Luke, since he had to work full time. After a day at work, which is an hour away from home, to come home and have dinner and put the kids to bed, then try to look at sign language video tapes is very hard for him. Abby has worked part-time most of the time since Jena was born. She said that when she worked a 30 hour job, Jena really missed out, because she had to stay with a sitter who did not know sign language, and did not know to communicate with her. Jena did stay with Rachel Holder for a while, and that worked out very well. She also talked about how much Jena's frustration level dropped when she began staying home after Mica was born. She said it dropped from about 80% frustration to maybe 20% frustration, from her having temper tantrum after temper tantrum, to just accepting that when Abby said no, she meant no. Being at home and not feeling guilty about being away from Jena

made it easier for Abby to respond firmly to Jena's requests.

Jena also has a hard time understanding why Luke is not home during the day. Luke was Jena's full time caregiver for the first few months of her life before they moved here. They were very close, and when Luke began to work full time, and Abby and he switched roles, Abby felt that Jena was mad at him, because she missed him. Jena signs about her dad all day, asks if he is at work, and then when he comes home, Abby thinks she gets mad because he has been gone.

The Realities of Sign Language Learning

Which Language is Learned?

While Abby began the process of becoming enculturated in the language of the deaf community with enthusiasm, not all the professionals who continued to work with Jena were fluent in ASL. Like them, I am not fluent in ASL, either. In actuality, the sign language used most by the Byers, by me and the others at the university clinic is Pidgin Signed English (Maxwell, 1990; Mayberry, 1993), which means using ASL signs in English word order without the morphological variations that are used in manually coded forms of English. The primary language used by school teachers is Signed English, with ASL being used for clarifying aspects of story telling

that the younger children do not understand. The deaf children sign all day at school, five days a week, with adults and peers, about a variety of curricular topics. The hearing parents are signing with the children after school, but it is easy to understand how some deaf children leave their hearing family members behind in signing skills unless the family members have a plan for keeping up and keeping ahead. Even if family work schedules do not interfere with weekly parent sign classes, it is easy to see how family members such as grandparents and aunts and uncles get left behind.

Summary

A serious heart condition, a palatal cleft, middle ear disease associated with the cleft, and diagnostic uncertainty delayed the acquisition of language learning in a young child who is now five years old and completely deaf. At least thirteen community institutions, and more than 50 professionals, have been involved in the child's care. The focus of most of her communication-related care in the first year was on her hearing loss, with little attention devoted to the language loss that was subsequent to it. The persons most influential in helping the family decide how to communicate with the child included the hearing daughter of 2 deaf parents who

the family met through their church, a speech-language pathologist who provided early intervention services in the home, and a preschool teacher for hearing impaired children who worked with the child both at home and in a hearing preschool setting.

Despite the mobilization of effort in response to the identification of the child's profound hearing loss, very little of the advice given by most professionals concerned the child's language learning, and even less advice concerned how the family should and could learn sign language. While the child's parents, an aunt, and her grandparents have taken a sign language class, other family members rely on the child's mother to provide them with the language needed for communication with the child during their infrequently visits.

Discussion

Multiple and Paradoxical Contexts

Deafness is a paradox. Deafness has historically been defined by what a person does not hear, but not hearing normally is not the sum total of the problem created by deafness. Deafness also means not being able to communicate, to use language, and to fit in a family and a community, unless special measures are taken.

The question asked in this study was “What are the sign language learning experiences and contexts of a hearing family when the parents of a deaf child decide to learn and use American Sign Language (ASL)? Multiple informants including both professional and non-professional participants, and multiple methods of data collection and analysis provided some answers to that question. In this chapter, the answers will be examined through the lenses of multiple theories.

Family Ecology

Figure 3 is an eco-map depicting the three generations of Jena's family and the people and institutions involved in her care. If nothing else, this type of eco-map should remind practitioners that

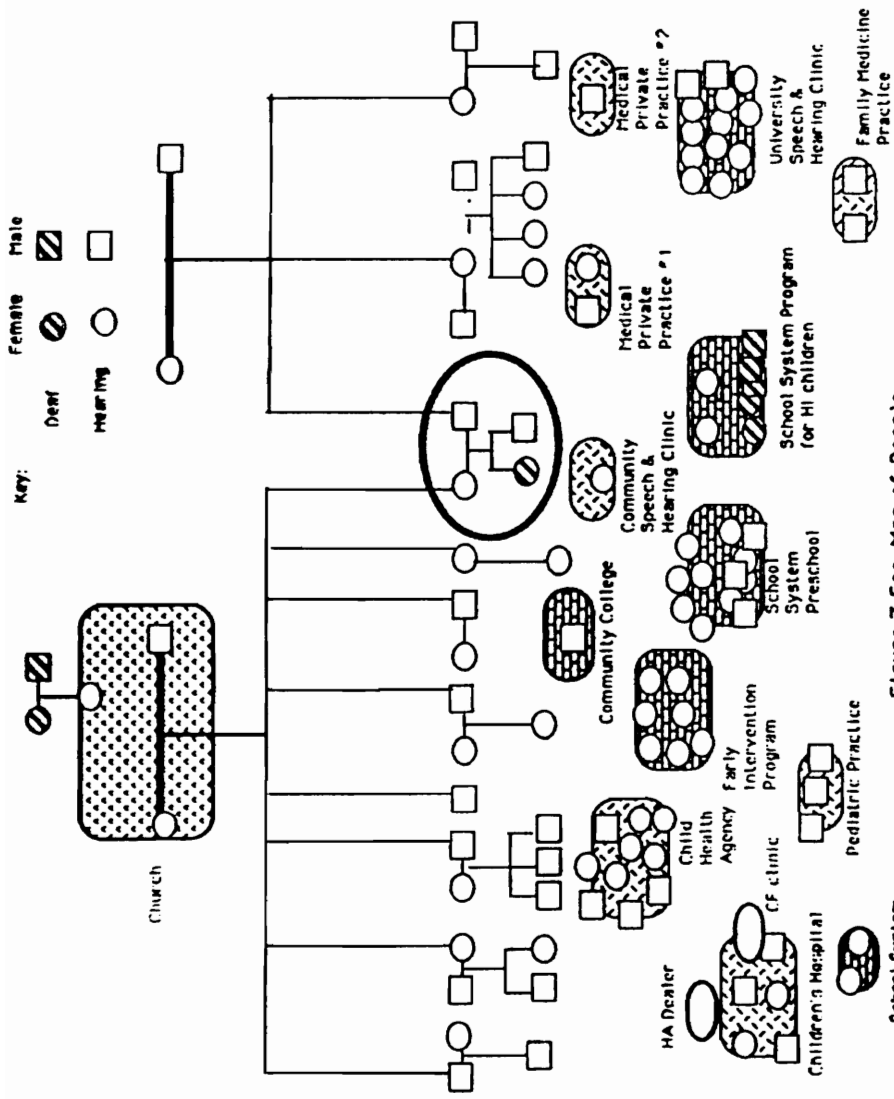


Figure 3 Eco-Map of People and Institutions Involved

children develop in complex systems within families and communities. The map should also emphasize the realities of a deaf child's family communication needs. Deaf children typically have hearing parents, but very little is written about their hearing siblings, cousins, aunts, uncles, and grandparents. Examining the family's experience using a theory of family ecology showed that mesosystem, chronosystems, and exosystems overlapped and intertwined, sometimes providing support for Jena and her family, and sometimes obscuring their path to mutually satisfying communication. Virtually every agency, individual, and institution involved in this child's care both constrained and facilitated some aspect of her communication and language learning and that of her family.

The Byers' experience in the context of the children's hospital provided an initial standard for hospital-home communication and expectations. Jena's life threatening heart condition was fixed; but her irreversible hearing loss was only identified through screening and confirmed by evaluation. Abby and Luke heard some complex messages delivered understandably, without false hopes and without a message of hopelessness. Other messages were equally complex, but not understandable or hopeful. Professionals who assessed

Jena's hearing and treated the middle ear disease that was thought to make her hearing loss worse recognized the urgency of her situation and responded quickly and consistently to try to provide improved hearing. No such urgency ever characterized a reaction to her lost language learning time, or her future language learning needs.

The early intervention team used a family centered approach, and the speech-language pathologist recommended a communication strategy, total communication, that allowed the child to be successful in communicating. The trail of written records revealed no evidence that language learning was viewed as a more urgent need than any other aspects of development, such as her gross and fine motor development. On the first IFSP, outcome objectives concerning language skills such as following directions appeared to have equal weight with fine motor skills such as "Jena will make marks with a crayon." Jena was seen weekly by an infant educator and a physical therapist who did not sign, and only 45 minutes weekly by the professional who did sign. Several of Jena's developmental evaluations were completed by individuals who did not indicate whether they were fluent signers or knowledgeable about sign language. The professional who first introduced sign language to

Jena estimated her own signing skills as “similar to a two year old.” The early intervention plan (IFSP) did not include any plan for the parents or others in the family to learn sign.

The Byers' family church provided support in many forms. Through the church, the family met Rachel Holder, and her parents, the deaf adults that the family mentioned interacting with after Jena was found to be deaf. Through the church, they took their first sign language class. Yet, not every person at church who interacts with Jena understands her unique communication needs. Her Sunday school teachers and the other children do not know much sign language, and her family is concerned about her feeling isolated in a context that provides the rest of them a core of strength.

The community college where Abby and her sister took sign language classes is a repository of linguistic skill and cultural knowledge, and the classes are offered in a flexible format, through distance learning as well as in more traditional didactic formats. The college offers a variety of sign language learning tracks, from a certificate for those members of the community who just want to learn ASL, to more advanced educational interpreter training programs. The classes are geared toward communicating with deaf adults, and the early emphasis in the classes is on the learner's

comprehension of sign language. Abby and Luke have had difficulty taking the classes together, both for scheduling reasons and financial ones. Abby is eligible for grants because she is interested in interpreter training, but Luke is not. The language taught in the community college is ASL. I am forced to ask why the plan for training interpreters is more complete and productive than a plan to train family members to communicate with their children.

The context of the Byers' family network which includes their parents, their siblings and their spouses, and Jena's cousins provides consistent emotional support to Jena and her parents. Abby, Luke, Beth, and Jena's grandparents use the collective pronoun **we** when they talk about responding to Jena's needs. They have learned sign language together, though at different paces. That support is illustrated in these comments.

Abby: Yeah, ..I think you know, I bounce everything off my mom, you know. Our families have both been real supportive, and I have so much frustration with it, you know, and sometimes I don't know what to do, and especially with this education thing. "What if I do the wrong thing, you know, what if I, you know, mess her up (laughs) for life, you know, ..and my mom, you know, ..it basically came to the point, you know, where she would tell me, "You do what you think is best now, and if it's the wrong decision, you can change it in the future. And she said, you

know, as long as you love Jena, and you're trying to do what's best for her, she said, you know, she just really encouraged us.

Abby's sister Beth described how important their church was in helping them cope with Jena's deafness.

Beth: It's very important. I mean, we have all prayed together,.. as a family. We constantly pray for Jena. And we've seen her improvement. And, you know, we have the support of the, of the church. And we've had problems within the church, because of.. Jena being deaf. But, you know, the Bible, we, you know, we know God made Jena. And God loves Jena, and God has a special purpose for Jena, and she is very precious. God has put us here, to give Jena what she needs. And so we need to be good stewards. And so, you know, we draw on the Bible, and stuff, and we believe..you know, God is going to do something, but we need to do our part. We need to..give Jena the language. We need to let her.. and she.. might be just, you know, a really good force in the deaf community.

Investigation of the family context revealed some unseen and obvious needs. The obvious needs are those associated with the infrequency of using sign language. Family members who only visit Jena two or three times a year, as well as her grandparents who do not see her daily, struggle to retain their signing ability. The family members who have studied sign in a formal class have no plan for

retaining what they have learned, yet all express the understanding that their learning is incomplete. The unseen needs are those of Jena's young cousins and her brother. The family is committed to communicating with Jena in sign, but the children in particular are limited in their ability to do so. The adults who do not sign are not likely to be involved in physical contact such as hitting, pushing, or scratching as a result of a communicative impasse, but the children fall back on these means of solving problems when they cannot communicate quickly and easily.

The family's work schedules have made it difficult for them to attend classes, and perhaps more importantly, when Abby has had to work at times when Jena was not at school, Jena stayed with babysitters who did not know sign.

Family enculturation

It is interesting to compare Jena's family's process of enculturation with that of the family of BoMee, the Korean-American deaf child described by Wilcox and Corwin (1990). Table 3 summarizes some of the similarities and differences in these families. The major differences are linguistic. BoMee's parents were fluent sign language users who were enculturated before BoMee joined their family. Jena's family is more typical of most families

Table 3 Comparing Enculturation

	<u>Jena</u>	<u>BoMee</u>
Hearing Loss	Profound	Profound
Family	Parents hearing Younger brother hearing Multicultural Grandparents, aunts, uncles, cousins either took sign classes or learn PSE vocabulary from parents	Parents hearing Younger brother hearing Multicultural, Multilingualistic Grandparents, aunts, uncles, cousins either took sign classes or learn PSE vocabulary from parents
Sign Language (SL) Background of parents	Parents did not know sign Visits from deaf adults rare Has sign language video tapes of children's stories	Mother signs English & PSE Father has B.S. degree in SL interpreting, is fluent in ASL, Signed English, & PSE Frequent visits with deaf adults Has sign language video tapes of deaf adults telling stories

Table 3 Comparing Enculturation (cont.)

	<u>Jena</u>	<u>BoMee</u>
Identity	<p>? understanding of what it means to be deaf</p> <p>Learning about healthy interactions with hearing people</p>	<p>firm understanding of what it means to be deaf</p> <p>Healthy interactions with hearing</p>
Watching others think	<p>Problem solving is emerging as parents learn to sign their private speech</p>	<p>sophisticated problem solving; parents sign private speech</p>
Sociolinguistic Variation	<p>? whether Jena knows why deaf & hearing people communicate differently</p> <p>-frequently signs to brother when he can't see her, but also uses single signs or two sign combinations to Mica</p> <p>Early affinity for ASL</p> <p>Learning PSE, English, ASL ? which is dominant</p>	<p>Knows about variations in communication</p> <p>Early affinity for ASL</p> <p>ASL preferred, written English is second language</p>

into which deaf children are born. They were not fluent signers when Jena joined their family, but they are in the process of enculturation. The Byers' family has not had the opportunity to interact with adult members of the deaf community on a regular basis, a situation which will be addressed below.

Institutional contributions

The picture of institutional contributions to the Byers' family sign language learning is a muddled one. Multiple institutions, including medical, social service, and educational professionals, were certainly involved in Jena's care, but the institutions did not have nor implement a cohesive plan for the family's sign language learning; neither did the institutions present a cohesive and consistent plan for Jena's communication and language learning. Some professionals, perhaps in an attempt to make certain that the family was provided with information about educational philosophies, tried to remain neutral and deferred the decision making about communication mode and educational needs to the parents.

Rob Tranchin, producer of For a Deaf Son, (personal communication) called this type of policy **institutional dishonesty**. Another name for a policy that asks parents to assume

the burden of deciding what is best for a deaf child is **institutional dereliction**. Professionals who have graduate degrees in deafness related professions have spent years studying how to respond to deafness. I have asked my students in junior level college classes in language development to estimate the numbers of hours they have spent coming to their understanding of language, speech, and hearing. They roll their eyes and laugh. They cannot even estimate the number. Even if they do not read any of their assigned readings, and most of them do, they spend about 42 clock hours in the classroom for each class in their curriculum. That is 42 hours for just one class, the first of 20 some undergraduate and graduate classes they need just to graduate from college with minimum professional credentials. Even a poorly trained student has an enormous informational advantage over the parent who suddenly discovers that a child is deaf. I do not suggest that professionals ought to have more clout than parents when it comes to deciding how the family will communicate with the deaf child. I do suggest that a menu of choices must contain realistic statements about costs and consequences of choices. Professionals need to recognize that the parents must have enough time to understand what is involved with each child's situation. Similarly, professionals who assume the role

of advisor about language and communication needs must be fully informed themselves about the language and communication consequences of using an oral or manual or Cued Speech approach with each individual deaf child. The most obvious test for the success of a communication choice ought to be measures that show how well a child's language development is progressing, regardless of the mode used to express that language. Such a confirmatory approach is rarely taken.

Violations in the Zone of Proximal Development

A return to Vygotsky's (1978) concept of the zone of proximal development is helpful for examining the language learning paradoxes that emerged in this case study. Vygotsky viewed the child's social interaction with adults (who can be assumed to be more capable linguistically than the child) or more capable peers as essential. Within the zone of proximal development, adults or more capable peers negotiate with children so that they can achieve some mutual agreement about a situation, using language to mediate the negotiation (Wertsch, 1984). Writing in the Afterword to Vygotsky's (1987) Mind in Society, John-Steiner and Souberman reminded us that Vygotsky viewed learning as a profoundly social process that "emphasizes dialogue and the varied roles that language plays in

instruction and in mediated cognitive growth” (p. 131).

I began this study with a frame of mind that located the blame for the language learning struggles of deaf children on their hearing families, at least in situations when professionals decided that the best way for the children to learn and interact was through sign language. What I have learned is that I was just as guilty of placing the blame in the **parents** as other researchers were inclined to locate blame for language learning failure in deaf children. A contextual and ecological look at this family that did decide very early to use American Sign Language with a profoundly deaf child revealed that even the most motivated parents encountered a system of service delivery that essentially ignored the profoundly social process of language learning for both the deaf child learning a first language and the family members who are trying to learn a second one.

The system approached service delivery with a theory of language acquisition that is better described as the Twilight Zone than the Zone of Proximal Development. That is, the professionals reacted to Jena’s language learning needs with vague or strange understandings of the qualitative and quantitative differences experienced by a child in her situation, and no systematic plan for

ensuring that Jena's first and most important language learning context, her family, would be able to provide a rich language learning environment. In addition, they neglected to consider the language learning child's need for scaffolding, as well as the family members' needs for scaffolding.

Recall that scaffolding, the communicative assistance that adults provide to language learning children within the zone of proximal development, allows a child to use language that is more semantically complex and more decontextualized (Bruner, 1978; Norris & Hoffman, 1993). In typical language learning contexts, the adult or older peer leads or pulls the child along to higher levels of language usage (or mental functioning) in the ZPD by using a more sophisticated language system to engage the child in the negotiation and achievement of mutually understood meaning, or intersubjectivity (Bruner & Haste, 1987; Stremmel & Fu, 1993). Most of Jena's adult family members are stalled in the zone, and they have no plan for moving along. This situation raises questions about the zone of proximal development for the entire family. As Jena's sign language learning progresses, will she have to lead the adults in sign language learning? Will the adults lose confidence in their ability to negotiate communication with her? Will Jena have the

pragmatic skills to realize that the adults will need scaffolding?
The findings of this study, and these questions prompt suggestions for change.

Changes Grounded in Research

Semantic changes

The first implication for changing service delivery for children in Jena's situation is to **eliminate the word deaf**, because it does not mean what the textbook definitions say it should mean, particularly to the professionals who have been trained to respond to the condition of being deaf. Rather than understanding deafness to mean not enough hearing to crack the linguistic code, professionals seem to understand deafness as only a partial loss, a reversible loss, an ignorable loss, even when an aided audiogram shows that a child might hear a train go by, but not her mother's voice. One of the professionals who participated in this study may have inadvertently coined a term that may be more useful for deaf children's language learning. Although I always referred to Jena as a deaf child during our conversation, the term deaf never appeared in her conversational turns in the transcript. She said that Jena's deafness was **unaidable**. Perhaps that term would communicate quickly and with the appropriate sense of urgency that this child, and others like her,

is a **seeing** child, not a partially hearing child. A colleague asked me how Deaf people would feel about eliminating the term deaf. I think that would be a valuable question to ask; I do not know what the answer would be.

Philosophic Changes

The second implication is that the service delivery system needs to be streamlined, more holistic, and more **child-centered**. Additionally, the system needs to be more **language-centered**, rather than hearing-centered. Rather than having 40 to 50 professionals, the large majority of whom are not fluent in any form of sign language, diagnose and treat individual body parts such as ears, the service delivery system needs to provide care that is beneficial to the whole child. That means taking an ecological perspective about the most efficient and most effective ways of helping a family construct a viable zone of language learning. A system that has a better plan for training interpreters than for constructing a family language zone speaks of territorialism and the continued battle between the school and the family.

Practical Changes

The findings of this study lead me to offer a number of suggestions for improving actual sign language learning practices

for hearing families, regardless of any controversy concerning which language, American Sign Language or some manually coded form of English, should be a deaf child's first language. The issue of first language learning for deaf children is an issue that is not likely to be resolved any time soon in the United States (Maxwell, 1991).

Examination of research about second language learning and teaching, particularly research about practices used with similar families in other countries with different cultural and language histories supports these suggestions.

Suggestion 1. Emphasize hearing parents' role and communicative abilities. A repeated theme that emerged in this study was how difficult sign language learning was. Many family members said that it was like learning a foreign language, implying that it was an unreachable goal. Enculturation of hearing families might be enhanced if they thought signing was more possible. Harlan Lane is a well known hearing advocate for deaf people, but his comments in For a Deaf Son are divisive.

Lane: The educational system has put an unconscionable burden on parents like yourself. You're supposed to act as the language model for your child , but you can't. No matter what you do or how much you commit, you cannot be a language model for your child. It's an absolute necessity, if that child is to have a full and natural language, for that child to

be where there are deaf adults and deaf kids of deaf parents, and **other deaf kids**, so that kid can learn that language.

Lane's comments recognize a deaf child's needs for a full and flexible language system, and social interaction with other deaf people. However, he ignores all the people who learn to be interpreters in adulthood, all the hearing parents who have learned sign (Davies, 1991), and all the deaf adults who have learned a second language in adulthood (Mayberry, 1993), as well as all the adults who have ever learned a second language after childhood. He offers families less hope for cohesion or satisfying mutual communication than the most vehement oralist. At least the oralists promise that the child can remain part of a hearing family. An elitist and a separatist stance on the part of any group is no better than institutional dereliction or dishonesty.

Shawn Neal Davies (1991), a managing editor in Curriculum Development, Research, and Evaluation in Pre-College Programs at Gallaudet University, conducted a four month study of deaf education programs in Sweden and Denmark. She reported on three aspects of language learning: (a) deaf children's learning of sign language as a first language, (b) deaf children's learning of Swedish or Danish as a

second language, and (c) hearing parents' and teachers' learning of sign language. Examination of Davies' findings concerning attitudes, philosophies, and language learning practices in those countries provides specific ideas for improving the situation of families such as Jena's, as well as some challenges to theory.

Davies found that deaf children in Denmark and Sweden learn sign language as their first language. After brief periods of experimentation with sign language systems that attempted to encode spoken Swedish, deaf educators discarded those systems and relied instead on Swedish Sign Language, the language used by deaf people among themselves, as the first language to be used by deaf children. Swedish Sign Language (SSL) is a different language than spoken Swedish, just as American Sign Language (ASL) is a different language than spoken American English. Davies found that deaf children in these countries were immersed in sign language interaction with other deaf children and deaf adults in preschools whose emphasis was on play, interaction, and providing rich learning environments, not language development. She also found a "tremendous emphasis in Sweden on the importance of involving deaf adults at the preschool level" (p. 175).

In Sweden and Denmark, a striking difference in institutional

approaches with parents is the practice of emphasizing to the parents that they **can** communicate with their children, and that they are the primary communicators with their children, even if they may not be the primary language model for their children (Davies, 1991). One parent compared hearing parents' skills in sign language to her own use of English as a second language. That is, her English, while perfectly serviceable, is obviously not native-like. While the parents might not achieve native like fluency in sign language, they are comfortable enough to communicate fully with their children. This emphasis, in contrast to a message that hearing parents cannot possibly provide a full and natural language model, seems far more productive a strategy.

Suggestion #2: Provide a clear and consistent message. Davies' research revealed many striking differences between Jena's situation and the services provided to children in rural areas of Sweden and Denmark. Unlike the confusing menu of choices about communication options presented to parents of deaf children in the U.S., parents in Denmark and Sweden are presented with a **clear and consistent messages** through the medical professions, the social workers, the teachers, and the parents' organizations. These messages are that parents need the support of

other parents with deaf children, and it is extremely important that deaf children interact with other deaf children who sign and for hearing parents and deaf children get to know deaf adults. In Jena's case, Abby and Luke met Rachel's parents, and one other deaf couple, but they did not get such a consistent and clear message from the majority of service providers.

According to Davies, Swedish parents seemed to have a much more relaxed attitude about learning a second language, whether the language is spoken English or Swedish Sign Language. Since Swedish is a minority language in the world, and since there are many minority language users in the country, learning a second language is taken for granted. One hearing parent who was influential in coordinating sign language retreats for parents told Davies that almost all parents of deaf children in Sweden sign. She attributed this phenomenon to early diagnosis, consistent messages from professionals, and *“parents’ real acceptance that Swedish Sign Language is the language that their children will be using for life”* (p. 187).

Suggestion #3: Apply knowledge about second language learning. What is the optimal second language learning environment for parents of deaf children? A college class? Watching a videotape?

Burt and Dulay (1983) reviewed the literature on the topic of second language learning and come to four conclusions. Their conclusions can be applied to sign language learning for hearing families.

1. A natural language learning environment is necessary for optimal language learning. Such an environment exists when the speakers (signers) focus on the content of communication rather than on the language itself. Ordinary conversations, exchanges at a bank, and what is said at a party are natural. If the sign language learners are parents and children, instruction should occur in naturally occurring exchanges, with content selected that reflects the actual topics of interest to young language learning children and their parents. For example, content can be selected that is germane to the communicative intentions, social needs, and educational curriculum of children, rather than the social topics shared by adults.

2. Communicative Interactions must match the learner's level of language development. Learners of spoken languages have been shown to naturally begin by listening to a new language or engaging in only partial responding in the first language or with nonverbal replies. Burt and Dulay concluded that initial periods of focusing on comprehension were helpful to new language learners. These

conclusions may or may not be applicable to sign language learners, although Davies (1991) described how focused practice on sign language comprehension was used to improve skills for both hearing parents and hearing teachers. Perhaps it would be helpful for hearing parents to observe young deaf children signing early on in their sign language learning. It also seems important for expert sign language learners to gear the pace of their communication to the level of expertise of their partners. However, if parents are to provide any scaffolding for young deaf children in early stages of language development, it seems logical that they must also be able to use signs contingently, not just understand, react to, or interpret their children's signs.

3. Target language input must be comprehensible to the learner. Concrete referents help older language learners just as much as younger ones. Providing context for first and second second language learners is addressed by several authors (Hadley, 1993; Norris & Hoffman, 1993; Shrum & Glisan, 1994).

Additionally, the pragmatic skills of sign language learners, particularly their ability to gauge the signing capability of conversational partners and adjust their signing accordingly, need attention. The Signing Naturally videotape series (Smith, Lentz, &

Mikos, 1991) addresses adult conversational repair strategies, but specific attention to the negotiation between adults and children, and between children and their hearing siblings, cousins, and peers seems warranted.

4. Language learners attend to and acquire the language and dialect spoken by people with whom they identify. It would be important to investigate how this issue affects parents' sign language learning, as well as that of children.

Suggestion 4#: Provide sign language immersion for hearing parents. Davies interviewed a prominent Swedish researcher, Inger Ahlgren, who described a language learning zone for deaf children and their hearing parents that differs slightly from the ZPD described by Vygotsky. Ahlgren felt that it was more important for deaf children to meet and interact **with each other** rather than deaf adults, since children imitate the language of their peers rather than their parents. While Vygotsky viewed language development as a process led by more capable peers or adults, Ahlgren felt that deaf children did not have to depend on their hearing parents to be linguistic models because the children "will take up and develop - from wherever they find it-the true form of the language" (p. 174). Ahlgren, and others who were interviewed by

Davies, shared an attitude of respect for both the parenting instincts of hearing parents and the knowledge of deaf people about what is good for deaf children.

The parents in Sweden and Denmark had a variety of opportunities for learning sign language, including in-house tutoring from home teachers in early stages, intensive weekend sign-language retreats sponsored by parents' organizations, one- and two-week courses offered through adult education centers, and semester-long university courses. Parents were able to get released time from work and recovery of lost wages by petitioning their local communities. The most significant strategy for learning and teaching signing language in these two countries was the practice of offering sign language courses in intensive one- or two week blocks. Intensive weekend blocks were also found to be better than shorter periodic blocks. Sign language lessons focus on receptive skills, so that parents and teachers understand the children. Davies was skeptical about whether the deaf adults in these countries would fully share their sign language knowledge with hearing teachers and parents, but she learned that deaf adults are proud of sharing and are open with parents about their language.

Throughout this case study, I was concerned about the language

learning gap between parents and children that might occur when deaf children are immersed in sign language learning at school while their parents are not immersed in a formal or informal language learning setting. However, Davies reported a different view from one Swedish parent, who felt that interaction between parents and children was the best learning situation for the parents, since the children come to realize that the parents will be life-long students of the children's language, just as the children will be life-long students of the parents' language.

Reflections and Future Directions

All the data gathered during the course of this ten month study, the interviews, transcriptions, document and record reviews, and my own reflexive process encoded in journal form only begin to tell a complex story. The part of the process described here is like peeling the outermost thin skin off a giant onion (see Nelson, 1993, who likened the examination of causes of language disorders to peeling an onion). While saturation is a desired outcome for some qualitative researchers (Stake, 1995), saturation is not a logical outcome in a study of language learning. The language learning onion grows and grows as time passes, whether the layers get peeled or not.

There were many things that I did not find out, and many reasons why. My role as a participant, clinician, supervisor, and researcher meant that my attention to the research questions was often translocated by Mica's darting out of a clinic room, or the opportunity to respond to Jena's interest in a paper lion pasted to the wall in the clinic. Although I have been talking to parents for many years, I was often reluctant to push or intrude into the Byers' family life because it seemed to serve only my purpose. On the other hand, playing multiples roles means bringing multiple perspectives to the analysis and interpretation process. As a supervisor, I was free to watch Jena interact with her clinicians, free to ask Abby questions that emerged from past sessions, and free from some of the mundane aspects of planning treatment sessions and materials. As a researcher, I had a clearer purpose and probably learned far more about Jena's language learning background than I would have in ordinary clinical interactions. I usually do not visit my clients' homes or interview their grandparents in person and their other relatives by phone. As a mother, I was more aware of how quickly a small child can get into trouble than the clinicians, and I often found myself redirecting Jena and Mica if they wandered too far away from our reach. My parenting role emerged when I witnessed hitting and

shoving incidents, and reacted to them if I was the first adult to get to the scene. Whatever objectivity was compromised by my multiple roles was balanced by the additional depth of understanding this case. Throughout this study, I was consciously aware of the enmeshed relationships between the university clinic where I work and the other people and agencies who were involved in the study. I knew from the beginning that my relationships with these people and agencies would have to be maintained when the study was completed, but I also realized that being an insider gave me a base of understanding built up over 7 years time.

With regard to the research process, I stumbled across some of the more useful analysis procedures at very late stages in the study. For example, I experimented with using several different time ordered displays (Miles & Huberman, 1994) in an attempt to winnow the vast amount of information that I had gathered (Wolcott, 1990), and found that completing them revealed some gaps in information that would have been useful to fill in (see peeling the never-ending onion, above).

The ethical dilemmas faced in this study were complex. If conjoint interviewing of couples creates risks, then interviewing mothers, fathers, in-laws, siblings, and professionals in a densely

connected network posed extra challenges. One professional complained to me about appointments that Abby had missed. I certainly was not in a position to go to Abby and tell her to keep her next appointment. Witnessing Jena and Mica hit and scratch each other in Abby's presence was disconcerting. I was not able to watch those events in the detached manner of an observer, but used the opportunity to show the children how to use language to solve their differences. We tried to anticipate the situations that provoked these outbursts, but sometimes we were not quick enough or vigilant enough to prevent them. The differences of opinion about how to discipline Jena when she hurt another child were mentioned by several different family members, and I worried about how sharing this would affect the people involved.

Lastly, the experiences of all Jena's family members are not equally represented here. Not all the family members returned my requests for participation letters, and I did not have equal access to the family members who did participate. I did not push those who did not indicate a willingness to participate. In particular, I would have liked to spend more time talking with Luke. Both at home and in the clinic, he responded quickly to his children's needs and behaviors, and in doing so, was frequently out of range of the microphone or at

a place far removed enough that conversation about confidential issues was not appropriate or physically possible.

Future research is needed regarding many issues raised in this case study. Specific descriptions of the linguistic aspects of interactions between Jena, her parents and brother over time would provide useful information about changes in pragmatic as well as grammatic aspects of their using sign language. Many questions about the best way to provide sign language for parents and other adults who will be interacting with deaf children, compared to adults who will be communicating with adults language users need to be answered. The cost effectiveness and efficiency of service delivery models need to be investigated, as do the issues relating to referral paths between professionals.

Conclusion: What if the Language Were French?

A fitting conclusion to the study of this paradoxical phenomenon would be to pose a series of questions, to suggest an analogy for both the child's language learning and that of her parents. My position is that accepted principles concerning both first language learning on the part of deaf children and second language learning by hearing family members should be applied when families are faced with learning sign language along with their deaf

child. It might be helpful to use learning **French** as an analogy for the sign language learning situation of the family and the child. Perhaps then the missing sense of urgency about a deaf child's language learning and that of her family might be restored.

If Jena and her family needed to learn French, would it have made sense to ignore or neglect Jena's language learning for her first year? If it turns out that a child has not learned English through the auditory channel by age two, how long will it take her and her family to make up that lost language learning time if they only begin learning French when the child is two years old? If a child started learning French as a first language at age four, provided that her family were immediately conversant in French, how long would it take her to catch up to the children she begins kindergarten with at age five? How long would it take the child's family to become conversant in French? Would it have made sense for the communication specialist who introduced French as Jena's first to have the French language skills of a two year old? Would we expect a parent and grandparent who took a 10 week course in French, or a 3 credit college course in French to be able to lead a child through the ZPD? Would watching videotapes augment the French language skills of adults who had taken a 10 or 14 week course sufficiently well for

the adult to feel confident about communicating in French? Is the French vocabulary needed for adult discourse likely to be the French vocabulary needed by the French-learning child? Can the French speaking child lead her French -learning parents in the language learning zone?

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Appendix A

Cover letter to parent groups

On department letterhead

July 16, 1995

Dear NAD President:

I am a doctoral student in the Department of Family and Child Development at Virginia Tech. I am conducting a study about family communication when children are deaf and parents are hearing. I am especially interested in talking to parents who do not use sign language when their deaf child does. I obtained your name from the 1995 reference volume of the American Annals of the Deaf.

I am hoping to encourage parents to participate by contacting them through parent groups or informal support networks rather than through school systems. I can distribute the circulars myself if I had names and addresses of local or regional parent groups in Virginia. Is it possible to obtain such a list from you? If you think my request would be more credible if it came from you, would it be possible for you to distribute the enclosed circulars to parent groups or individual parents who might be interested in talking with me? If parents are interested, they can return the postage-paid cards to me or simply call me. I would then send them a complete description of the project. I have obtained approval for this study through the Institutional Review Board for Research Involving Human Subjects at Virginia Tech.

I would be happy to send you more circulars if you need them. Please feel free to contact me (540-552-1986) if you have any questions. Thank you very much for your help.

Sincerely,

Claire M. Waldron

Appendix B

Circular inviting parent participation

On department letterhead

Dear Parents:

When a child is deaf, families are affected in many ways. Parents of deaf children get lots of advice from different people about how to communicate with the child. What advice helps parents decide whether to use speech or sign language? One way to find out is to ask parents directly.

I am a doctoral student conducting a study about family communication when parents are hearing and children are deaf. I am looking for people who may be willing to participate in this study. I am especially interested in talking to parents who do not use sign language to communicate with their deaf child.

If you would like to know more about the study, could you please fill out the attached postage-paid card and return it to me? Alternately, you could give me a telephone call (540-552-1986). Thank you.

Claire Waldron

Appendix C

Postal reply card for parents

_____ Yes, I would like to know more about your study.

_____ Please send me the information. My name and address are

Name: _____

Address: _____

_____ Please call me. I'd like to know more. My phone number is

Phone number: Area Code (_____) _____ - _____

Appendix D

Follow-up letter to NAD presidents

On department letterhead

September 21, 1995

Dear NAD President:

I thought I would write to follow up my letters concerning my search for parents who do not sign when their children do sign. I appreciate your letting me know about your group's meetings this fall. If it is still possible, I hope the circulars can be distributed when the parents begin meeting again. I would be happy to correspond with the new President of the Virginia Association of the Deaf if you think that would be appropriate.

Again, I appreciate your help very much and I hope your vacation was a good one.

Sincerely,

Claire M. Waldron

540-831-5453 TDD
540-831-6370 FAX number
540-552-1986 Home number

Appendix E

Cover letter to school programs

On department letterhead

August 16, 1995

Dear Program director:

I am a doctoral student in the Department of Family and Child Development at Virginia Tech. I am conducting a study about family communication when children are deaf and parents are hearing. I am especially interested in talking to parents who do not use sign language when their deaf child does.

I had originally hoped to encourage parents to participate by contacting them through parent groups or informal support networks rather than through school systems. However, that avenue has not been productive. I am writing to request permission to solicit parent participation through your office. I have been in contact with the department of Pupil Personnel Services and was advised most kindly that I would probably be working with Lisa Tuck.

The enclosed proposal explains the study I would like to conduct. I have described the characteristics of the parents I seek and their children in the Procedures section of the proposal. I have enclosed one copy of a circular and postal reply card that could be distributed to potential participants. If the proposal meets with your approval, I would provide the necessary number of copies to be distributed and follow your advice concerning the most appropriate avenue for distributing the circulars.

If parents are interested, they can return the postage-paid cards to me or simply call me (collect is fine!). If the parents and their children meet my sampling characteristics, I would then send them a complete description of the project. I have obtained approval for this study through the Institutional Review Board for Research Involving Human Subjects at Virginia Tech.

Please feel free to contact me at work (540-831-5204) or home (540-552-1986) if you have any questions. Thank you very much for your help.

Sincerely,

Claire M. Waldron

Appendix F

RESEARCH PROPOSAL: Family Communication Choices

Submitted by Claire Waldron
Family and Child Development
Virginia Polytechnic Institute and State University

Demographic data for the 1993-94 school year show that 84.08 percent of deaf children are instructed using a method of communication that depends on visual-manual sign language (Schildroth and Hotto, 1995). However, in 43.2 percent of families with deaf children, neither parent signs, and both parents sign in only 25 percent of families (Kluwin & Gaustad, 1991). In order to provide support and improve communication, experts who work with hearing parents of deaf children must understand why parents make certain choices about communication mode. Why would parents choose to use a communication mode (spoken language) that is inaccessible to the deaf child? The purpose of this study is to investigate the factors that are involved in hearing parents' choices of communication modes with their deaf children, from the perspective of the parents, not the experts. This proposal seeks answers to the question, "Why don't hearing parents of deaf children learn to use sign language?"

PROCEDURES

A grounded theory approach (Strauss & Corbin, 1990) will be used to construct knowledge about hearing parents' decisions concerning communicating with their deaf children.

The communication mode used by the parents and the deaf child is the most critical sampling boundary. The deaf children whose parents participate should be between the ages of 8 and 16 years. The children should have present with a severe to profound hearing loss in the better unaided ear and be dependent on vision for language and communication, even with the use of amplification systems. The primary

communication modality used by the child should be visual/manual sign language. Use of speech or voice would not preclude participation as long as the child relies primarily on sign language for social communication and learning. The child should present a history of using sign language as a primary communication modality for at least one year. The child's educational setting should be one in which instruction is provided via total communication or sign only.

Parent participants will be selected primarily on the basis of the communication mode used by family members. Only normally hearing parents whose deaf children rely primarily on sign language for social communication and learning will be asked to participate. At least one parent must **not** rely on manual signing for primary communication with the deaf child. The parent who uses occasional signs, gestures, or fingerspelling with the child will not be excluded from the study as long as the parent describes his or her own communication interaction as primarily oral.

Several forms of data will be collected. Six sets of hearing parents will be interviewed as couples; individual interviews with parents may be conducted to follow up the conjoint interviews. Interviews will take approximately two hours. All interviews will be audiotape- recorded. Verbatim transcriptions of the interviews will be completed on a word processor. Parents will also be asked to provide documents concerning their child's hearing assessments and developmental, educational, and psychological assessments and recommendations. The parents will also be asked to provide and identify any written sources of information they have about parenting a deaf child, including pamphlets, books, correspondence from deaf education programs, parent magazines, parent newsletters and so on. Copies of the documents and any other written sources of information will be made by the investigator and returned to the parents. If possible, the documents will be converted into text files using an OCR scanner . The

investigator will also complete a reflexive journal throughout the research project.

In open-ended interviews, a questions will be posed concerning general categories such as process of decision making, people/institutions who were influential in parents' decision making, past experience with deafness, understanding of terms (deafness, communication, and language development, past experience with and understanding of family and parenting, and the parents' understanding of the deaf child's contribution the the decision-making process.

RISKS AND BENEFITS

Risks to the participants are minimal, but might include unintended self-disclosure, disagreements between spouses, or confusing the researcher's role with that of an expert or therapist. Issues of unintended self-disclosure will be approached by emphasizing participants's rights during the process of obtaining informed consent, checking with participants periodically about their comfort level, withdrawing segments of data from the record if they threaten confidentiality or participants' comfort, and actively encouraging the participants not to talk about topics that make them appear anxious or stressed (Daly, 1992).

In return for their participation in the study, the participants will be offered a chance to tell their stories from their own perspectives and to offer suggestions to the professionals about their family communication needs. The researcher will provide informational and counseling referral sources to all families who participate. These sources have been obtained from the Virginia Department for the Deaf and Hard of Hearing. (See Appendix B)

CONFIDENTIALITY/ANONYMITY

Given the low incidence of deafness and the uniqueness of deaf children's histories, measures that will be taken to ensure confidentiality of the participants are

to 1) recruit them from a variety of locations, some well removed from the immediate geographic area, 2) not recruit participants from the counties immediately surrounding the university, 3) change names of participants, their cities, school districts, medical institutions, and 4) make minor changes in the ages, occupations, or other demographic details of the participants. I would not want to change data that concern parents' education, their socioeconomic status, family constellation, or gender. These are factors that have been implicated as important in families' choices of communication mode .

Confidentiality of the the tape-recordings, transcripts, documents, and field notes that are gathered will be maximized by replacing the participants' names with pseudonyms, and locking tapes, written transcripts, and documents in secure cabinets. Electronic data will be stored on floppy disks that can also be locked in a secure cabinet.

CONSENT

Participants will be provided with a description of the study that includes a description of their expected participation (Appendix C) . This description will also contain a statement about potential risks and benefits, as well as a statement concerning their right to withdraw from participating at any time. They will be asked to sign a statement of informed consent prior to the beginning of the interviews (Appendix D).

References

Daly, K. (1992). The fit between qualitative research and characteristics of families. In J.F. Gilgun, K. Daly, & G. Handel (Eds.), Qualitative methods in family research. (pp. 3-11). Newbury Park, CA: Sage.

Kluwin, T.K. & Gaustad, M.G. (1991). Predicting family communication choices. American Annals of the Deaf, 136, 28, 34.

Schildroth, A. & Hotto, S. (1995). Annual Survey of Deaf and Hard-of-Hearing Children and Youth, 1993-94 School Year. Center for Assessment and Demographic Studies, Washington, DC: Gallaudet University.

Strauss, A. & Corbin, J. (1990). Basics of Qualitative Research. Newbury Park: Sage.

Appendix G

Conventions for Transcriptions

Conversations transcribed in standard English orthography.

CL:	Interviewer
Other initials:	Identities noted on transcript
XXX	unintelligible utterance of undetermined length.
[Cl:	means speaker has interrupted the preceding turn
..	Short pause less than 3 seconds, but worth noting.
...	three seconds or more
**	Conversational device used by interviewer to acknowledge or extend longer segments of participant's discourse.

Appendix H

Open Coding -Initial Categories

Acceptance of deafness	acquiescence
adults are differ than children	ASL
aidable hearing loss	ASL is hard
battle over hearing aid	began to sign
budget constraints	bureaucratic discontinuity
cannot be bothered	Ch 5 research needs
child best interest	child pragmatic failure
child pragmatic struggle	child will choose
choice	choices
chronosystem	church community
class was not good	closer school than family
cochlear implant	college context
comm failure results in separation	communication
communication change for better	communication frustration
communication strategies	communication struggle
consequences	context
costs	culture of inclusion
deaf	deaf is a different priority
deaf parents	deafness as a location
deafness what do with life	degree of hearing loss
denial	diagnoses fr oth people
dictated by what is available	diff cuz family can sign
different language	diff memory of exp
difficulty comprehending	disability check
distance communication	distance learning
do not have that many here	do not know how to parent
do not know why it is imp	dropout after one course
economics of service delivery	early intervention
educational opportunities	enculturation
English for school	ethical issues
experience difficult for cousin	experience
family does not sign	family left out
family ultimate decision maker	fear of deaf people
fear- taking it away	fight the system

Open Coding -Initial Categories (cont.)

frustration with communication
geographic spread
good mind
haphazard unplanned learning
her case is unique
how do pros make decisions
immersion
income level
institutional dishonesty
interpreter training
it is up to parents
lack of enthus for sign class
lack of familiarity options
lack of family support
language staying ahead
lifetime commitment
making language accessible to family
many service providers
menu without consequences
money gotta have it
no space in brain to continue
not deaf before two
nothing wrong
noticing improvement
oralist information
parent impression of school
parent opin profe neg
parent opin profe
parents already decided
parents in charge
parents learning sign
parents roles
part of both worlds
participant benefit
personal opinion oral
play -trying to negotiate
politics of neutrality
foreign to my experience
give information to parents
guilt at not starting sooner
hearing aid
hitting and fighting
how long does it take
importance of faith
influence
institutional caution
intervention priorities
keeping on and keeping up
Kinney
lucky to have right parents
language
learning sign is hard
low incidence
medically based
Mom was right
my hands are tied
no systematic plan
not want to leave family
nothing you can do
options limited by location
parent employment
parent network
parent opin profe pos
parental acceptance
parents education
parents lack information
parents need free class
parents time
part of our family
peeling an onion
physician influence
political power and influence
pos prof pragmatics

Open Coding -Initial Categories (cont.)

priority not language
prof assess parent competence
professional territorialism
PSE
real life gets in the way
reasons to sign
recs for service or research
reflexivity
research process
resistance to sign
role of researcher
sadness about what deaf miss
schedule problems
school has no audiologist
school system responsibility
sign language limited knowledge
sign lang know she needs more
sign lang learn cousins
sign language age as factor
sign language as foreign lang
sign language everybody
sign language infrequent use
sign language learning opps
sign language staying ahead
sign language Utopia
sign with deaf people
source of profess influence
staying on top of things
stressful
stuck under physician
total communication
true total comn kids
uncertain about diagnosis
voice of
we push oral
weird theories lang acquis
what is it like to be deaf

professional competence
priority
proxemics and power
quote for chapter IV
reasons not to sign
recs for improvement
referral path
rejecting aud training
research question
role of professional
saturation
school as villain
school for the deaf
school is her home
sign lang expertise
sign class could not do it
sign lang learn children
sign lang learn from family
sign language alphabet
sign language course
sign lang has not learned
sign language is HARD
so good at signing
sign language technology
sign language video
speech
stagnation

strictly up to parents
support fr family
translocation of attention
Unaidable
violations in the ZPD
want her to fit in
weird acquisition theories
what if your child deaf
where is the knowledge

Open Coding -Initial Categories (cont.)

who is responsible
you get what is available

who teaches sign
zpd

Appendix I

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY Informed Consent for Participants of Investigative Projects

Title of Project Family Communication Choices

Principal Investigator Claire Waldron

I. THE PURPOSE OF THIS PROJECT

You are invited to participate in an exploration of family communication and sign language learning.

II. PROCEDURES

Participation in this study will involve an interview with family members of a deaf child and persons outside of the child's family who have helped or influenced the child and/or the child's parents in their process of learning sign language. The interview will take approximately one to two hours. A second interview might be requested to clarify information. The setting and time of the interview will be arranged for your convenience. The interviews will either be summarized in written form or audiotaped and transcribed. This information will be stored electronically on computer disks. Participants' names and the names of cities, institutions, schools, or any persons discussed will be changed in the transcriptions and written records.

The possible risks or discomfort to you as a participant may be uncomfortable reactions to discussing your child's deafness. If you do not wish to discuss any particular subject, you are encouraged to pause, postpone, or cancel your participation.

III. BENEFITS OF THIS PROJECT

Your participation in the project will help provide information about family communication from your own perspective as a family member of a deaf child. Professionals need to know more about parents' and families' needs and perspectives when they provide services to deaf children.

No guarantee of benefits has been made to encourage you to participate. You may receive a synopsis or summary of this research when completed.

IV. EXTENT OF ANONYMITY AND CONFIDENTIALITY

The results of this study will be kept strictly confidential. Participants' names and the names of cities, institutions, schools, or any persons discussed will be changed in the transcriptions and deleted in the copied documents you provide. Future written documents and oral presentations (e.g., dissertation, journal articles, conference presentations) will use pseudonyms. Some interviews will be audiotaped. These tapes will only be reviewed by me and a graduate assistant who will help transcribe the tapes. The tapes will be erased at the completion of the project.

V. COMPENSATION

No monetary compensation is offered to participants in this project. If as a result of this study, you or the investigator determine that you should seek additional information or counseling, you may contact the agencies or individuals named on the attached list of referral sources.

VI. FREEDOM TO WITHDRAW

You are free to withdraw from this study at any time without penalty. You have the right to withdraw any and all information provided during the interviews or in the child's records.

VII. APPROVAL OF RESEARCH

This research project has been approved as required by the Institutional Review Board for projects involving human subjects at Virginia Polytechnic Institute and State University, by the Department of Family and Child Development.

VIII. PARTICIPANT'S RESPONSIBILITIES

I know of no reason I cannot participate in this study.

Signature

IX. PARTICIPANT'S PERMISSION

I have read and understand the informed consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.

If I participate, I may withdraw at any time without penalty. I agree to abide by the rules of this project.

-----	-----
Signature	Date
Should I have any questions about this research or its conduct, I will contact:	
Claire Waldron 540-552-1986	Dr. Andrew Stremmel 540-231-4671
Investigator	Faculty Advisor
Ernest R. Stout 540-231-6077	
Associate Provost for Research	

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
Informed Consent for Participants
of Investigative Projects-Participant's Copy

Title of Project Family Communication Choices

Principal Investigator Claire Waldron

I. THE PURPOSE OF THIS PROJECT

You are invited to participate in an exploration of family communication and sign language learning.

II. PROCEDURES

Participation in this study will involve an interview with family members of a deaf child and persons outside of the child's family who have helped or influenced the child and/or the child's parents in their process of learning sign language. The interview will take approximately one to two hours. A second interview might be requested to clarify information. The setting and time of the interview will be arranged for your convenience. The interviews will either be summarized in written form or audiotaped and transcribed. This information will be stored electronically on computer disks. Participants' names and the names of cities, institutions, schools, or any persons discussed will be changed in the transcriptions and written records.

The possible risks or discomfort to you as a participant may be uncomfortable reactions to discussing your child's deafness. If you do not wish to discuss any particular subject, you are encouraged to pause, postpone, or cancel your participation.

III. BENEFITS OF THIS PROJECT

Your participation in the project will help provide information about family communication from your own perspective as a family member of a deaf child. Professionals need to know more about parents' and families' needs and perspectives when they provide services to deaf children.

No guarantee of benefits has been made to encourage you to participate. You may receive a synopsis or summary of this research when completed.

IV. EXTENT OF ANONYMITY AND CONFIDENTIALITY

The results of this study will be kept strictly confidential. Participants' names and the names of cities, institutions, schools, or any persons discussed will be changed in the transcriptions and deleted in the copied documents you provide. Future written documents and oral presentations (e.g., dissertation, journal articles, conference presentations) will use pseudonyms. Some interviews will be audiotaped. These tapes will only be reviewed by me and a graduate assistant who will help transcribe the tapes. The tapes will be erased at the completion of the project.

V. COMPENSATION

No monetary compensation is offered to participants in this project. If as a result of this study, you or the investigator determine that you should seek additional information or counseling, you may contact the agencies or individuals named on the

attached list of referral sources.

VI. FREEDOM TO WITHDRAW

You are free to withdraw from this study at any time without penalty. You have the right to withdraw any and all information provided during the interviews or in the child's records.

VII. APPROVAL OF RESEARCH

This research project has been approved as required by the Institutional Review Board for projects involving human subjects at Virginia Polytechnic Institute and State University, by the Department of Family and Child Development.

VIII. PARTICIPANT'S RESPONSIBILITIES

I know of no reason I cannot participate in this study.

Signature

IX. PARTICIPANT'S PERMISSION

I have read and understand the informed consent and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this project.

If I participate, I may withdraw at any time without penalty. I agree to abide by the rules of this project.

Signature

Date

Should I have any questions about this research or its conduct, I will contact:

Claire Waldron 540-552-1986
Investigator

Dr. Andrew Stremmel 540-231-4671
Faculty Advisor

Ernest R. Stout 540-231-6077
Associate Provost for Research

Appendix J

Written consent to obtain information

I authorize Claire Waldron to obtain information, including spoken and written reports, concerning my child _____, from the following individuals and/or agencies as part of the study "Family Communication Choices." I understand that results of this study will be kept strictly confidential. All participants' names and the names of cities, institutions, schools, or any persons discussed will be changed in the transcriptions of tape-recorded interviews and deleted in the copied documents provided.

Person or Agency

Parent

Date

Appendix K

Letter Clarifying Revision in Study

February 13, 1996

Dear Abby and Luke,

When I talked with you at your home back in October of 1995, I was beginning my dissertation study about the decisions that parents make concerning communication modes when their children are deaf. I had originally intended to interview parents who had decided not to use sign language with their deaf children.

My attempts to identify parents by contacting deaf advocacy and parent groups and schools systems in Virginia were not productive. Meanwhile, as I talked with you about Jena, and as I began to understand more about what you went through in deciding to use and learn sign language, I realized that I had a much more interesting situation right at hand. Your family was unusual because you decided to sign with Jena when she was so young, and because you decided to use American Sign Language (ASL) with her. You also told me your whole family was learning to sign.

Figure 1 is a graphic display or eco-map of the original familial contexts that I had planned to investigate. The interviews would have focused just on the parents' understanding of communication modes. Preliminary analysis of interview data and the documents you provided has shown that Figure 2 is a much more accurate representation of the complexities of the contexts and the extended boundaries of just Jena's language learning system. At least 24 different professional adults representing a variety of medical, social service, and educational agencies have been identified as significant participants in Jena's language system.

I am writing to formally ask your permission to investigate Jena's language learning system by talking with the adults in your family and the adults who have helped you and them learn sign language and how to communicate with Jena. I would interview Jena's grandparents, your siblings and their spouses, and many of the professionals who have been involved. If people live far from here, I would telephone them at a convenient time.

I would not interview anyone without your written consent. Although Jena is at the center of the eco-map model, this study focuses on the sign language learning contexts and experiences of the adults in your family rather than her. I do not plan to interview the other children in your family. Pseudonyms will be used for all participants, institutions, and locations. The risk to participants remains minimal.

I would be happy to answer any questions that you have. My dissertation advisor, Dr. Andy Stremmel, can also be contacted if you have any questions.. His telephone number is 231-4671. I have attached a revised informed consent protocol for each of you to read. If you agree to participate, please sign it, return it to me, and keep your copy of the protocol.

Thank you for sharing so much important information already.

Sincerely,

Claire Waldron

831-5204 (office)
552-1986 (home)

Appendix L

Axial Coding Paradigm

CONDITIONS THAT DELAYED SIGN LANGUAGE LEARNING

Co-construction of denial

- Paradox of hope
- Hearing centered practice
- degree of hearing loss
- diagnostic uncertainty
- battle over hearing aid

Bureau-Centric practice

- multiple service providers
- no systematic plan for family learning
- institutional caution
- intervention priorities
- menu without consequences
- language teaching dictated by what is available
- politics of neutrality
- referral path

CONDITIONS THAT FACILITATED SIGN LANGUAGE LEARNING

Acceptance of deafness

Addressing communicative needs: Child centered practice

- early intervention
- child best interest
- reasons to sign --feeding
- child pragmatic failure/struggle
- communication frustration
- child will choose

Family culture of inclusion

- understanding enculturation
- we want to be her family
- not leave family for school
- we want her to fit in
- part of both worlds

Support from family

- lots of family support
- importance of faith
- family members learning to sign

CONTEXTS FOR LEARNING SIGN LANGUAGE

People

- Rachel & deaf parents
- Aunt Beth
- Jennie Harris
- Lee
- children's pragmatic issues
- multiple service providers
- Leigh
- other sign language instructors
- everybody in family

Places

- multiple health & educational agencies
- community college
- distance communication
- church community
- home
- sign language course

STRATEGIES FOR LEARNING SIGN LANGUAGE

Strategies implemented

- began to sign
- sign with deaf people
- take sign language class
- interpreter training
- sign language learning from family
- everybody learning sign language
- sign language technology
- sign language video

Rejected strategies

- cochlear implant
- inclusion
- school for the deaf
- school is her home

Proposed strategies

- immersion
- making language accessible fam
- distance learning
- parents given same priority as interpreters
- sign language Utopia
- sign language video

INTERVENING CONDITIONS THAT CONSTRAINED SIGN LANGUAGE LEARNING

Real life gets in the way

- parent employment
- parents' time
- schedule problems
- financial constraints

ASL is a Foreign Language

THE REALITIES OF SIGN LANGUAGE LEARNING

Which language is learned?

- ASL
- PSE
- English for school

Violations in the Zone of Proximal Development

- limited opportunities for adults to use sign
- teaching comprehension versus production
- who leads the sign language learning ?
- who is intended consumer of sign language course?
- staying ahead of the language learning child
- language learning across the life span
- lack of immersion in culture

Using technology

- distance learning
- learning sign language via videotape

CONSEQUENCES

Consequences of Family Sign Language Learning

- scaffolding within the family
- signing with Deaf people
- emerging enculturation
- social & familial communication with Jena

Consequences of Family NOT Learning Sign Language

- inability to communicate with Jena
- separation from Jena
- family left out of child's life
- stressful family interaction, especially for children
- family guilt about lost time
- child custody awarded based on failed communication

RESEARCH ISSUES

- research needs
- ethical issues
- recommendations for improving service
- role of researcher

Vita

Claire M. Waldron
1836 Azalea Drive
Blacksburg, Virginia 24060
e-mail address: cwaldron@ruacad.ac.runet.edu

Education

Bachelor of Arts, Speech Pathology	University of Missouri-Columbia	1971
Master of Arts, Speech Pathology	University of Missouri-Columbia	1972
Ph.D., Child Development	Virginia Polytechnic Institute and State University	1996

Professional Employment

September, 1990 - present	Assistant Professor Department of Communication Sciences & Disorders Radford University, Radford, Virginia
September, 1988 - August, 1990	Instructor Department of Communication Sciences & Disorders Radford University, Radford, Virginia
September, 1982 - August, 1988	Instructor Department of Speech Communication, Theatre, and Communication Disorders Louisiana State University and Agricultural and Mechanical College, Baton Rouge, Louisiana
September, 1977 - August, 1982	Associate in Speech, Instructor Department of Speech University of Florida, Gainesville, Florida
March, 1977 - September, 1977	Speech-Language Pathologist Department of Communicative Disorders Morton F. Plant Hospital, Clearwater, Florida
June, 1976 - February, 1977	Speech-Language Pathologist All Children's Hospital Speech and Hearing Clinic St. Petersburg, Florida
June, 1974 - January, 1976	Speech Pathologist Language Clinic/Neurology Service The Massachusetts General Hospital

Boston, Massachusetts

1973-74 Academic year

South Central Area, Dade County Public Schools
Miami, Florida

1972-73 Academic year

Southwest Vermont Supervisory Union
Bennington, Vermont

Professional Affiliations and Honors

American Speech-Language-Hearing Association

Council of Exceptional Children, Division for Communication Disorders

Speech and Hearing Association of Virginia

Member editorial advisory board, Language, Speech, and Hearing Services in Schools,
appointed 1996

Member of editorial advisory board Journal of the National Student Speech-
Language-Hearing Association, appointed 1993.

Member editorial advisory board, Journal of Childhood Communication Disorders,
appointed 1990

Recent Professional Activities

Polderman, R., Waldron, C.M., & Garn-Nunn (1995). Whole language vs. traditional assesment. Poster Session, Speech and Hearing Association of Virginia Annual Conference. Norfolk.

Oyler, R.O. and Waldron, C.M. (1994). Preschool hearing screening in Southwest Virginia. Journal of the Speech-Language-Hearing Association of Virginia. 34-(10)

Waldron, C.M. and Seyfried, D. (1993). Current Intervention Principles & Practices: Hearing Impaired Children Birth to Five. Miniseminar. American Speech-Language-Hearing Association Convention.

Seyfried, D. & Waldron, C.M. (1993, March). Pediatric aural habilitation: Combining the expertise of audiologists and speech-language pathologists. Speech and Hearing Association of Virginia. Reston.

Waldron, C. M. (Producer) and Dotson, E. (Co-Producer). (1992). Mountain Children:Speakers and Storytellers. [Videotape]. Radford, VA: Radford University Tele-communications Bureau. Supported by a Faculty Instructional Development Grant from the Radford University Foundation.

Damico, J., Waldron, C. and Damico, S. (1989). Regulatory Trends in Language Assessment Across the Nation: A Survey. Poster presentation: American Speech-Language-Hearing Association. St. Louis, Missouri.

Damico, J.S., Damico, S., and Waldron, C. (1988). Oral Language Sampling in Schools: Addressing Concerns and Overcoming Problems. Poster presentation : American Speech-Language-Hearing Association. Boston, Massachusetts.

Waldron, C. and Williams, W.N. (1986). Management Considerations for Voice Patients with Temporomandibular Joint Disorders. American Speech-Language-Hearing Association Miniseminar. Detroit, Michigan.

Williams, W.N. and Waldron, C. (1985). Assessment of Lingual Function when Ankyoglossia (Tongue-Tie) is Suspected. Journal of the American Dental Association. 110, pp. 353-356.

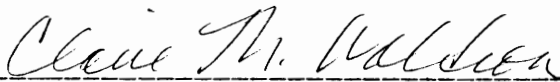
Grants

Waldron College of Nursing and Health Services Faculty Development Grant. Family Communication Choices. May, 1995. \$3, 600.00

Parent training in Emergent Literacy: 1995 Summer Language Clinic.Co-authors with Mary Calloway and Laura Turk. Scottish Rite of Virginia. June, 1995. \$15,000.00.

Radford University Faculty Professional and Instructional Development Grant for the production of a videotaped documentary Mountain Children: Speakers and Storytellers. Amount: \$1530.00.

USOE Personnel Preparation Grant, University of Florida, Department of Speech, \$27,000.00 awarded to Dr. Thomas B. Abbott and Claire M. Waldron. 1981.



Claire M. Waldron