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LINGUISTIC AND CULTURAL INTERACTIONS AMONG DEAF/HEARING FAMILY MEMBERS:

IMPLICATIONS FOR FAMILY PARTNERSHIPS IN EARLY EDUCATION

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A DISSERTATION

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The seed for this dissertation was planted when I became a classroom teacher and developed my first parent-teacher relationship with Nancy and George Herhei. The Herhei's were the first to invite me into their home and posed the question, "Well, we've tried everything--what do you suggest?" I am grateful to the Herhei's, and their four beautiful daughters (Brenda, Jennifer, Christy, and Katie) for teaching me at the inception of my career that there are no clear-cut solutions to any one problem. They also taught me that team work, unbending faith in God, and a good sense of humor will get you through just about anything.

ABSTRACT

The purpose of this ethnographic study was to describe how a deaf child and his hearing family members make sense of each other's deaf and hearing worldviews and how those perspectives guide their actions. Data were collected and analyzed while recognizing that a problem exists in this setting that typifies the home and family experiences of 90% of deaf children. In this scenario, the deaf child does not have auditory access to the (spoken) language that is predominantly used in the home. The deaf child's access to family communication is often limited, making opportunities for language acquisition and identity development restricted or unavailable. This lack of early access to language and communication often produces a deleterious effect on later educational experiences and academic potential.

Many researchers, teachers, and parents of deaf children have framed deaf students as disabled or deficient beings, attributing their unsatisfactory use of spoken and written English and subsequent academic performance to an inherent biological "problem" rather than linguistic or cultural differences. This research strives to further develop a socio-cultural perspective on individuals who are deaf. The researcher assumes the socio-cultural position that recognizes diversity in human growth and social behavior and encourages scientific investigations that are conducted in a holistic context.

The researcher lived in one family's home as a participant observer for a 10-month period. The database consists of daily fieldnotes and analytic memos generated by the field worker, selected videotaped interactive episodes, medical and school documents regarding the deaf child, and interviews with significant adults in the deaf child's immediate and extended home environment.

Data were analyzed using the theoretical contexts of symbolic interactionism and Erting's schematic representations depicting deaf and hearing interactive opportunity structures. The theoretical position for this investigation is that people make sense of their lived experiences through the reciprocal exchange of symbols, using the medium language and communication. The investigator anchored this study in symbolic interactionism theory in order to organize and make sense of the different linguistic and cultural symbols used by deaf and hearing family members (e.g., American Sign Language [ASL] and spoken English). Analysis was conducted using qualitative methods recommended by Ely, Agar's strip resolution procedure, and Erickson's approach for micro-analyzing social interaction.

The primary discovery of this investigation provides support for the socio-cultural view of the condition or experience of deafness. Evidence indicates that it is possible for hearing and deaf family members to live in the same physical environment, yet develop perspectives and views of the deaf experience from different or entirely opposing positions due to their differing ways of accessing linguistic and cultural information during day-to-day interactions. Consequently, this dissertation details the diverse perspectives of the deaf child, his parents, older siblings, and extended family members and are presented within the context of family stories and descriptions of their interactions.

Finally, this research hopes to contribute to the field of deaf education by providing a much-needed naturalistic description of the day-to-day home and family experiences of a developing deaf child. The conclusions suggest that there is a critical element missing from many educational programs for children who are deaf or hard of hearing and their families: a framework that recognizes and conveys the development of cross-cultural awareness among deaf and hearing family members. The author makes recommendations to address the missing cultural component from within the deaf education curriculum, as well as its absence in teacher preparation programs. Finally, this dissertation suggests an alternative, collaborative approach to developing parent-teacher relationships and early intervention practices based on using ethnographic methods to gather and make sense of information about young deaf children and their families.

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PREFACE

Information About the Larger Ethnographic Investigation that Supports this Dissertation

This dissertation research project stems from a larger, ethnographic project being conducted at Gallaudet University. The larger project is entitled Language, Literacy and Cultural Development in Bilingual Homes and Classrooms (from this time on termed "LLCD Project"; see Appendix A for the larger project's abstract). The Directors for the Language, Literacy, and Cultural Development Project are Dr. Carol J. Erting, who is also my research advisor for this dissertation project and Dr. Ben Bahan. I worked for the LLCD Project from April 1996 to July 1997 as a research assistant. My work within the larger project involved, in part, gathering in-depth information about one family (the Camillos),[1] using the fieldwork strategies of participant observation (Spradley, 1979), and ethnographic interviews (Spradley, 1980). These qualitative data collection methods are grounded in the discipline of cultural anthropology wherein ethnographic methods are used to study and describe cultural phenomena. I was "in the field" documenting and learning about the Camillos' family life from May 1996 to July 1997. For 10 months of that period (October 1996 to July 1997), I lived in the family's home as a researcher. The data that were analyzed for this dissertation project were collected as part of the larger LLCD Project. The last two weeks of data collection were partially sponsored by a Small Grants Project through the Gallaudet University's Graduate Research Institute.

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[1] All names used within this document are pseudonyms. Sara and Mark Camillo are the hearing parents of Daniel (6-year-old, hearing), Henry (4-year-old, deaf), Madeline (2-year-old, hearing), Mary (1-year-old, hearing), Luke (1-year-old, hearing), and John (1-year-old, hearing).

Technical Information about the Presentation of Analysis

It is important for the reader to understand two important variations from traditional APA writing style that I used in the following chapters. First, in Chapter II of this dissertation, I reference Stokoe's practice of using GLOSS, a linguistic method of representing American Sign Language in written form (Stokoe, Casterline, & Croneberg, 1965). In communication situations described throughout this dissertation, when a deaf person uses American Sign Language (ASL) or signs without spoken English, I used GLOSS to represent the informant's signed intent rather than English words written in upper- and lower-case letters. This dissertation examines the intersections of signed and spoken communication among deaf and hearing family members. I believe the practice of making the written distinction between signed and spoken communication will help the reader see communicative and cultural tensions more clearly within the context of the different stories presented.

Second, three different types of data were presented within the dissertation's context: (1) fieldnotes, (2) transcripts from interviews, and (3) transcripts from interactive video clips. Each type of data were explicitly cited so as not to mislead the reader. There is an important distinction between the information provided in transcripts from audio/videotapes and fieldnotes. Transcripts from interviews and interactive videotape are the <u>exact words</u> used by informants and therefore will be presented in traditional APA format as direct quotes (e.g., using quotation marks to distinguish the text if it is 35 words or less, and within indented, single-spaced paragraphs if there are 36 words or more). Fieldnotes in their condensed and expanded forms are the researcher's way of restructuring the events that occurred during participant observation. My condensed fieldnotes "often included phrases, single words, and unconnected sentences" (Spradley, 1979, p. 75) that I jotted down while conducting fieldwork. Later, expanded notes were created that provided a richer account of events and conversations that transpire among informants in the field. Because the majority of my condensed and expanded fieldnotes contained my recollection of events and not the exact words of informants, they should not be considered exact or quotable representations of what the informants said. Therefore, *fieldnote data are presented in italicized format to indicate that the information is factual, but not an exact chronicle of the situation.*

Lastly, on the recommendation of Oswald Werner, I provided a list of pseudonyms for "expert informants" in Appendix B. I cited the location of their contributions in my fieldnotes (FN), interview transcripts (INT), and interactive video clips (VC) (Werner, 1998, p. 29), the same as I cite Werner's expertise and recommendations in this sentence. For example, the following is a statement made by an informant during a videotaped interview: "I really don't think it's that much of an issue. You just do it" (INT: 19:42:23). INT means the data are derived from an interview. The numbers that follow INT provide the exact location where the informant's statement is located on the interview transcript. The first number in the sequence (19:42:23) represents the number of the interview, fieldnote, or video clip. The second number (19:42:23) indicates the page number of the transcript, and the third number (19:42:23) labels the line number where the statement begins on the page of the database.

CHAPTER I

STATEMENT OF THE PROBLEM

The Problem

The purpose of this research is to contribute to the body of literature and knowledge that systematically describes the social environments where deaf children live and grow. This dissertation tells the story of one family's social, linguistic, and cultural experiences among their own relatives, immediate and extended.[1] In order to tell their story, I systematically documented and analyzed the interactions that took place at the intersection of the family members' use of two languages (e.g., American Sign Language and English), as well as their differing behaviors and understandings related to deafness. I studied the family within a holistic and developmental context. Holistic, in the context of this research, means that I gathered information and attempted to build an understanding about Henry Camillo (the deaf child) and his family from multiple sources. I focused on the communicative behaviors and social understandings that developed within and outside their family's immediate social climate. The central research question that guided this investigation was:

> *How do a deaf child and his hearing family members make sense of each other's worldviews, and how are their perspectives demonstrated in their actions?*

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[1] The members of the Camillo family communicate using two modalities (oral and visual-gestural, sometimes used simultaneously), two languages (ASL and English) and their cultural composition is multiple and developing (Deaf, hearing, Spanish, and Caucasian).

The story told in professional literature about deaf children and their families often begins with the reality that children who are deaf are most often born into families that possess a hearing identity or auditorily-oriented worldview (Erting, 1982/1994; Padden & Humphries, 1988). Often, hearing parents, siblings, and extended family members of the deaf child have never met or interacted with another individual who is deaf (Garretson, 1994; Meadow-Orlans, 1990). Padden and Humphries (1988) observed this circumstance and assert that hearing parents possess an auditory (hearing) perspective that can interfere with their ability to understand how their deaf child makes sense of their environment (i.e., visually). Their intrinsically auditory orientation is coupled with extensive contacts with members of their social support system, most often comprised of hearing educators, medical experts, and family. Padden and Humphries (1988) suggest that the ongoing, prevalent nature of these hearing social interactions may prohibit parents from moving towards "a different [or visual] center" when interacting with their child (p. 39). In other words, hearing family members create their own realities by living their day-to-day lives based on hearing experiences. Therefore, they may not be able to see the world through their deaf child's eyes as readily as they are able to understand a hearing child's perceptions.

Another part of the problem encountered by hearing families with deaf children is that deafness is usually involuntary and often unexpected (Erting 1982/1994). The identification of a deaf child in the context of a family with a hearing identity is a shock and a dilemma, likened to a family crisis and the grieving process that follows a significant loss or death (Erting, 1982; Meadow-Orlans, 1990; Moses, 1985). It is common to hear stories from parents and family members about their feelings of shock, anger, disappointment, and denial. Often it seems as though the emotional component of this complex problem seems to override the parents' ability to gather and make sense of information provided by deaf educators, audiologists, and medical experts. Parents take on the responsibility of this burden, and assume additional roles such as educational advocate, interpreter, and speech therapist (Turnbull & Turnbull, 1997). Assuming roles in addition to parenting can intensify stressful feelings of grief, anger, and disappointment, and the involuntary flavor of parenting a deaf child is intensified (Erting, 1982).

Schlesinger and Meadow (1972) were the first to attest that a medical diagnosis of hearing loss is minute in light of the socio-cultural ramifications of growing up deaf in a society where interactions are built on the experience of hearing. In other words, while hearing family members are often distressed when a child in their family is identified as deaf, the identification of the deaf child's hearing loss, per se is not necessarily the most significant problem for the child or the family (Meadow-Orlans, 1990). Meadow-Orlans (1990) elaborates on the early years of child rearing and the challenges that hearing parents of deaf children face:

> they [hearing family members] must face the difficulties of communicating with their child in the absence of a common [that is, a spoken] linguistic system. This is the central feature of the early experiences of deaf children: The language readily available to deaf children is not the language used by their parents. (1990, p. 285)

Differing communication strategies (both linguistic and modality differences) used by hearing parents and their deaf child frequently create communicative tensions between deaf and hearing relatives. Both lack of access to the primary language of the home and communicative tensions can produce a deleterious effect on the child and family's interpersonal communication and social interactions, as well as the deaf child's ensuing identity development (Erting, 1982/1994; Johnson, Liddell, & Erting, 1989; Meadow-Orlans, 1990). The result is often a young child learning and living on the periphery of activity and interaction in his own home.

Nash and Nash (1981) posit that while deafness is framed by the majority of society as an audiological or medical condition, many others define the deaf experience using a socio-cultural perspective (Jacobs, 1974; Lane, Hoffmeister, & Bahan, 1996; Meadow, 1980; Padden, 1989). As a result, the experience of being hearing while nurturing and raising a child who is deaf is further complicated as parents try to make sense of these divergent understandings of deafness.

Within the field of Deaf Education, the age-old "oral-manual debate" within the United States reflects both the medical and cultural understandings of deafness, exemplifying the mixed messages that parents receive when faced with the need and desire to make informed decisions about their child's education. During one of the most vulnerable periods for making sense of their child's deafness, parents are frequently presented with dichotomous sets of facts and figures, communication methodologies, and teaching philosophies. Nash and Nash (1981) describe the beliefs of the oral doctrine as one that always operates from the criteria prescribed for interaction in mainstream society. The worldview of a deaf child from an oral or medical position involves measuring the child's interactive competence by determining "how closely it resembles the speech of hearing people and whether or not the child can 'talk to anyone'" (Nash & Nash, 1981, p. 48). In other words, the medical perspective of deafness believes that the closer a deaf child can emulate the behaviors of a hearing child, the more successful and productive they will be as members of society.

In contrast, Erting (1994) characterizes the Deaf[2] experience from a socio-cultural perspective and describes it as a primarily visual experience (Erting, 1994). In other words, those who view deafness as a cultural phenomenon, acknowledge that individuals who are Deaf learn to organize and make sense of their life experiences using a different (visual) perspective of the world than their hearing parents and family members. While culture and language are distinct phenomena, they are explicitly embedded in one another (Spradley, 1979; Woodward; 1982). Stokoe (1994) asserts that "sterility is the result of studying a language without studying its use and those who use it" (p. 266). Language serves a variety of purposes in the lives of social beings. It is typically viewed as a medium for interaction, but it also serves as a symbol representing cultural knowledge and social identity (Markowicz & Woodward, 1982). Erting suggests that in hearing families with deaf children the problems that exist are evidenced in the family members' use of dissimilar symbols and behaviors. Symbolic linguistic and behavioral compromises are evident when one observes interaction between hearing parents, and their deaf and hearing children.

Linguistic and cultural conflicts within hearing families of deaf children produce increased stress levels for parents and children alike, contributing to the

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[2] Woodward (1972) began the practice of distinguishing between a person with an audiological hearing loss (deaf), from individuals who identify themselves as part of a cultural community (Deaf). From this point forward, Deaf will be used to refer to a person or situation that identifies with a cultural worldview.

sustained tensions within the family (Meadow-Orlans, 1990). Hearing family members often do not have the ability to communicate with their deaf child immediately and fluently, nor know how to provide a physical environment in the home that is visually accessible (Lane et al., 1996). Because the social systems of hearing families are comprised of individuals who hear, supportive social relationships with extended family members and friends are often dismantled or disrupted (Erting, 1982, 1994; Markowicz & Woodward, 1982; Meadow-Orlans, 1990). Friends may distance themselves from the family or feel uncertain about how to respond to the deaf child or changes in communication. Disruptions in family social support may also occur because of increased stress levels, relationship discord, and feelings of grief and hopelessness among family members (Meadow-Orlans, 1990).

Markowicz and Woodward (1982) point out that the early childhood experiences of deaf children raised in a hearing family context are quite different than what is experienced by hearing family members. They indicate that while growing up "most deaf children do not have any contact with Deaf adults" (p. 4). This phenomenon occurs in part because hearing family members have not had previous social or communicative experiences with individuals who are Deaf, and are less likely to incorporate Deaf people into their family's social context (Erting, 1982/1994). The absence of culturally Deaf adults is pervasive in the lives of many children who are deaf. The result is that they are denied access to those who are culturally and linguistically most like themselves.

Lane (1993) theorizes that abundant access to hearing individuals, coupled with the absence of Deaf adults, constructs the "problem of deafness" worldview.

Lane suggests that hearing parents of deaf children often perceive their child's deafness as a problem or deficit because they are introduced to their child from a medical or pathological perspective of individuals who are deaf. McDermott and Varenne (1995) explain that worldviews are socially constructed when individuals are labeled as deaf or hearing. Consequently, a collective social response occurs that strengthens the label or stereotype that has been applied to an individual or community.

Another far-reaching problem encountered by deaf children and their families is the deaf education system. Deaf education has failed to provide an adequate educational experience for individuals who are deaf (Johnson et al., 1989). Problems start at the point the deaf child is identified as deaf; parents and family members are presented with an array of educational and communication "options." These multiple definitions and philosophies of how to educate deaf children are presented to parents from professionals with different specialties and areas of expertise (i.e., audiology, medicine, speech pathology, deaf education, etc.). The presentation of abundant and conflicting educational placement and communication options often results in information overload, which can lead to confusion and disagreement among family members. Most hearing family members also experience ambiguous feelings about learning and using sign language, as well as becoming involved with members of the Deaf community. Professionals in the field of deaf education are also known for possessing strong opinions about the best methods for educating and communicating with deaf children. Many teachers and administrators become angry and defensive when their opinions are challenged or questioned by parents, establishing even more barriers that prevent positive parent-teacher relationships, rather than providing support (Blackburn & Everton, 1994).

Lytle and Rovins (1997) suggest that teacher preparation programs for deaf educators need to restructure their curriculum content. For example, deaf education teacher preparation curricula possess a heavy emphasis on speech and audition methods but fail to prepare teachers in pedagogical areas. Johnson et al. (1989), in their controversial working paper entitled Unlocking the Curriculum: Principles for Achieving Access in Deaf Education, proposed that deaf children's low achievement is the result of two conditions: teachers' low expectations for them and lack of linguistic access to the curriculum at grade level (Johnson et al., 1989). More recently, Lytle and Rovins (1997) responded to the ideas presented in Unlocking the Curriculum by asking the question, is the curriculum currently presented to deaf students worth unlocking? Lytle and Rovins (1997) agree with Johnson et. al., and take the position that "curriculum goals, strategies, and materials for deaf students are not the equivalent to those provided to hearing students" (p. 8). These systemic problems have a cumulative, negative effect on the deaf child's social interactions and identity development.

Utilizing Ethnographic Methods

In response to the problems faced by hearing families with deaf children, most research in the field of deaf education has looked empirically at separate variables related to the deaf child and his family; most have not taken a holistic stance (Evans, 1994; Nash & Nash, 1981). There is also a significant absence of naturalistic research that systematically investigates and describes the environments where individuals who are deaf grow and live (Stokoe, 1995). In contrast, ethnographic methods, grounded in the field of anthropology, are used to develop an understanding of the meanings informants make within the context of their environment, and then translate those understandings into writings that can be understood by individuals outside the informant's context. The task of the anthropologist is to learn about people based on what they say and what they do. Finally, the anthropologist attempts to find out if what people say and do makes sense in terms of their behavior in different contexts (C. J. Erting, personal communication, November 3, 1997).

Few attempts have been made to understand the lives of hearing families with deaf children using an ethnographic approach. The deaf education literature base lacks a description of families with deaf children from an "insider's" perspective. The family's perspective is important because it contributes to a view of the child that presents a whole person, rather than a list of deficiencies or behaviors gathered in the school or clinical setting alone.

Significance of this Study

The central problem for families with deaf and hearing membership is the communication conflict that is presented in the context of their everyday living (Erting, 1982/1994). This conflict is found at intersections of their differing modalities (voice, sign, and simultaneous voice and sign), languages (ASL and English), and culture (Deaf and hearing). This dissertation aims to present an interpretive perspective of family life and the deaf child's home environment as it presents the voice of one deaf child and his hearing family members.

Complex issues require a search for meaning using multilayered forms of investigation, like ethnographic methods. We know hearing family members struggle to make meaning of the deaf experience and we need to look to and inquire about the process of their living to locate more pertinent solutions to the problem. This dissertation provides a story that may help others understand that complexity, in light of one deaf child and his hearing family's experience.

Stokoe's (1995) writings provide support for the investigation of environments where individuals who are deaf live. Stokoe reviewed Paul Bohannan's book (1995), How Culture Works, and further defined the predicament for hearing parents of deaf children. Stokoe believes that hearing parents are not provided information about "Deaf language" and questions the interventions and educational procedures used to introduce parents and family members to the concept of Deaf Culture.

Stokoe contends that learning a culture is next to impossible without interaction in the language of the culture. Ninety-two percent of deaf children are from hearing families--raised in home environments where information is accessed in fundamentally auditory ways. In addition, many deaf children today are educated within oral/aural environments where the use of sign language is at best limited, and at worst, nonexistent.

Stokoe (1995) encourages future researchers to begin "looking for the structure of cultural patterns and their processes and explaining them so that appropriate action can be taken" (p. 93). He posits that the task of investigating the processes of Deaf Culture "becomes an urgent task as the 21st century draws nearer" (p. 94). Stokoe encourages the investigation of Deaf Culture because he believes that an understanding of that culture may lie at the root of problems generated by deaf education. Investigations of culture are often overlooked because they require research investigations that examine the processes of cultural learning. Instead, society supports more traditional scientific strategies that examine and quantify human behaviors, producing a view of the outcomes of interaction, but not the process itself.

The intent of this research is aligned with Stokoe's recommendations. For hundreds of years, individuals within the field of deaf education have puzzled and debated over the supposed failures of deaf children (Moores, 1996). Perhaps the puzzle has remained unsolved because we have not thoroughly investigated the roots of deaf children: their families and their culture. This dissertation contributes to the lives of deaf children and their families by looking beyond the typology of their use of language and communication, to the cultural milieu in which they have been raised.

Lastly, this research is important because the results hold the potential to improve early intervention services for young deaf children and their families. The findings provide opportunities for researchers and practitioners to shift their present worldview from the deaf child as disabled, to the deaf child as a developing child with social, linguistic, and cultural differences. This research also sheds light on how to improve family involvement in schools as well as family-school partnerships by developing a more thorough understanding of what happens in the homes where deaf children live.

Research Questions

In order to identify and describe the family's process of understanding deafness, I began the analysis of the data with the guiding questions below. Due to the nature of qualitative, ethnographic methods, additional questions emerged throughout the course of my analysis and will be discussed in ensuing chapters:

1. What linguistic and other symbols did the Camillo family members use during their social interactions to construct their knowledge and understanding of deafness?
2. How did the family members socially construct their knowledge and understandings of deafness among themselves and with others?

CHAPTER II

THE CONCEPTUAL CONTEXT

This chapter frames the scientific problem so the reader can move from a general understanding of deaf children and their hearing family members, to a more specific knowledge of the Camillo family's lived experiences. From a public perspective, American society views and understands the Camillo family through different socio-cultural lenses. For example, the Camillos are Roman Catholic. They are also a military family. They are often referred to as "the family with triplets." The Camillos are also categorically labeled by the special education system as a hearing family with a deaf child. Privately, the Camillos have their own individual and group perceptions through which they make sense of their environment. These public and private components of the family's identity assist in socially constructing an image of the family for society (Gubrium, 1988), and in turn contribute to how the family understands and behaves toward it's individual and collective members.

Framing the Problem: The Philosophical Orientation of this Research

Mertens and McLaughlin (1995) recommend the philosophical orientation of any research should include a statement of position that clarifies the researcher's "assumptions about the nature of knowledge" (Mertens & McLaughlin, 1995, p. 5). This dissertation is about the differing worldviews that people share and develop in both individual and collective ways. Therefore, as the primary investigator, I believe including this section is critical in order for the reader to understand the philosophical grounding of this dissertation.

In order to understand the unique experiences and problems associated with deaf children and their hearing family members, one must also understand the limited and conflicting research contexts where the informants' lived experiences have been systematically investigated. Therefore, this chapter provides a scholarly argument supporting why it is important for the lenses focused on the Camillos' life to be examined, and their story to be told from their insider's or interpretive perspective. An "insider's perspective" means using the family's own interpretation of how they understand and make meaning of their interactions with others and within their intimate social group. Interpretive research presents the worldview of informants, rather than the situation or problem as it is defined by the researcher or larger society (Blumer, 1969; Maxwell, 1996).

Maxwell (1996) defines an interpretive approach as one where the purpose of the research is to ask informants to describe the meaning of their situation for the field worker. In other words, I framed this investigation with the intent and understanding that the Camillos would teach me about what it means to them to be a family with deaf and hearing members. By choosing ethnographic methods and symbolic interactionism theory as a theoretical construct, I became involved in a long- standing debate in social science research that is termed the "positivist-interpretivist debate" (Prus, 1996, p. 3).

The interpretive approach is controversial because its theoretical position stands in direct contrast to what scientists deem a traditional, positivist position. A positivist researcher studies independent and dependent variables (inside or outside the "subject"[3]) that are considered to influence human behavior. A positivist position also supports the idea that scientific knowledge must be measured in quantitative forms in order to be substantial and accurate (Mertens & McLaughlin, 1995).

Prus' (1996) position provides support for the interpretive investigation of deaf children and their families (i.e., "the human experience," p. 1). In other words, his argument has grounded the belief that people create their own realities or "worlds" by living their lives, thinking about their actions, and interacting with others--people make sense of their world in intersubjective ways (Blumer, 1969; Prus, 1996). A scientific intersubjective position means that when investigating and attempting to understand the lived experiences of human groups, data must be collected and analyzed in ways that allow for the informants to interact, reflect on their actions, and share meanings as a social group. Prus asserts that "positivism is basically flawed as it does not account for the human production of meaning and action" (p. 3). As a result, while traditional data-gathering methods (i.e., questionnaires, observation and event sampling, and some interview formats) have made useful contributions in part, they have not been fully capable of capturing the actions and interactions (i.e., the meaning of lived experiences) of deaf children and their family members.

Anchoring the Problem: A Review of the Literature, Preliminary Discoveries, & Addressing Researcher Bias

The next section reviews pertinent literature from the research base that represents how general society views Henry Camillo and his family--families with

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[3] Interpretivist scientists tend to refer to the people who participate in their research as "informants," while Positivists most often call their participants "subjects."

children who are disabled or chronically ill. The second section is devoted to discussing some of the unique strengths and weaknesses of the research that describes hearing families with deaf children. Third, findings from the pilot study that led to this dissertation provide a more focused view of four families with deaf children. The last section describes my personal interests, experiences, and biases as the researcher of this project.

Families with Children who are Disabled or Chronically Ill

Historically, hearing families with deaf children have been socially and categorically associated with families with disabled or chronically ill children. Consequently, there is a common perspective in society that understands and portrays hearing families with deaf children as "special, problematic, or dysfunctional" because deaf family members are considered disabled. This research project is grounded in the belief that hearing families of deaf children are qualitatively different from families with disabled children in that deaf children are not disabled by the nature of their hearing status. Instead, deaf children become disabled, in part because they are socialized and understood by general society as participants who are deficient. Because deaf children are viewed and treated as disabled, it is necessary to consider the worldview of general society that describes the lived experiences of families with exceptional children when developing the conceptual context of this investigation.

Buscaglia (1994) estimates that there are 18 million disabled children in the United States today. He elaborates, "Each hour of each day, children are born who are blind, deaf, have some form of cerebral palsy, some degree of mental retardation, or some minimal brain damage that will later result in learning problems" (p. 23).

Buscaglia describes how parents with a child who have a disability are introduced first to the child's condition, and then to the person. From the very beginning, there is an evident stigma attached to their child that causes the parents and other family members to experience immense feelings of grief and, in some cases, to fear their own family members.

Parents of disabled and chronically ill children encounter additional challenges and stresses beyond the scope of their family's personal adjustment. Hanson and Lynch (1995) account for potential family adjustments in interaction patterns including increased financial burdens and expenses, additional childcare needs, and less time for leisure activities and the accompanying social support provided by friendships. Turnbull and Turnbull (1997) define family adjustments in terms of eight additional roles that are assumed as parents of a disabled child. To name a few of the roles, parents of disabled children become organization members, teachers, political advocates, and educational decision makers for their disabled child. These additional roles and responsibilities to a child with a disability or chronic illness require additional time and energy and have the potential to take time away from or alter other important family relationships (i.e., marital, parent-child, and sibling relationships) (Falik, 1995; Turnbull & Turnbull, 1997). Gath (1993) and Hanline (1991) point out that special family accommodation often creates an effect across the family's lifespan, with the intellectually disabled child maintaining highly specific needs and vulnerabilities into adulthood (Gath, 1993; Hanline, 1991). Accommodations for the disabled child in the family translate into lifestyle changes for nondisabled siblings.

Seligman and Darling (1989) characterize sibling relationships as "the longest and most enduring of family relationships" (p. 111). Consequently, siblings of children with disabilities are at greatest risk for experiencing the effect of sibling dependency over the span of a lifetime. The able child often experiences extensive care-taking responsibilities, feelings of anger and guilt, as well as feelings of anxiety associated with identity development (Krauss, Seltzer, Gordon, & Friedman, 1996; Seligman & Darling, 1989).

The overall picture within the literature concerning family life with a disabled child has several distinct components. This body of literature has made a shift from investigating the specific impact of the child's disability, to a more positive perspective on the child and family. This shift is evidenced in several ways. First, current intervention efforts focus on enabling the child to reach their full, individual potential (Hanson & Lynch, 1995). Second, the literature reflects efforts to support mothers and fathers, while identifying their unique sources of stress and developing intervention strategies that remediate those feelings (Diamond, 1994; Krauss, 1993). A third group of writings discusses the social stigma associated with the severity of the child's disability and the related social support that parents and families prefer (i.e., friends and families before professionals) (Llewellyn, 1995). Finally, Gallimore and his associates have investigated the families' early responses and ensuing functional accommodations throughout early and middle childhood. He encourages more environmentally based interventions that respond to the family's day-to-day living (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Gallimore, Weisner, Kaufman, & Bernheimer, 1989).

Deaf Children and their Hearing Families

Traditionally, positivist studies investigating deaf children and their families have been unsuccessful at portraying the lived experiences of deaf children and their families because the research was designed to consider and manipulate specific variables that were associated with the condition of deafness, such as the degree of the child's hearing loss, and comparisons of communication modalities used by the child at home and school (Vess & Douglas, 1995). High quality quantitative investigations have contributed to the body of literature concerning populations of deaf children and their family members (Calderon, Bargones, & Sidman, 1998; Meadow-Orlans, 1990). Survey methods are useful to establish large demographic databases. However, the methodology used for this traditional approach to gathering and interpreting data presents findings that imply broad meanings for groups of people. Gatty asserts that questionnaires by the nature of their structure tend to focus on distinct aspects of deafness as a disability, in some cases presenting a view of the deaf child as a list of symptoms rather than a whole person, thus oversimplifying solutions for parents and family members (Gatty, 1996). For example, some previous studies have produced the following critical, variable-based information.

Young children who are deaf or hard of hearing comprise a small, heterogeneous population (Goppold, 1988). The rate of early identification of severe to profound deafness is approximately 1 per 1,000 children (Calderon & Greenberg, 1997). One-quarter of this population of deaf children also have disabilities such as mental retardation and learning disabilities that require exceptional educational practices (Schildroth & Hotto, 1996). Variables such as varying degrees of hearing loss and diverse family background are considered effects that contribute to the complexity of a small, heterogeneous population.

The variables of parental need, response, and adjustment to the child's deafness are parts of family life that have been frequently investigated. Others extend the family members' responses and attempt to answer questions about marital satisfaction and family relationships related to the child's deafness (Henggeler, Watson, Whelan, & Malone, 1990; Morgan-Redshaw, Wilgosh, & Bibby, 1990; Rienzi, 1990). Sources of stress and support have also been examined and discussed at length (Koester & Meadow-Orlans, 1990; Meadow-Orlans, 1995; Meadow-Orlans & Sass-Lehrer, 1995). This traditional approach to research is similar to the body of knowledge that investigates and discusses families with children who are disabled. However, the greatest qualitative difference in discussions contained within these two literature bases is the subject of language, communication, and culture. Consequently, the literature describing deaf children of hearing families contains a large presence of topics concerning the deaf child's language acquisition (Meier, 1991), the family's choice of communication modality (Henderson & Hendershott, 1991; Luetke-Stahlman & Moeller, 1990), and studies that examined parent-child dyads and the resulting interaction between deaf parents of deaf infants and hearing parents of deaf infants (Meadow-Orlans, Greenberg, & Erting, 1990; Spencer, 1993; Spencer, Bodner-Johnson, & Gutfreund, 1992; Spencer & Gutfreund; Swisher, 1992).

This investigation agrees with others who recognize that the disability perspective on deaf children and their families has not been effective in either research or practice (Calderon & Greenberg, 1997; Feher-Prout, 1996). The disability position presents a deficient view of deaf children and their families and perpetuates negative practices as well as lower social and academic expectations in both the literature and among educators in the field of deaf education. In order to shed light on the complex problem of managing deaf and hearing perspectives within the same family, it is necessary to approach the problem from a different philosophical stance: a socio-cultural perspective. The next section operationally defines the cultural view of individuals who are deaf and provides a small selection of scholarly examples that contribute a socio-cultural interpretation of the lived experiences of deaf children and their families.

Defining Culture and the Deaf Experience

Schneider views the American family as "a cultural system or a system of symbols" (Schneider, 1980, p. 1). He states that studying and defining culture is a complex and elusive task with each culture having an essence that is more complex than the sum of its parts. Consequently, considerable debate has occurred among scholars in the fields of anthropology, sociology, and education concerning how people and their cultures should be studied and defined.

Early efforts to study communities and their culture produced static definitions of social groups and communities. Traditional descriptions of human interaction resembled "checklists" of typical language use, symbols, and behaviors exhibited by the "natives" (Turner, 1994). The checklist approach alone to defining culture is problematic. Developing checklists of cultural behavior fails to address the interactive process of cultural and identity development. Individuals are not born with a particular cultural persuasion, but learn the values and mores of their community through their interactions with community members over time. Turner (1994) agrees that it is possible for an individual's behavior to fit a cultural construct or definition while that individual has not gone through the interactive and developing process of becoming a community member. As anthropology and fieldwork matured, scholars balked at defining or creating a checklist of cultural attributes because the practice created stereotypes and stigmatized the group members who were represented (Bohannon, 1995).

Wolcott (1995) reminds us that learning cultural behavior is a process-oriented task, deeply embedded within the linguistic and behavioral interactions of communities of people. Consequently, he prescribes a process-oriented approach to fieldwork and analysis. He refers to fieldwork, the method of systematically studying culture, as a strategy that constitutes both science and art (Wolcott, 1995). Scientists are required to be systematic and precise during data collection and analysis efforts. In contrast, the artist needs to be creative within the changing tempo of informants' day-to-day interactions.

I am using Spradley's definition to operationalize the term <u>culture</u> for this investigation: "Culture refers to the acquired knowledge that people use to interpret experience and generate social behavior" (Spradley, 1979, p. 5). In other words, people make meaning of their individual and collective worldviews through reciprocal exchanges of social information. Because individuals who are deaf are classified by the majority of individuals in American society as disabled, and the study of Deaf people and their culture is relatively new, defining and describing Deaf Culture is complicated.

The Deaf Culture Experience

Markowicz and Woodward (1982) point out that in the past, individuals with a deficit perspective on deafness have labeled cultural differences as deficiencies in deaf persons. However, they explain that apparent cultural tensions are a way that boundaries are formed around members of an ethnic group. Tensions are illuminated when cultural boundaries are crossed, and differing behaviors "stand out" within the community of people as unusual or socially unacceptable.

Erting (1994) identified two themes that are central to the Deaf experience: "The first is that deafness is primarily a visual experience. The second is that deafness results in dependence on those who are not deaf" (p. 3). The first theme is straightforward in that vision is the "central organizing principle" in the lives of culturally Deaf people (Erting, 1994, p. 4). Erting explains that hearing people have the "dual" advantage of accessing information using both vision and hearing as they interact with and manage information. The second theme of dependency imposed by society's macrostructure has been misinterpreted (C. J. Erting, personal communication, November 7, 1998). Erting (1982) states that while Deaf people do not consider themselves dependent, from the worldview of mainstream society, the Deaf experience consists of "everyday interactions with hearing people [who] repeatedly reaffirm the deaf individual's exclusion from full participation in mainstream life and the impossibility of complete acceptance by the majority and thus movement out of their stigmatized status" (p. 7). In other words, the nature of the structural dependency of the Deaf experience is an inevitable situation of oppression. Any person in society who is perceived as, or identifies with, a minority group is in some way dependent upon the rules and mores of the majority society.

Padden and Humphries' (1988) description of the Deaf experience as a social condition adds to and clarifies Erting's original use of the term dependency:

> Deaf people must live almost entirely within the world of others. This particular social condition leads to a longing of their own, a longing to live lives designed by themselves rather than those imposed by others. (p. 112)

Padden and Humphries (1988) elaborate on the Deaf experience by explaining that the intent of their book, Deaf in America: Voices from a Culture. They state that their book was written to shift attention away from the worldview of deafness as an audiological condition to a greater focus on "the way Deaf people live--to their culture" (p. 110). Consequently, Padden and Humphries define the Deaf experience as a fundamentally different way of viewing the world from "a different center" (p. 110).

These descriptions of the Deaf Cultural experience led me to operationalize the task of observing and documenting cultural differences that created tensions between deaf and hearing family members in the Camillo home. While family members did not use the term cultural tension, Sara and Mark Camillo searched for cultural and linguistic understanding regarding their son Henry's deafness on a regular basis. Frequent communication breakdowns among family members were associated with more subtle lapses in cultural understanding that occurred. For example, when Henry repeatedly roughhoused with his younger sister Madeline, a common question was discussed, *Is Henry behaving like a typical deaf child, or is he acting like a 4-year-old?* (FN:157:3:1). Henry's parents persisted in their efforts to communicate to Henry that he shouldn't play rough or hurt his sister. Despite their explanations, physical tussles between Madeline and Henry reoccurred, leaving Mark and Sara shaking their heads in frustration and saying, *Even though we've told him a thousand times, he acts as if he doesn't understand what we're saying* (FN:131:1:5). Mark and Sara also seemed to experience a sense of isolation and remarked, *No one seems to be able to answer our questions about what to do* (FN:15:2:21).

One is left to question that while Henry's behavior in the context of a group of hearing people may have appeared odd or puzzling, could he have moved about unnoticed as he interacted in a social group where all members are Deaf? It was also evident that Henry often perceived the behavior of hearing people as equally peculiar. He often expressed his bewilderment by directly asking family members about their apparent "hearing" behavior. Behaviors that I take for granted as a hearing person using a spoken language quickly became "strange" through the eyes of Henry Camillo. For example, it was an everyday occurrence for hearing family members to talk to one another in separate rooms of the house. When Henry witnessed a person standing in a room alone, moving their mouths, he repeatedly asked, *WHY TALK TALK?* meaning, *Why is your mouth moving and no one is in the room with you?* or *What are you saying and who are you saying it to?*

Research in Environments Where Deaf Children Live and Grow

There is a tremendous lack of naturalistic research studies concerning deaf children and their families in refereed journals. A discussion in Kathryn Meadow's dissertation (1967) was one of the first writings that addressed the socialization of deaf children within the context of their home environment. Meadow illustrates symbolic interactionism theory as one of four perspectives to use when studying human socialization. She made three points that are important to this dissertation's position:

1. All human interaction, including that of parents and children, is reciprocal. Actions are based on indications, interpretations, and cues from prior acts.

2. Socialization should be viewed as the process, which enables the individual to interpret, not merely react to or mirror, the prescriptions and proscriptions of society. Thus, the outcome of the socialization process need not be social conformity.

3. The total social matrix is important to the socialization of the child (Meadow, 1967, p. 44).

Symbolic interactionism is a fitting theory for anchoring the human socialization that I documented in the Camillo home, rather than the scenario that is portrayed in most deaf education literature. Before I began my fieldwork, when considering the nature of family interactions, I made the common error of conceptualizing interaction from the worldview of the adults only. In other words, the parent or teacher provides a model for the child, and the child receives the information or input from the adult. The underlying assumption within this line of thinking is that the parent initiates the interaction, and the child responds accordingly. However, Meadow (1967) expands upon the "reciprocal nature" of family interactions to include parent-child, parent-parent, and child-child interactions, providing a more process-oriented position to growth and development. Meadow explains that both the child and parent initiate interactions, and both receive enjoyment and information from the process. It is important to note that the literature that follows has taken Meadow's pioneering philosophical stance.

David Goode's dissertation (1980), republished 20 years later in book format, describes the life and social construction of "Breta." Breta is described as a deaf-blind, mentally retarded, "Rubella Syndrome" child. Goode's study sought to remedy a lack of naturalistic data concerning families with deaf-blind and mentally retarded children, while establishing naturalistic ethnographic procedures as useful data-gathering tools. Goode's dissertation is based on fieldwork conducted in Breta's home. One of Goode's primary research goals was to document and describe the complexities of her life. He wanted to investigate how the social perception held by others in Breta's social world, affected, or limited the development of her identity. Goode was particularly interested in Breta's language development. He described her as alingual or without language. While conducting his dissertation research in the late 1970s, scientists were still questioning the thought processes and cognitive potential of individuals who did not speak or possess a "formal [spoken] language" for communication. In order to answer his research questions about social identity and language use, Goode gathered data for a year, using videotaping, and "intensive ethnographic observation" in Breta's home.

Concerning his most recent works, Goode (1994) combined his investigation of Breta with additional fieldwork that focused on a second deaf child named "Christina." Goode's book details longitudinal information that encompasses a 20-year span of Breta and Christina's lives, as they lived and grew in different home contexts. In contrast to Breta's early experiences, living in a traditional home context among her blood relatives, Christina was institutionalized at an early age and lived her life in an institutional setting. Goode's persistent and prolonged contact with Christina, and those who cared for her in an institutional setting, allowed him to learn about, describe, and contrast the constructions of these two women's lives, based on a variety of different social perspectives and settings.

Judith Evans' dissertation and related publications (1994, 1995, 1998), are pivotal contributions to the knowledge base concerning the lived experiences of deaf children and their hearing families. Evans was driven to conduct this dissertation research with the understanding that the disability perspective as it is applied to deaf children is not a productive course of action in research, school, or family contexts. Evans studied the home life and conversations between "Kristen," a 7-year-old deaf child and her large hearing family. Evans' dissertation provides a detailed overview of Kristen's conversational practices with other family members and an analysis of language samples produced to assess Kristen's language use. Evans also conducted an in-depth contextual analysis that produced a variety of family themes as they pertained to Kristen's deafness.

A critical finding of Evans' research produced a different and more encouraging view of the home communication environments of deaf children in hearing families. Evans placed Kristen's communication experiences in the home on a continuum which ranged from inclusion to exclusion. She noted that Kristen had opportunities for full inclusion in family life and communication when interacting in dyads and small group settings. In contrast, during family gatherings that included large, interactive groups of people, Kristen was left to "fend for herself" in order to understand and access communication.

Evans (1994) grounded her investigation of Kristen's communication situation in Halliday's (1989) social-semiotic perspective. Halliday suggests that there is a relationship between the language used (text) and the social situation (context) where it is exchanged. In other words, Evans interpreted Kristen's communicative position as a social being who is able to adapt in social situations in order to function effectively in a variety of environmental contexts, both deaf and hearing, large and small group. Evans' findings eventually raised the question that if Kristen (the deaf child) can make communicative accommodations in different social settings, it is not a foreign or impossible notion that family members (hearing adults and children) can make the same if not additional contributions (i.e., develop fluency in sign language, make the communication environment more visually accessible, etc.).

Waldron's dissertation (1996) explores the sign language learning experiences within the context of a hearing family. The family that Waldron investigated decided to learn and use American Sign Language (ASL) to communicate with the deaf child in their family. Waldron interviewed multiple informants from the deaf child's (named Jena Byers) ecological environment, including teachers, other school personnel and family members. The central research question for this investigation 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?" (Waldron, 1996, p. 102). While Waldron describes her methods as ethnographic, her database was composed primarily of interview transcripts that she analyzed using only an "open coding" strategy. Later she supplemented and refined the categories that resulted from this initial coding using a qualitative computer program.

From both an educational and family studies perspective, Erting's dissertation (1982/1994) presents a way of understanding and viewing families composed of deaf and hearing members using a socio-cultural lens. Erting (1994) takes the theoretical position that deafness "is not primarily a physical disability; rather, it is a set of attitudes and a way of behaving" (p. 33). Consequently, she suggests that hearing families and their deaf children are presented with a problem: the continuous task of making sense of discrepant cultural symbols and resolving cultural tensions within their immediate family.

Erting conducted fieldwork for three years at a school for deaf children. Her observations and interviews produced multiple interpretive perspectives from informants within and outside of the school social environment. The family component of Erting's investigation was based on an in-depth analysis of three sets of parents of deaf children: one set of hearing parents and two sets of deaf parents. Erting's ethnographic account built the foundation for this investigation and provided the theoretical framework for what I observed over the course of an academic year in the Camillo's home.

One of the most compelling results of Erting's dissertation is her models of individual social actors, representing the complex structural, personal, and interactional influences that result in an individual's worldview (Erting, 1982). As described earlier in this dissertation, the presentation of Erting's models of individual social actors developed from her central position regarding the Deaf experience is as follows:

> There are two themes that structure the lives of deaf people in fundamental ways....The first is that deafness is a visual experience. The second is that deafness results in dependence on those who are not deaf. (Erting, 1982, p. 4)

My theoretical position agrees with Erting in that these biologically and socially grounded constraints cause deaf people to construct their view of the world in fundamentally different ways than hearing persons in society. Concerning the first theme, Erting (1982) posits that deaf people possess a primarily visual perspective of the world. She asserts that deaf people's ways of gathering and using information are more than a peripheral part of their lived experience but rather, viewing the world through the channel of vision-only is the "central organizing principle for their lives" (p. 5). She explains that success and survival in society depend upon one's ability to effectively process and manage information exchanges with members of the majority society. Thus, the second constraint experienced by deaf people, concerning structural dependency on the rules and behaviors that govern the majority of social interactions in society, is even more far-reaching.

These central issues produce what Erting (1982) deems "a dynamic tension" that occurs among deaf and hearing people as they interact and construct their views of the world. This dynamic tension creates a unique family problem in the lives of deaf children with hearing parents and family members. The dynamic tension is created in part through their interactions and creates a momentous influence on family roles and relationships. Eventually the distinct worldviews and identities developed by both deaf and hearing family members create the irony that it is possible for blood-related kin to live in the same environment, but understand and respond to that same environment in drastically different ways.

Therefore, the dynamic tension that Erting identified and described is the guiding principle for this dissertation. Later in this dissertation, findings are presented that emerged as I used several of Erting's models of individual social actors to consider the interplay of structural, personal, and interactional influences among Henry Camillo and his family members.

Preliminary Discoveries

I was hired during the Spring semester of 1996 as a research assistant in the LLCD lab. Before my employment within Dr. Erting's project, I assumed several research assistant positions with individual faculty members at the university and elsewhere. Working with Dr. Erting and her team of researchers was unlike my prior research assistant experiences in a variety of ways. First, Dr. Erting's research team consisted of Deaf and hearing researchers, classroom teachers, undergraduate and graduate students, and research scientists with expertise in the fields of anthropology, education, sociology, and linguistics. I found the laboratory environment to be consistently positive, supportive, and intellectually stimulating. Within the first week of my employment, Dr. Erting met with me and asked me to identify who and what I wanted to study, as well as the specific research questions I would like to investigate. Our researcher advisor/research assistant relationship was vastly different from the former research positions I held because she encouraged me to create my own research design within the boundaries of her larger project.

The Pilot Investigation

The pilot investigation began in May 1996 and culminated in October 1997 when I moved into the Camillo home (Blackburn, 1997). The primary purpose of the pilot was exploratory. I wanted to investigate the composition of four families with deaf children (see Appendix C for a list of pseudonyms representing the four families).[4] I selected this research goal for the pilot study to develop a clear picture of each family's relationship structure. I wanted to be able to understand and elaborate on whom the family members considered to be kin, and why. In addition, I wanted to describe the roles, boundaries, and relationships within each family.

I used the qualitative methods of ethnographic interview (see Appendix D for a collection of interview protocols), and participant observation. My experience as I began the pilot study agrees with Spradley's notion concerning the degree to which a researcher becomes either a participant or observer at any given moment of the investigation. He suggests that the researcher's roles change depending on the activity, geographic location, and time frame established by the informants (Spradley, 1979). The data I gathered for the pilot investigation were heavy in interview and observation, with fewer occasions in the participant role.

Each family chose the mother as the key informant (Maxwell, 1996) who would initially represent the family in one ethnographic, videotaped interview. These videotaped interviews established the formal boundaries of the study, which began with the Arnold family interview on June 4, 1996, and concluded with the Bartholomew/Norris interview on September 18, 1996. Other informal interviews were conducted and recorded during field visits and telephone conversations. My goal

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[4] The four families who participated in the pilot study were: (1) *The Arnold family* (Deaf parents with deaf children; intact marriage; Anglo-American ethnicity); (2) *The Bartholomew/Norris family* (hearing parent with one deaf child, and three hearing children; divorced, single parent, Anglo-American ethnicity); (3) *The Camillo family* (hearing parents with one deaf child and five hearing children; intact marriage; Anglo- and Spanish-American ethnicity); and (4) *The Small/Young family* (hearing foster mother and her partner with one deaf foster child and two hearing foster children; intact relationship; African-American ethnicity).

to interview each family representative for at least an hour was met; interviews ranged in length from one to three hours.

To analyze the pilot data, I examined the database for categories and themes that were shared by all four families. Three themes emerged: (a) fairness, (b) kinship, and (c) communication issues. For the purposes of this dissertation, only the theme "communication issues" will be discussed.

Family Communication Issues: The Pilot Findings

The issue of communication access through the use of American Sign Language (ASL) or a Manually Coded English System (MCE) was a tension that emerged in all the pilot family stories. I identified cultural tensions that were frequently embedded in the mothers' stories of communication access. For example, for the seven weeks Sara Camillo was on bed rest in the hospital, the issues of communication access for her son Henry was often on her mind. Sara discussed this topic with deaf individuals who worked at the hospital, in addition to those who visited her there. She told me about an instructional assistant who is deaf (Matt) from the school where her son attended, who offered to take Henry for an outing in order to ease some of the pressure at home. Sara described this man's suggestion, offered from a culturally Deaf perspective, as an insult to her. What he proposed as a solution conflicted with her family's values. Sara details:

> Remember when I was talking to you about that Matt guy? That Matt who wanted to come over and stuff? How he wanted to just pull one of our children, which would be Henry--pull him out and mess with him because he is deaf, and Matt is deaf, and they could do their thing? I mean, without him knowing, it was like an insult immediately, 'How dare you?' You know, 'No!' Well, first of all we can take our own children to the zoo and to the park. I mean, we are their parents; we are their mentors. They don't need outside mentors! We will provide our children with what they need. (INT:1:42:20)

Sara's emphasis on what we do as a family was her way of drawing a boundary around her family as a social system. She viewed this offer from Matt as odd, which is a classic signal identifying when a cultural more had been crossed or violated (Rosaldo, 1989; Spradley, 1979; Turner, 1994). As a result, I interpreted Sara's reaction to Matt's offer as an example of cultural tension. Sheryl Bartholomew's family values differ, perhaps because her children are older. She talked about her family's decision to sign, and how she valued the participation of the Deaf Community in their home life:

> Well, the other thing is, I've always loved Indians [sic]. And John [her deaf son] is my little papoose, I guess is what I've always called him. So we just decided [when John was identified] that we're just learning another language. And, I also believe that if you have a child that's different, then they need to be with people who are like them. The same as with an Indian [sic] baby--if I'd had adopted a biracial baby, or um African American, they need to still be with African Americans or other biracial children. That's just the way I view it. And you can't tell them that they're the same as you; they're not. (INT:P4:12:34)

The findings of this exploratory study provided support and demonstrated a need for further naturalistic investigations of cultural variation within families and communities who have deaf and hearing members.

Researcher Personal Interest, Bias, and Experience

Qualitative inquiry requires the researcher to define ones' biases and subjective self as the tool or instrument that "weighs and measures" the data (Wolcott, 1995). It is critical to the research process for the field worker to acknowledge and document subjective thoughts and feelings. The interactions between field workers and informants are considered cultural interactions, and therefore they provide a framework for gathering and understanding data. In other words, my social interactions with Henry and his family are what illuminated our cultural differences. Also, it is critical for the field worker to be able to consider his or her subjective cultural biases at a "cognizant" level of understanding, so that they can be examined and documented. Therefore, I am including the next section, which provides a narrative of the personal interests and experiences that led me to this research project. This section also provides a description of the initial context of my research with the Camillo family.

The interest defined in this dissertation evolved over time, beginning with my early family experiences and extending through my adult years as a classroom teacher of young children who are deaf. I grew up in the same home with my paternal uncle, Bill Blackburn, who was deaf. My strong personal relationship with him led me to a teaching career in the field of Deaf Education. During my latter years as a classroom teacher, several events occurred that served to mold and construct my personal and professional identities. These events also began to illuminate my principal research interests and permanently changed how I made sense of the world.

Throughout my eight years of teaching experiences in both public and residential programs for deaf students, I met and developed relationships with parents and family members of my students. I began to recognize that while all the families I met had diverse structures, values, and backgrounds, they shared two common behaviors.

First, all family members had stories to tell. However, I realized that the stories of hearing parents and family members shared a common, reoccurring theme regarding the joys and complexities of raising a deaf child in a household where all other family members are hearing. I recognized that the parents love to talk about and relate stories concerning for example, the challenges of learning sign language and understanding the intricacies of the special education system. These stories were told repeatedly and with an extraordinary sense of urgency and drama. I developed the idea that the key to understanding the complexities and often challenging dynamics in hearing families with deaf children is embedded in the content and posture of these family stories (Wolcott, 1992).

Apart from the family stories, I also noted a discrepancy in the words and actions of families who chose sign language to communicate with their deaf child. Frequently family members claimed, "We sign all the time at home" and "Everyone in our family is learning to sign." However, during my home visits or when presented with social opportunities to interact with deaf adults who used sign language, I observed family members who either signed in surprisingly rudimentary ways, or who didn't sign at all.

I had difficulty finding literature that responded to my questions about those behaviors and discrepancies. At the same time, teaching colleagues commented that parents only wanted to talk about their problems and relied on educators to "do the work" regarding communication with their children. I decided, in part, that the understanding I sought lay within the families with whom I worked and within my own family of origin.

The Influence of My Family Experiences

My father died in the summer of 1991 after a long, unpleasant battle with cancer. I was attending math and cognition classes at Gallaudet University during the work week and drove home on the weekends to help my mother and siblings provide home health care. Ironically, my father and Uncle Bill were both bed ridden that summer and therefore were unable to communicate directly with one another. Several years before my father's illness, Bill had experienced a relapse of childhood polio. He lived in a nursing home facility several miles from my parents' home. My father and I were the only family members who were fluent signers, and as his death became imminent, I gradually assumed the role of "family interpreter." This role included many responsibilities I had not anticipated. I became responsible for updating my uncle about my father's condition, relaying farewell messages between brothers, and finally, describing to my uncle the details of my father's death.

I began to ask myself with a good degree of bitterness, "How did I get this job?" I often questioned why my siblings never learned to sign. For the first time, I saw a parallel between myself and the families I served. I caught myself repeatedly telling the story of our family's changing dynamics. I also noticed that many hearing family members didn't sign as much as they claimed, or in other cases never learned to sign with their deaf family member at all. I struggled with the picture of dependence that was suddenly evident. I also noted that regardless of whether or not sign language was present, it was typical for one hearing family member to assume primary responsibility for their deaf kin. I was puzzled because I knew that my family's care-taking tradition with Bill was intended as an act of love. My new lens on the world was troublesome as it allowed me to see "down the road" into adulthood for deaf children in similar scenarios, and I didn't like the story that unfolded for them.

Three years after my father's death, during the second year of my doctoral studies (January 1995), the scenario I had dreaded played out for our family. I found myself in an emergency room attempting to interpret for Bill as he thrashed and screamed on the gurney. Nurses, doctors, and family members looked to me to relay critical information about establishing his vital signs. The nurses were afraid to touch him because he was *combative* and *resistant to treatment*. I heard myself repeatedly explaining, "He won't hurt you – his voice sounds 'funny' because he doesn't often use it." "No, he is not retarded; he's deaf," and "I can't tell him that information unless he opens his eyes."

For two hours, no amount of shoulder tapping or hand stroking could encourage Bill to open his eyes. At some point my sister-in-law, who is a nurse, stepped in and inserted the IV containing medication to relax him. A short time later Bill opened his eyes and we finally had contact. I explained that he was having a heart attack because his kidneys were failing. I told him we loved him, and that they were moving him to a room to rest. I teased him with the wag of my finger and wink of an eye signing, *PLEASE COOPERATE WITH NURSES*.[5] Bill smiled and we shared a long look before they wheeled him away. The next morning he regressed into a coma, and within two days, he was dead.

The true understanding of my uncle's life and identity unfolded for me at his viewing. Deaf people of all ages and walks of life came to pay their respects and celebrate his life. Some of them I remembered from summer visits to our home when

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[5] This quote, typed in all capital letters, is written in glosses (Stokoe, 1965). Gloss is a linguistic method of representing American Sign Language. Usually one gloss represents one word or sign.

I was a young child. As we entered the funeral home, my mother also recognized them: "Those are Bill's people," she whispered. As soon as I raised my hands to sign, they nodded, smiled, and put their arms around me. I was astounded at how sheltered I felt by people I barely knew. I realized that as much as I loved my uncle, I never really knew him: We did not share this community of people.

From that point, I began to notice that hearing and deaf family members who signed with one another seemed to create the sense of unity and integration I experienced at my uncle's funeral. I realized that deaf and hearing family members create their own unique reality and shared understandings as a result of their shared symbols (in this case, the symbols are ASL and English). I began to envision a life for deaf and hearing family members that fostered cross-cultural understandings rather than the care-taking, disability scenario that occurred in my family of origin; my lens on the world had shifted again. I also realized how the cycle of research and practice affects families with deaf children. I recognized the limited body of research that describes the lived experiences of families who wrestled with this issue. I began to envision a different approach to research and providing educational services for young deaf children and their families.

CHAPTER III

METHODOLOGY AND VALIDITY

This chapter describes the multiple forms of data I collected as well as my approach to conducting analysis in preliminary and final forms. I have also included an account of the research relationships I established and maintained with members of the Camillo family. The conclusion of this chapter details the measures I took to ensure validity, credibility, and the ethical treatment of my key informants and the people in their familial and social environments.

I chose qualitative, ethnographic methods because I wanted to study the communicative processes, behaviors, and interactions between a deaf child (Henry Camillo) and his hearing family members. I made this methodology choice with the understanding of several basic premises concerning the nature of interpretive, post-positivistic research (Sherman & Webb, 1988). I understood that:

1. The best way to capture family life is to observe and participate with informants in the context of their day-to-day lives. Therefore, I understood that I would have to immerse myself in their setting (the home), rather than expect them to come to mine (the research laboratory or school).
2. I would have to regularly consult and analyze my own lived experiences in order to consciously identify and document my own biases and subjectivities.
3. The contexts of my inquiries and observations should occur in a natural and uncontrived manner and setting.

4. Our research relationships would be interactive and collaborative; trust and a deeper understanding of the family's life would develop over time.
5. Using their words and actions, the persons studied (the family members), would teach me (the researcher) about their lives. Family members would set their own pace and degree of participation in our research relationship.
6. I would collect, learn, and represent information about the family in a holistic manner, rather than attempt to separate or segregate the data into variables to be weighed and measured.

Qualitative research presents a variety of scientific strategies that can be used to investigate social problems. Fetterman (1989) and Wolcott (1995) describe ethnographic methods and fieldwork as the art and science of describing a group or culture. Therefore, I chose ethnographic methods because they are best suited for studying human cultural conditions.

The Nature of Ethnographic Methods

The nature of ethnographic, qualitative methods are inductive. The term inductive means that scientific understandings emerge from the data collected, rather than the researcher beginning with an established hypothesis to be measured. Qualitative methods are used to discover new theories or develop existing ones. Jarrett (1992) suggests that when theories are identified and applied within the context of real people and their day-to-day lived experiences, they are most likely to illuminate the social reality of informants.

During the data collection and preliminary analyses of this investigation, I was engaged in prolonged and persistent fieldwork in the Camillo home for a 10-month period, using multiple ethnographic methods to document and collect information about their family. One of my data collection goals was to learn and gain understanding about the complexities of their family relationships through my direct personal involvement (Van Maanen, 1988; Wolcott, 1995). Using multiple data collection strategies over time was the most thorough and systematic approach to reaching this research goal (Ely, Anzul, Friedman, Garner, & Steinmetz, 1991). As I collected the data and conducted preliminary analyses, I kept in mind the encompassing task of in-depth analysis. I wanted the final product of this dissertation research to be a written representation of how the Camillo family made sense of Henry's deafness and how their understanding informs their actions--a detailed account of their family's diverse beliefs and understandings and how they came to be.

Because I am an apprentice researcher and not an anthropologist, I relied heavily on the works of Agar (1980; 1986), Spradley (1979, 1980), Van Maanen (1988), Ely and her students (1991), Wolcott (1991, 1995), and Maxwell (1996) for methodological understanding and support while I was in the field. The writings of these scientists also assisted me in the creation and adjustment of my design throughout this project.

I was also fortunate to have the experience of conducting my dissertation research as part of a team of researchers, rather than in isolation.

I used the following methods of data collection from May 1996 to July 1997: (a) participant observation (ranging from full observer to full participant); (b) informal interviews (written up as fieldnotes or captured on electronic mail interactions); (c) in-depth, ethnographic interviews (transcribed from videotape and audiotape); (d) selected videotaped family interactions; and (e) documents and artifacts gathered from the school, community (a parent listserv, church, and neighborhood social groups), medical, and home environments. In-depth, final analysis of the data occurred in tandem to the writing of my dissertation (July 1997 to December 1998) and will be described later in this chapter. Fieldwork occurred in a cycle of four stages that I used to organize the contents of this chapter: (1) entering the field, (2) fieldwork immersion, (3) exiting the field, and (4) returning to the field.

Entering the Field: Maintaining an Ongoing Relationship with Informants

Entering the field and establishing a trustworthy relationship with informants is both rigorous and precarious to those who engage in the participant observation methods. When novice field workers gain entry and begin data collection, they cope with adjusting to a new living environment as well as experiencing what Wolcott (1995) deems life shock. Wolcott explains that many young academicians spend a great deal of time "in the library studying about life, [while] everybody else [is] knocking about in it" (p. 93). Consequently, this section describes the tools that I used to collect and organize data in the research setting as I conducted participant observation. I found being organized--possessing a plan, accompanied by an organized field notebook, was crucial to the success of data collection.

Participant Observation

Wolcott (1995) suggests that novice participant observers begin data collection using a wide lens to view the family's interactions, while casting a large net into various bodies of literature, in an attempt to structure and "ground" observations and experiences (Glaser & Strauss, 1967). I entered the Camillo's home with an intent to observe a variety of family activities, as often as possible, until I learned the rules and acceptable behaviors prescribed in their family. The literature as well as the family members' behavior and my fieldnotes helped me to determine when and how I should move from an observer to participant stance.

What is a Field Notebook?

Spradley (1980) suggests a basic format for field workers to follow when organizing their field notebook. He defines the field notebook as the database that includes four different types of fieldnotes: (1) condensed notes, (2) expanded notes, (3) analytic and emic memos, and (4) journal entries. Fieldnotes are products of participant observation activities. Fieldnotes typically include at least a daily, descriptive account of the informants' words, behaviors, and physical surroundings.

As I spent time with the Camillo family, I found that I developed a very individual approach to gathering and organizing the data that included some of Spradley's organizational suggestions. Keeping in mind that fieldnotes are an account of observed cultural behavior, it is fitting that field notebooks are assembled in various forms. I learned that the design of a field notebook depends on the informants that one is studying, the environmental context, and the habits of the field worker leading the investigation.

Condensed fieldnotes. The majority of my earlier fieldnotes were "condensed accounts" (Spradley, 1980, p. 69) of observations and interactions in the field. Condensed fieldnotes are the basic form of raw data resulting from fieldwork. Condensed notes are "jottings and key phrases that describe interaction in concrete ways" (Spradley, 1980, p. 68). I wrote my condensed notes as I interacted with informants, or shortly after I left the field setting.

Initially I felt awkward about carrying a notepad into the Camillos' home, or writing down notes and ideas when we were in the midst of a conversation. Because there were six young children in the home, and due to the nature of communicating in sign language (i.e., using my hands for signing rather than writing), it was often challenging to take notes while I was in the field. As trust developed and our research relationship deepened, I began to use a hand-held tape recorder to support my hand-written jottings. I found it easier to let the tape recorder run and talk into it while my hands were occupied (i.e., chatting with Henry, making bottles, or burping a baby). Having an audio recording of the day also allowed me to mentally "revisit" the field as I wrote up my expanded fieldnotes at the end of each day.

Expanded fieldnotes. While my condensed notes were recorded on audiotape, notebook paper, and available scraps of paper (i.e., store and bank receipts, napkins, matchbook covers), my expanded notes consisted of specifically formatted and, "expanded accounts of key notes and phrases" (Spradley, 1980, p. 70). During data collection, I developed my condensed notes into expanded accounts in the evening after the Camillo children were asleep. Because my days in the field were mentally and physically rigorous, I also expanded the daily fieldnotes on the weekends, when I had quiet time to step away from the activities of the family.

I formatted my expanded fieldnotes using a word processing software program (Microsoft Word). I set up each expanded fieldnote page to include numbered lines, line spacing set at 1.5, and left/right margins of 1.25 inches. The extra space between lines and at the margins allowed areas for me to write thematic codes and analytic comments (see Appendix E for a sample expanded fieldnote page).

Analytic memos. Analytic memos are a form of "thinking on paper" (Spradley, 1980, p. 72) or "brainstorming" about what is happening and being documented in the field. During member checks,[6] Mark often commented that expanded fieldnotes were boring because they were only a description of their day-to-day activities. He would ask, *What is the point of these*? (FN:59:1:17) or "Are we really that boring?" (INT:19:63:21). In contrast, the Camillos found my analytic memos more interesting and enjoyable to read because they were written accounts of how I made sense of and pulled together information I was gathering and recording from the field. The analytic memos allowed them to be more introspective and self-reflective about their behaviors and interactions. Mark and Sara's typical responses to analytic memos were either, *No that's not what's happening here--where did you get those ideas*? or *Oh how neat! I hadn't thought of us in that way before but yes, that's us*! (FN:59:1:24). Table 3.1 details a summary of number and length of fieldnote data presented in my field notebook.

Field notebook journal. Spradley (1980) recommends that ethnographers maintain a journal section in their field notebook that is separate from condensed, expanded, and analytic accounts. The purpose of a field journal is for the field worker to have a method of identifying, looking at, and evaluating subjective thoughts, experiences, and biases that could influence the investigation.

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[6] A member check is a strategy used to confirm the validity of fieldnotes and writings that will be described later in this chapter.

I found it difficult to keep subjective thoughts and field observations separate in my fieldnotes. My time alone in the field was very limited. I discovered that if I tried to separate expanded observations from reflections, one or the other was excluded from that day's documentation. I grew to depend on the fact that during analysis I was able to separate which writings were reactive and which were observational reports. However, because I was not able to keep journal entries separate from raw data, I had to be particularly careful to separate fact from feeling before sharing fieldnotes with the informants during member checks.

The Roles of the Participant Observer

Gradually my researcher role changed from observer to a role with frequent opportunities for full participation in the Camillos' home life. Therefore, my roles in the Camillo home were multiple and sometimes conflicting. I managed the conflicting roles of participant observation by making and responding to daily efforts to maintain open communication with all members of the Camillo family. I followed Maxwell's counsel that suggested the success or effectiveness of ethnographic methods relies heavily on the research relationship that is established between researcher and informants (Maxwell, 1996). The agreement between field worker and informants should exemplify open communication that occurs as part of a long-term, working agreement. Establishing a research relationship involves an investment of time and commitment on the part of field worker and informants--the relationship is not, nor should it ever be based on a single event or interaction. Field workers refer to the initiation of this research process as gaining entry or establishing rapport (Agar, 1980; Maxwell, 1996; Spradley, 1979, 1980; Wolcott, 1995).

Table 3.1. Summary of the Fieldnote Database.

Month of Data Collection	Number of Fieldnotes	Fieldnote Range of Length
September 1996	14	1-11 pages
October 1996	11	1-5 pages
November 1996	10	1-9 pages
December 1996	21	1-6 pages
January 1997	15	1-8 pages
February 1997	13	1-8 pages
March 1997	31	1-14 pages
April 1997	15	2-6 pages
May 1997	17	1-6 pages
June 1997	22	1-19 pages
July 1997	17	1-7 pages
Total	186	

Establishing and Maintaining the Research Relationship

The Camillo family and I engaged in an ongoing, collaborative research relationship (Ely, et al., 1991; Maxwell, 1996; Spradley, 1979; 1980). This section will describe how we established and maintained our research relationship over time, and the ensuing contributions I made to their family as a researcher. A description of ethical considerations is also included in this chapter. See Appendix F for additional information concerning ethics in the profession of anthropology, including the Principles of Professional Responsibility (as amended through October 1990), the

Statement of Problems of Anthropological Research and Ethics (adopted by the American Anthropological Association [AAA] in March 1967), and the Resolution on Freedom of Publication (adopted by AAA in December 1948).

The research relationship with my key informant (Maxwell, 1996) or gate-keeper (Ely, et al., 1991) began on May 14, 1996, when I met Sara Camillo, wife and mother, in the lobby of the Parkwood School.[7] I use the Wolcott's (1995) terms key informant or gate-keeper to describe my relationship with Sara because starting with this first interaction, Sara held the "key" to the "gate" to her family's experience. I did not know it initially, but over time, I learned that all access to family information, including interviews and documents would be provided for me with Sara serving as the conduit of information.

Criteria for selection of informants. I purposefully chose the Camillo family from the LLCD database and pursued an interview with Sara for my pilot investigation (Blackburn, 1997) because their family fit the criteria defined below. The pilot study was conducted as an exploratory investigation that helped me understand the systemic structure of four families with deaf children. During the pilot study, I wanted to see how the identification of a child who is deaf affected all family members. I wanted to establish a baseline of understanding about four specific but diverse families. The Camillo family was one of four families chosen for the pilot project because they fit my research criteria for choosing informants. I wanted to investigate the lives of deaf children and their families who fit the following criteria: (a) the deaf child had participated in the larger LLCD Project for at least one academic year prior; (b) the

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[7] "Parkwood" is my pseudonym for Henry's school.

deaf child had at least one older sibling who might be accessible for observation and interviews throughout the course of the project; and (c) extended family members appeared available for observation and interviews.

At the time of Sara and my first meeting, I had been working for the LLCD research project for two weeks as a student researcher. I was at the Parkwood School that morning because Henry's classroom teacher arranged a meeting between Sara and me. This meeting was set up because I was looking for families who were interested in participating in a collaborative research project.

Our initial meeting was memorable for both Sara and me. She had just returned from a doctor's appointment where she, and her husband Mark, had been told that she was pregnant with multiple babies, rather than a single child. This initial conversation was characteristic of our later interactions because the conversation was directed by Sara. Throughout the research relationship, she often opened planning times by asking, *How is everything? Is everything okay with you?* After my response she would ask, *Okay, what can I do for you? What are we doing today?* (FN:129:1:15). Through these ongoing conversations, we established and built on our research relationship. At this initial meeting, I explained the criteria and intent of my research to Sara. We agreed that if the initial interview was successful, I might be invited to join the family on outings as a participant observer.

Shortly after our initial meeting at the school, Sara was ordered to bed rest because of her pregnancy. The hospital was located 45 miles away from the Camillos' home. Because of Mark's work schedule and visiting-hour rules at the hospital, Sara was only able to see her children (Daniel, Henry, and Madeline) once a week for a 2-

hour visit. While these circumstances were stressful for the entire family, Henry was at the greatest disadvantage because he was not able to have daily conversations with his mother on the telephone. In a gesture of fair return (see enclosed AAA ethics in Appendix F and the section on Ethical Issues in this chapter), I asked if there was any service I could provide that would assist the family. Sara and Mark brainstormed, and asked if I would make weekly visits to the hospital. Throughout Sara's 7-week stay, I drove to the hospital every Thursday morning, conducting field visits and making video recordings of her to send home to her family.

The Camillo triplets were born August 2, 1996, premature at 32 weeks, and were kept in the hospital Neonatal Intensive Care Unit (NICU) for eight additional weeks. During this 8-week period after their birth, my contact with the Camillo family consisted of brief, weekly telephone contacts. On Labor Day weekend 1996, Sara invited me to go with her and her mother to feed the babies at the hospital. This commute marked another memorable occasion in our research relationship. Sara again prefaced our conversation by asking me about my plans as a research assistant for the upcoming school year. She continued by saying that if I really wanted to learn about their family life she and Mark felt that I would understand it best by living with them. She concluded with, *We have a place for you* (FN:27:1:10).

We made a tentative agreement for me to move into the Camillo home in October. I needed time to meet with the LLCD project director about this step, and Sara preferred that her mother help her in the early weeks after the babies came home from the hospital. I moved into the Camillo home on October 21, 1996 and lived in the family's home until July 15, 1997. In order to maintain my personal life and the ability to posture (Wolcott, 1992; 1995) or process my observations from objective and subjective perspectives, we agreed that I would live in the Camillo home from Sunday night to Friday afternoon. I arranged to stay with a close friend (who I call Molly) on the weekends. This arrangement provided the family and me an opportunity for respite and privacy.

Sara and Mark Camillo initiated the rudimentary rules for these living arrangements. Sara stated them briefly and clearly (FN:31:4:9):

1. *We understand that you want to observe and participate in family time with all of us together, but we will need our time alone too. Therefore, you will be invited to share some evening dinners with us. Otherwise, after 5:00 PM you may feel free to "do your own thing" in the basement of the house [where my room was located], or elsewhere outside the home.*
2. *You must understand, first and foremost, that* <u>*we*</u> *are the parents of* <u>*our*</u> *children. We are responsible for disciplining and caring for them.*
3. *You may contribute the most to our family by doing your fair share as a member of our household.*
4. *We do not want or need another person to take care of, or interact with Henry only, and not the other children.*

Our research relationship grew on a daily basis and changed over time. The relationship was also developed on the principles of collaboration that are defined by the larger LLCD Project. Team members on the project define research relationships as: (a) built on trust that develop over time; (b) relationships of equals with different roles, skills, and perspectives; and (c) based on shared interests between the informants and the researchers (C. J. Erting, personal communication, June 23, 1997).

Within the spirit of these collaboration principles, Sara and I met every evening before I retired to the basement to plan for the next day. Based on the family's schedule, we looked for regular opportunities for me to go to the university and work in the laboratory. Sara and Mark also searched for and provided me with opportunities to observe and participate with them in family activities (i.e., decorating the Christmas tree, attending Henry's IFSP meeting, observing Sara at parent meetings at the Parkwood School, etc.).

Every day, the presence of my notepad and tape recorder served as a subtle reminder that I was in the Camillo home as a researcher. Often the richest observations were noted while Sara and I exercised together, or while I sat on the floor with the babies in my "baby-sitter" role. In the midst of changing a diaper, making bottles, or folding laundry (household duties are what I did for the family in order to contribute to their household), I witnessed and documented communicative and social interactions between deaf and hearing siblings, the babies' first signs, conversations between visiting Deaf adults and Sara, and the family's ritual of reading books before bedtime with all the children participating.

As my fieldwork continued and became more focused on the daily lived experiences of the Camillos, I was able to integrate other forms of data collection into my investigation. I conducted information interviews with informants during activities in the field, as well as semistructured, ethnographic interviews that were arranged by advanced agreement with informants.

Informal Interviews

The informal interviews occurred primarily among Sara, Mark, and visitors to their home. Often visiting friends, relatives, or neighbors noticed Henry's signs or the absence of his voice during communication, as well as his interactions with the other children. These observations sparked conversation or comments from the visitors and always elicited a response or explanation from Sara or Mark. Sometimes during those social interactions, I attempted to clarify the meanings used by Sara and Mark, or the visitors during their interactions with one another and the children. When I felt it was appropriate, I followed Agar's (1980) lead and paraphrased their comments as a test to be sure I understood their intent. For example, if a visitor commented, *Henry is really coming along these days*, I would paraphrase and ask, *Oh, you think he's making progress?* And then add, *In what way has he progressed?* (FN:145:1:21). My goal was to gather more in-depth information about the visitor's perspective of Henry and to invite them to comment if I was wrong. Often when I used this paraphrasing technique, the results were a brief, unstructured interview led by one of the adults in the setting.

It was my overall impression that the informal interviews were much different accounts of individual beliefs and perceptions than scheduled interviews in front of the video camera. For example, acting as my key informant, Sara was often helpful in soliciting information during unstructured interviews. For a reason never disclosed, one of Sara's brothers (Ernest, Jr.) was resistant to participating in a scheduled interview with me. However, Sara felt that having Ernest's perception of Henry and his meanings of deafness documented was critical. Sara asked Ernest once if he wanted to interview for the project, and he responded, *Right now, I'm thinking no* (FN:185:2:10). One evening at the end of the last week of data collection (7/13/97), the family was gathered in Sara's sister's living room. We had just finished the evening meal and a full day of swimming. The babies were crawling on the floor while the older children watched a video and doodled in coloring books. Unexpectedly, Grandmother Medina asked, *Ernie, are you going to give Laura an interview darling?* There was a pregnant pause in the room, and not wanting to pressure Ernest to participate, I quickly interjected, *Nah, we're all just hanging out here Grandmom. He doesn't need to interview with me right now*! (FN:185:2:20).

Jerry, Sara's brother-in-law, burst into laughter and said, *Good answer!* With his remark, the tension seemed to escape the room. However, Sara saw the opportunity to conduct an informal interview with Ernest. She asked, *So, what do you think of Henry, Ernest? This is the first time you've met and you're his Godfather. Is he what you expected? Was it okay communicating with him*? (FN:185:2:30). The information Ernest provided for Sara might have been vastly different from the type of data I could have gathered in a scheduled interview in front of the camera. If I had formally interviewed Ernest, the presence of the video camera combined with our short-term relationship as researcher and informant would have produced a different, and less naturalistic outcome.

In spite of the naturalistic context, accurately recording the content of informal interviews was often a challenge. Scrambling for a note pad or turning on the tape recorder would have obviously disrupted informal social environments. Often I relied on my memory, jotting down notes and reflections as soon as it was appropriate to detach from the group and record the information. Sara was also helpful in remembering events as they unfolded. For example, for several months in the midst of my stay in the home (November 1996 to February 1997), Sara and I made time in our schedule for mid-morning aerobics in their living room. After several weeks of exercising together, I began to recognize a pattern in our conversations while we worked out. Often Sara brought up the most interesting information while we were exercising. She frequently asked questions or made comments when my hands were occupied with weights, or in the middle of stomach crunches! By December, Sara and I had established a strong, open research relationship. I felt comfortable about bringing this data collection situation to her attention and asked her permission to audiotape our exercise sessions.

Scheduled, Ethnographic Interviews

The scheduled, ethnographic interviews were conducted in a different social context and consequently set a much different tone from interviews that took place naturally during fieldwork (see Table 3.2 for more detailed information about the ethnographic interviews). Informal and scheduled interviews seemed to glean two different types of data. During formal interviews, informants often appeared to be looking for the “right” answer.

Most informants that agreed to be interviewed were very conscientious and good-natured about the interview process. Participants were often concerned about conducting a “good” interview and providing me with the information that I appeared to want. This component of scheduled interviewing often concerned me. While I transcribed the interviews, I questioned repeatedly whether or not the informants were

Table 3.2. Characteristics of the Participants, Length, and Format of Ethnographic Interviews.

Interview # & Date	Interview Participant(s)	Interview Length	Interview Format (Audio or Video)
1 – 6/10/96	Sara Camillo	3 hours	Videotape
2 – 10/23/96	Ernest & Peggy Medina (maternal grandparents)	21 minutes	Videotape
3 – 12/27/96	Bobbie (Medina) & Jerry	57 minutes	Videotape
4 – 1/20/97	Mark & Sara Camillo Justin (reading mentor)	1 hour, 10 minutes	Videotape
5 – 5/27/97	Gerilyn (Henry's first audiologist)	37 minutes	Audiotape
6 – 5/27/97	Jessica (Henry' first TC early interventionist)	1 hour, 19 minutes	Audiotape
7 – 5/31/97	Steve Camillo & Nicole (Henry's babysitter)	40 minutes	Audiotape
8 – 7/1/97	Joe & Geneva Camillo (paternal grandparents)	48 minutes	Videotape
9 – 7/1/97	Harry & Maura Camillo	1 hour, 5 minutes	Videotape
10 – 7/2/97	Steve Camillo	56 minutes	Videotape
11 – 7/3/97	Margaret & Christopher Camillo	—	Videotape
12 – 7/3/97	Bobbie (Camillo)	35 minutes	Videotape
13 – 7/4/97	Elaine (Camillo)	25 minutes	Videotape
14 – 7/4/97	Megan Camillo	24 minutes	Audiotape
15 – 7/4/97	Michael	32 minutes	Audiotape
16 – 7/12/97	Nannette Medina	42 minutes	Videotape
17 – 7/14/97	Francis Medina	18 minutes	Videotape
18 – 7/14/97	Mark Camillo	1 hour, 24 minutes	Videotape
19 – 2/13/98	Mark & Sara Camillo	6 hours, 25 minutes	Audio and Videotape

telling me what I wanted to hear or an actual account of their experiences with Henry and the family. This type of "wanting to please the researcher" or "face saving" behavior is a pitfall of formal interview approaches (Goffman, 1959). It was easy for me to draw a parallel between my research relationship with informants and the former interactions I had with parents and family members as a classroom teacher. Like parents attending a formally scheduled parent-teacher conference, many of the Camillo family members who knew they were going to be formally interviewed, understandably showed up looking their best and behaving in a cooperative and socially pleasing manner.

I used a semistructured format for the formal interviews by creating a protocol that broadly defined the concepts I wanted to investigate. These concepts emerged from my daily fieldwork and guided my formal inquiries. For practical purposes, it was also helpful to schedule interviews with informants who were newly entering the context of the family. Other "one-shot" formal interviews were conducted with extended family members and Henry's parent-infant teachers because they lived at a distance. These individuals' perspectives were important although they did not have regular face-to-face contact with the Camillo family. Regardless of geographic distance, grandparents, cousins, and some former sign language and early intervention teachers were deeply embedded within the family's social milieu.

Selected Videotaped Family Interactions

Fieldwork also requires gathering information from a variety of different individuals and contexts. This validity check strategy is called triangulation (Maxwell, 1996). I videotaped selected interaction and conversations in November, January, June, and July among the immediate Camillo family members, extended family, and visitors to the family's home. Captured videotaped interactions also provided a strategy for illuminating meaningful actions and behaviors that emerged from the data during in-depth analysis (J. Evans, personal communication, August 26, 1997).

In most cases, I was the primary recorder of interactive events. I either chose the location of the tripod and left the camera running for several hours to capture interaction over time, or I held the camera in the obvious role of "recorder." On several occasions, I was unable to attend activities where Henry was an essential player in the interaction. In those circumstances, I asked Sara or Mark to act as field workers and record interactions they felt were relevant to the situation.

I also found that the location of the video camera when recording interaction influenced the type of material I gathered. When the camera was left running on the tripod, informants were most likely to "perform" when they first became aware of it, and then quickly forget the camera was there. Overall, when the camera was positioned on a tripod, family members assumed it was running, and tended to monitor their behavior accordingly. Informants who entered the scene after the camera had been running often asked, "Is the camera on?" (VC:7:4:5).

My presence as a researcher was more prominent when I stood behind the camera. Table 3.3 details what videotaped interactions a person captured while holding the video recorder, or when the video recorder was positioned and secured on a tripod. It is important to distinguish between these two different forms of video recorded interaction because the presence of a person behind the camera makes data collection more conspicuous for the informants.

As an example of the influence of researcher presence, in one situation I started to record an interactive episode while standing behind the camera. In the midst of the action, I was called away to another room to help with a baby. I set the camera down on the couch and inadvertently left it on and recording. The active camera was found moments later by members of the Medina family, who assumed I left the camera running to "spy" on them. The family members never mentioned the spying episode to me, but recorded a series of remarks on the videotape to express their disapproval (VC:7:4:26).

Document and Artifact Gathering

Sara and Mark also provided the LLCD Project with a full set of documents that chronicle Henry's medical and educational history from his birth and identification (1992-1993) to the end of data collection (July 1997). These documents were helpful in building the framework for the chronology of events that are the Camillo's family story (Ely, Vintz, Downing, & Anzul, 1997).

Gathering Data in Various Environmental Contexts

The most frequent environmental context for my fieldwork was within the walls of the Camillo home. However, I also participated with, observed, and interviewed the informants in other settings. Goffman (1969) makes the point that human behavior is readily influenced by the environmental context or physical setting of social interaction. Therefore, it is important to be aware of alternative environmental contexts and how changes in physical settings can also change the behavior of informants (see Table 3.4 for information that details the number of

Table 3.3. Information Regarding the Length and Method of Capturing Videotaped Interactions.

Videotape number and date of taping	Number of video clips per each data collection event	Length of videotaped event (hour:min:sec)	Amount of time video camera was handheld (hour:min:sec)	Amount of time video camera was stabilized on a tripod (hour:min:sec)
1 – 11/27/96	—	03:00:00	00:00:00	03:00:00
2 – 1/20/97	5	00:34:13	00:00:00	00:34:13
3 – 6/30/97	6	00:51:08	29:07	00:22:01
4 – 7/2/97	26	01:19:35	01:19:35	00:00:00
5 – 7/8/97	21	00:57:13	00:57:13	00:00:00
6 – 7/9/97	39	02:12:22	00:11:54	02:01:08
7 – 7/10/97	16	01:08:44	01:08:44	00:00:00
8 – 7/11/97	24	00:26:07	00:04:24	00:21:23
9 – 7/11/97	21	01:53:23	00:23:47	01:30:16
10 – 7/13/97	4	00:45:00	00:45:00	00:00:00
11 – 7/14/97	39	00:13:05	00:13:05	00:00:00
Totals:	201 video clips	10:18:50	05:30:49	04:48:21

contexts where data were collected and the specific actors beyond the immediate family who participated in those settings).

Home: The immediate family context. As I have stated previously, the study of Henry and his family actually began in the hospital setting where Sara was ordered to have bed rest during her pregnancy with the triplets. We developed our research relationship in the hospital that eventually evolved into me moving into the Camillos' basement. I also ventured out with the family to a variety of settings including visits to both Daniel and Henry's schools.[8] Other events I attended with the family included church services (Stations of the Cross and one Sunday service), a holiday party and promotion ceremony at Mark's work, and social activities specific to Sara's interests (The Triplet Connection, the gym, and Mothers of Preschool Children [MOPS] meetings).

Revisiting "The Early Years." Apart from activities with the immediate family, Sara and Mark made arrangements during the time I lived with them for me to communicate with people who made a positive and significant impact on their understanding of Henry and deafness. They chose Gariann, the audiologist who identified Henry as a deaf person, and Tris, Henry's first early interventionist, as two people who provided them with critical information and support in "the early years."

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[8] My visits to Parkwood included attendance at both informational and educational parent meetings, visiting Henry's classroom for formal observations, birthday parties, and seasonal events, and finally his annual IFSP meeting. Near the latter part of my data collection, I was pleased at a remark made by Henry's teacher because it demonstrated evidence of my level of immersion in the field. I was alone on campus running errands separate from the research project, and I bumped into him in the school's hallway. We spoke for a few minutes and in parting he commented, "It seems strange to see you without the babies!"

Table 3.4. Environmental Contexts Where Data were Gathered.

Social contexts	Number of deaf actors present	Number of hearing actors present
The hospital (bedrest) (7 weeks)	1	40
Church (3 hours)	0	30
Celebrations:		
Henry's birthday party (2 hours)	12	6
Multiples Christmas (3 hours)	0	50
Mark's promotion (2 hours)	0	50
The parent meeting at Parkwood (2 hours)	11	6
Educational meetings for parents at Parkwood (10 hours)	8	6
Visits to Henry's classroom (20 hours)	14	3
Visits to Daniel's classroom (2 hours)	1	40
Extended family vacations:		
The Camillos (1 week)	1	
The Medinas (1 week)		

Note. The number of actors listed in columns 2 and 3 represent the mean number of actors I documented interacting over time with members of the immediate Camillo family in social contexts outside the home. The time spent in each field setting is indicated below each social context in parentheses.

Despite geographic distance, Sara and Mark agreed that Gariann and Tris' influence continued with them on a daily basis.

In early May 1997, Sara contacted Gariann and Tris because our conversations at home had sparked her curiosity about how their lives had progressed. After her telephone conversations with both women, Sara encouraged me to visit and interview Henry's first teacher and audiologist. Sara wanted me to have a complete picture of Henry's life starting with his birth and identification.

Because of Sara's tenacity as a key informant, I traveled to the state where Henry was born over Memorial Day weekend 1997. I stayed with Sara's brother Francis and his daughters, had dinner with her sister Nannette, and interviewed Gariann at the oral program where Henry and his family received early intervention services the first six months of his life. On the same day, Francis and I had lunch and conducted an interview with Tris. Before the interview with Tris, we watched a series of video clips that she collected during home visits with Henry and his family in 1994. The videotape includes rare clips of Sara and Henry's early mother-infant interactions, as well as some footage from his first educational play-based assessment. Tris gave the videotape to me to pass on to the Camillos.

The trip was productive in a variety of ways. Not only was I able to interview key individuals in Henry's educational history, but I was also able to participate with and observe one of Henry's favorite uncles and his cousins (Christine and Marie) from his mother's side of the family. Finally, the videotape that I carried back to the Camillos turned out to be the only videotaped footage they have of Henry as a baby. When Henry was almost a year old, robbers broke into their home and stole the family's camcorder that held a videotaped recording of Henry's interactions since birth. Mark and Sara were also excited to have the videotape in their possession because they had never viewed Henry's first assessment data before. During the final interview they remembered the video segments being recorded, but said that no one had ever shared the contents of the video with them.

The extended family reunion contexts. It is important to note that the last two weeks of the data collection experience were quite different from the nine months of fieldwork that preceded it. I conducted the last two weeks of fieldwork, accompanying the Camillos on their vacation to attend two reunions with extended family. The first week we drove to visit Mark's family (the Camillos) in a northern state on the east coast. The second week we flew to a southern state and stayed with Sara's sister, Bobbie (the Medinas). Extended family members from both the Camillo and Medina sides made efforts to meet in these locations and both families had close to 100% attendance of all aunts, uncles, and cousins. The two missing extended family members were Mark's brother who lives overseas with his family and Sara's father who decided not to make the trip to Bobbie's house.

During this period, I met some of the family members for the first time, while other faces and relationships were familiar to me based on previous visits family members made to the Camillo home. Despite familiar faces, establishing rapport with informants and conducting fieldwork in these two environments was the most challenging of the 10-month period that I lived with the family. The unspoken "rules" for data collection changed abruptly. During these trips, I experienced numerous changes in routine and encountered fluctuating cultural mores and expectations. I often felt unsure about how to gather data in a nonintrusive way, but more critically, I struggled with the "appropriate" way to conduct myself as a social being.

Fieldwork Immersion: Strategies and Obstacles

This section discusses the various and unexpected strategies and obstacles I encountered while immersed in the field. In some regards, this section includes information about fieldwork that one could never learn in books. Wolcott (1995), Spradley (1980), and the Spindlers (1991) provide writings that serve to support what I call my "adventures in ethnography." However, I did not learn the information in the next section by reading. I learned the following methodological and political lessons by doing and living ethnographic research strategies.

Practical Strategies for Data Collection in Various Contexts

As I prepared for the extended family reunions, I considered alternative strategies for data collection that I might have to use due to the change of environmental context. I considered changes in physical climate I would be experiencing (i.e., weather, where I would sleep and set up a writing area, etc.). I also gave considerable thought to what it would be like to travel with such a large group of people. I wanted to maintain an active role in the family. Using Sara and Mark's words, I didn't want to be "dead weight" (INT:19:119:11).

Therefore, while the family considered these two weeks a vacation, I viewed these trips as research work. I considered these journeys to be a rare opportunity to capture interaction among Henry and his extended family members. Concerning my role among family members, I knew that the comfort and safety of the children during travel was a priority. Finally, I tried to come up with alternative plans about how I could gather condensed notes, and later find the time and privacy to expand and format the information. I brought index cards, pads of paper, blank audiotapes, blank videotapes, and my laptop computer with the battery charged.

The biggest mistake I made in preparation for these data gathering events was assuming that my role within the family would stay the same. I managed this oversight by following a piece of advice that was critical to arranging for the changing roles and perceptions I would encounter. As I walked out of the lab with data-gathering equipment slung over both shoulders, my research advisor said, *Remember the rule of thumb used by all anthropologists. "When all else fails, sit back, watch, and keep your mouth shut"* (C. Erting, personal communication, June 26, 1997).

The first procedural challenge arose when Sara and Mark decided not to participate in the original research project that I planned. Initially, I designed a more contrived data collection event that was to take place at a national conference for teachers of children who are deaf and hard of hearing (Conference of American Instructors of the Deaf [CAID]). My plan was to submit a proposal to CAID that involved a co-presentation between Sara, Mark, and me. We wanted to present the concept of using participant observation as a way to improve collaboration and mutual understanding between teachers and parents. My initial small grants research plan, which was approved by the small grants committee, involved observing the family members' interactions while they presented and participated at the CAID conference. I wanted to see what types of information they learned and exchanged with other hearing and deaf individuals, as well as document their social interactions among teachers of children who are deaf and hard of hearing.

After we received approval, we began moving in the direction of preparing to attend the conference at the end of June. In preparation, we encountered a series of barriers that made the plan seem impractical. The following excerpts from my fieldnotes tell the story of why Mark and Sara decided to withdraw their participation in the first research project (FN:117:4:7).

Mark and Sara Decline from CAID

Sara came into the living room that afternoon and told me that she and Mark had decided it was not a good idea for them to go to the CAID conference. She told me that they could make arrangements so that I could still attend, but that they had changed their minds. Sara asked me to make the necessary contacts to cancel the reservations.

This conversation with Sara was precipitated by a recent trip the family took to visit Mark's family--the first family travel that had occurred since the babies were born. Sara explained that while the babies had traveled well, they had a difficult time sleeping in strange cribs. When the babies didn't sleep, it meant that Sara and Mark didn't sleep either. Sara also questioned Mark's ability to request two consecutive weeks off of work during the course of the summer. They decided that rather than go to the conference, they wanted to take their vacation time to visit extended family.

As our conversation progressed, Sara excitedly told me about one of their family traditions that occurred every summer when they visited Mark's home--Jamestown. It was family tradition to go to a tailgate party at the local drive-in theatre. The event was so important to family members that often Sara's parents flew from their home state to attend this celebration. At the tailgate reunion, the Camillo children and their cousins interacted on playground equipment while adult family members and friends in Jamestown socialized near-by. Sara explained that the time spent with their family members was simply too valuable to pass up. Consequently, Mark and Sara decided that they wanted to spend their time and money with family, rather than attend and present at a professional conference.

Sara also admitted that she had concerns about the children's safety and the practicality of this component of my research project. She questioned how I would be able to observe Mark and Sara interacting at the conference, when she was expecting me to be the primary baby-sitter for the trip. At this point, it became apparent that Sara and I had a different vision of how we would manage childcare at the conference. I was struck by how much our vision differed. I discovered that my vision did not match Sara's or fit within her "comfort zone" regarding the children's health and safety.

I had envisioned that Sara, Mark, and I would each take a baby, and that we would make arrangements in advance for different people to "take shifts" with the older children. I considered recruiting the assistance of Karen and Nicole (two members of the regular babysitting team). I also intended to ask their reading mentor Justin to help.

With these basic logistical differences on the table, I understood clearly why Sara and Mark made their decision to withdraw. Overall, there were just too many potential opportunities for the children's safety to be compromised. Preparation for the trip was also starting to become very complex because of the size of their family and the needs of young children. I shared with Sara that recently I had been puzzling about what it would take to get us all there safely, and under our $2,000.00 budget. What appeared to be a lot of money at first, just wasn't enough to transport and maintain a family of eight, plus me, for a 3- to 4-day period.

It occurred to me that my suggestion to travel to this conference from the beginning was an activity that I engineered from a "researcher's perspective." The plan was not driven from the family's perspective or interests. I also learned a considerable amount about Sara's primary focus for her family: maintaining optimal family functioning. She worked to maintain a balance between her responsibilities within the home and activities that interacted with their life outside the home. I believe that this was her primary goal to ensure that her home ran smoothly. At the same time, she made great efforts to relieve her own stress related to job performance. Sara focused on "getting things done" and became uncomfortable when responsibilities or loose ends were "hanging over her head."

During our conversation, she tried to explain to me a little bit more about how she managed stress. Sara felt psychologically uncomfortable when *things were not getting done* (FN:117:6:7). She used the analogy of *being thrown a curve ball* to describe her feelings. Sara emphasized that she understood that home management was her job, but sometimes she needed additional assistance. When Sara was *thrown a curve ball*, she sometimes wanted assistance from someone *in order to straighten it out* (FN:117:6:16). Sara explained that just like anyone else "on the job," it was not always conducive to work alone or in isolation, particularly when there were so many people who depended on her to *get the job done*. Sara described her job as wife and mother as one that was filled with critical deadlines and pressures. Resolving those challenges required teamwork and collaboration in order to re-establish and maintain some sort of balance in the community. Sara felt that working under a constant deadline was too stressful for everyone and *weakened the links* of the family (FN:117:6:14).

A Revised Research Project

Ten days later, a more family-centered plan for how the Camillo family would spend their vacation time began to emerge. This story exemplifies the emerging nature of qualitative research. Because qualitative and ethnographic research involves the study of human behavior, plans and outcomes are often unpredictable (Maxwell, 1996). While the original research plan to conclude my data collection became impractical, I was still interested in observing the family in environments outside of their home context. Consequently, Sara and I began to develop an alternative, more collaborative plan for using the small grants funds that we were awarded.

Shortly after the family decided to withdraw from the CAID conference, Sara's sister Bobbie called from her home in Marble Beach. Bobbie called Sara to tell her that she and her husband Jerry had bid on a house with a swimming pool. Sara interpreted the conversation for Henry and both he and Daniel began to jump up and down, begging to visit their Aunt Bobbie. Bobbie overheard the boys and suggested that Sara send Daniel and Henry to her house for a vacation over the summer.

Bobbie's offer was originally intended to provide Sara with a break and give the boys time to spend with their Aunt Bobbie. Sara and Mark discussed this option, and over the weekend, decided they would try to travel as a family to Bobbie's house for the week. By the end of the week, Sara found reasonable airfare rates, and the family scheduled a visit to Bobbie and Jerry's home between July 8th and July 15th.

After the family trips were planned, Sara shared with me that she and Mark were nervous to disclose their new vacation plans. They were concerned about hurting my feelings by making new vacation plans so soon after declining the trip to CAID. I told Sara that from my perspective, their change of plans was not a decision for me to take personally. I viewed the new arrangements as additional data about their choices for social interaction. We ended our conversation by agreeing that we could have accomplished more by communicating more clearly. Sara said, *Well, we learned from this* (FN: 129:2:20).

After the Camillos' flight reservations were made, word traveled through the Medina family grapevine that Mark, Sara, and the children were headed to Bobbie's house. Within several days, Sara's mother, her older brother Ernest Jr. and his family, and Sara's youngest sister Nannette, arranged to travel to Bobbie's house in July. The day after travel arrangements were made by most of Sara's siblings, she laughed about the nature of her family. What started out to be a trip for Daniel and Henry quickly became a family reunion, before anyone consulted Bobbie. Sara commented, *That's why we have an open-door policy in our family. We all do things together. Bobbie probably won't even question these arrangements. In our family you don't have to call ahead – just show up* (FN: 129:3:15).

The idea of my attendance at both family gatherings and the thought that perhaps the small grants award could still be used emerged simultaneously. I started to realize that a natural situation was emerging that would allow for data collection among both sides of the family. I planned to videotape meals throughout the week, interview extended family members and their understandings of deafness, and capture group social interaction and stories that shed light on the families' history.

I told Sara that I would contact the small grants financial manager and the chair of the small grants committee to determine if the idea of creating an addendum to the original proposal and budget would be acceptable. This addendum would describe the emerging nature of qualitative research, when the informants' life experiences changed, and how they adapted. Rather than consider the original proposal outdated, I presented the changes in the informants' plans as part of the data that emerged.

On Friday, June 27th at 4:00 PM, I received verbal confirmation from the small grants administrative secretary that the research project was financially sponsored and approved by the graduate school and the IRB. Data collection for this 2-week research event began the following morning at 7:00 AM, when we began to pack the truck for the first leg of the journey to visit Mark's family.

Analysis Strategies

An ethnography is the scientific study of human cultural conditions (Agar, 1986). The rigors of systematically examining a tangible product or social situation for cultural meanings are difficult. Imagine the complexities one encounters when trying to identify the meanings understood by particular groups of people because of their human living conditions. Thus were my tasks as the ethnographer of this project and the goal of my analysis.

Strategies Used During Preliminary Analysis

Analysis began on day one of fieldwork. Consequently, data collection and analysis were conducted in a recurring, cyclic fashion from the moment that I entered the community. The events I observed and documented guided my preliminary analysis, while "chunks of meaning" that emerged from the data were used to further guide data collection.

I used the strategy of expanded drop files (Wolcott, 1990) during fieldwork and preliminary analysis to make sense of what I was initially learning in the Camillo home. Expanded drop files complements a strategy termed "applying thinking units" (Ely et al., 1991), that I implemented during the in-depth analysis portion of this investigation. The methods of expanded drop files or applying thinking units involved repeatedly reading and categorizing the data, searching for and labeling chunks of text into analytic themes. The recurrent categorization of data into pertinent themes helped to guide analysis activities so that concepts were accurately identified and contributed to the closest representation of informants' meanings, rather than my own preestablished notions and biases (Maxwell, 1996). I used the strategy of expanded drop files during preliminary analysis in order to recognize themes and linking pieces of data that were significant to the family.

In order to complete the final, in-depth analysis of the data, I used three analysis strategies that view the data from differing perspectives. I chose the following strategies: (a) Margot Ely's sequence for final analysis (1991), (b) Agar's "building schema" strategies (1986), and (c) Erickson's ethnographic microanalysis of interaction procedure (1992).

Ely's Circles within Circles

Ely's strategies for analysis are delineated as an eight-step cycle and are detailed in the next section of this chapter. The steps of the cycle are recurrent, as the field worker interacts with the database while viewing it from a variety of perspectives.

Sitting Alone Looking at the Data

The first requirement for final analysis defined by Ely and her students is to separate from the field and informants. She describes this as "...sitting alone to look at the data" (Ely, et al., 1991). Separating from the field and the research participants is important during the final analysis process for a variety of logical reasons. First, a field worker who has been immersed in another social environment needs to re-establish a sense of self, independent of the community that was studied. The physical separation also provides an opportunity for the researcher to examine the database as well as one's biases and perceptions of the community from a distanced position. Spending time with the data helped me to gain a broad perspective on my fieldwork experience. It was during this time spent alone looking at my data that the preliminary themes I identified during data collection began to gel and take shape.

I accomplished the task of separating from the Camillo family in August 1997. Two weeks after the end of data collection (July 15, 1997), I moved about 1000 miles west of the family to begin a position as a faculty member at a midwestern university. After the move, Sara and I continued to have regular E-mail contact and brief telephone conversations. However, most of my first six months apart from the family were spent adjusting to my new single, childless lifestyle, which included teaching, attending faculty meetings, and literally "sitting alone" looking at my mountains of data.

Applying Thinking Units

I consider the categorizations I developed throughout data collection rudimentary in comparison to the final, more in-depth task of committing to specific applied thinking units. I began to arrange the data into logical units of meaning by asking myself the following questions:

- What is the smallest meaningful chunk of narrative that I will call a category?
- What concept does this narrative or transcript imply?
- What categories will help me to organize the essential aspects of what is written in my data? (Ely, et al., 1991)

I asked these questions repeatedly in an attempt to create categories, and establish links between those categories. Categories are intended to help "tease out" meaning (Ely, et al., 1991, p. 150). Developed categories are also helpful in the organization and presentation of data in its final form.

Coding and Finding Links Between Categories

Finding and coding categories served as a way to weed out and modify my database so that it was more organized and less overwhelming in size and complexity. For me, coding involved reading, highlighting, and then labeling chunks of data with descriptive notations in the margins of each fieldnote or interview transcript (see Appendix G for a sample of a coded fieldnote). As I listed the notations in a separate table (see Appendix H for a sample page from the database coding table), categories presented themselves more clearly. The final task of coding involved assigning colors to each category that emerged (i.e., red for the "Language Use and Communication" category, orange for the "Culture" category, etc.). The resulting database was a colorful and visual representation of contextual categories that had been "teased out" and organized within the data.

Developing Themes

The process of identifying a theme that was representative of the family's lived experience involved identifying meanings, language, and behaviors used by the informants that either: (a) "ran through all or most of the pertinent data (like a vein, or the main idea of a story), or (b) presented itself as a statement or concept used by informants that carried heavy emotional or factual affect" (Ely et. al, 1991, p. 68). As the themes were identified, I wrote emic memos--short narratives that involved analyzing and searching for the informants' meanings. I also wrote negative case analysis memos that detailed incongruent information found within the data. For example, Sara repeatedly told people in her social world, "Everyone in our family signs--grandparents, uncles, aunts and cousins." At the same time, I was documenting participant observation information that noted the varied amount of sign language fluency among extended family members. The process of writing negative case analysis memos allowed me to address these incongruencies in the data, which helped me to further identify the meaning of the informant's discrepant language and actions.

Developing Vignettes and Conceptual Constructs

Maxwell (1996) supports the idea that the act of writing facilitates and captures analytic thinking. My task was to write memos in the form of short stories or narratives that accurately described the informants' voice or how they thought about certain concepts relevant to the data. My experience agreed with Maxwell in that the process of developing and writing stories about the family helped me to develop tentative ideas about their lived experience. As my writing progressed, I had increased meetings with my peer debriefer[9] and research advisor. I attempted to "step into the shoes" of family members and then described the world as they saw it.

Writing short stories about the family also served as a good strategy for checking agreement between my perception of what happened, versus how Mark and Sara saw the story unfold. As I wrote the vignettes, I sent them to Sara and Mark as a member check strategy (Evans, 1998). Conducting member checks involved explaining to Mark and Sara that I was attempting to describe a situation or meaning as if they were writing about it. I asked them to tell me if I accurately captured their "voice" or perspective in the written description. The member checks provided me with input about my progress, and helped to ensure the authenticity of my writings and perceptions.

Including Numbers

Evans (J. Evans, personal communication, August 28, 1997) suggests that using numbers in qualitative research can be effective when attempting to illuminate or substantiate categories or themes. Ely et al. (1991) encourages field workers to quantify as often as possible, building support into theories that are developing. Including numbers in qualitative data analysis also allows the field worker to

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[9] The role of the peer debriefer and peer support is described in the validity section of this chapter.

substantiate findings with detail and precision. I used numbers to represent my data in the following ways:

Environmental context variation. It was important for me to be aware of the various environmental contexts where informants interacted, in order to understand their actions observed. Return to Table 3.4 of this dissertation for details regarding the various environmental contexts where data collection events occurred outside of the Camillo home.

Variation of social actors within and outside the immediate family context. It is important to be aware of what informants were present beyond the immediate family during interaction in order to understand the actions observed (see Appendix B for a list of expert informants that were present in the field of interaction outside of the Camillo home).

Exiting the Field

According to the terms of entry defined by Roberts and McGinty (1995) and others, I was also required to make efforts to leave the Camillo home in the same condition or better than when I entered (Agar, 1986; Roberts & McGinty, 1995; Rosaldo, 1989; Spradley, 1979). Consequently, my departure from the house in July was prefaced with an extensive search for one or more persons to assume my "mother's helper" role in the household.

We began to consider my "exit" in February when I began my formal job search at various universities throughout the country. I was looking for a faculty position that would begin in the Fall semester. An interesting phenomenon occurred as we began to consider my 'exit,' particularly when job interviews and outside responsibilities took me away from typical fieldwork time with the family. First, Mark and Sara began to have earnest discussions about their additional responsibilities and changing roles as mother and father. My brief absences produced a juggling of roles and responsibilities that caused Mark and Sara to consider, *What it will be like when Laura is gone*? (FN:97:1:7). Second, I observed that when roles and responsibilities fluctuated in the home, exemplary language use and behavior disappeared that had been typical up to that point. Lastly, discussions concerning my exit from the field seemed to speed up the intensity of fieldwork exponentially. The house was filled with discussion and activity concerning new attitudes and philosophies about educating deaf children. Abruptly, Mark and Sara seemed to be in the midst of making a thousand decisions every day. Suddenly they began asking questions like, *Is Parkwood an appropriate educational placement for Henry?* and *Is sign language effective alone as a form of communication*? (FN:79:1:5; FN:81:1:9; FN:134:3:13).

For me, the idea of separating from the field and the family was bittersweet. I began my fieldwork as a typical graduate student with student loans pending and an old car that broke down every other month. While I longed for my single life back--consisting of an income and greater control over my physical and social environment--the thought of leaving produced surprisingly strong emotions. By the time I left in late July, the relationship between Sara and I had deepened to a sister-like affinity and the babies were just beginning to crawl. From a third angle, the scientist in me wanted to stay with the family and watch Henry and his siblings grow into adulthood. I was constantly plagued with thoughts of, "A year is just not enough time to learn what I need to know!" and "I don't have enough data!"

Sara interviewed several graduate students from the university in search of my replacement. However, Mark and Sara decided not to replace the "mother's helper" component of my capacity. We agreed that the research relationship that developed among us was something that could not be replicated.

In the end, on a balmy day in July, my friend Molly and I pulled up to the front of the house with a Ryder truck. Sara sat on the front step of the townhouse with her neighbor and the triplets and directed our efforts. As we tore down my bed, and pushed boxes up the truck's ramp, Henry and Daniel remembered when I moved into the house 10 months earlier. Madeline was concerned that I was going to take her Mother's things. She carefully monitored the items I carried to the truck and with each trip asked, *Is that my Mom's*? (FN:186:6:34).

I was amazed that even in the last moments, Henry was able to give me an interaction to ponder. We had just closed the back of the truck, and Henry asked for about the fifth time that day, *TRUCK DRIVE DRIVE DRIVE MOVE* (FN:186:8:5)*?* I interpreted his question to mean, ***You're moving with that truck and you will be driving for a long time, right?*** We went through a series of other questions, ***Are you bringing your cat?*** and *Is Molly going with you*? (FN:186:9:1). At one point in our conversation, I tried to explain the distance and location of where I was moving. I compared my trip west to previous car trips Henry had taken to visit his extended family. Using signs and speech at the same time, my signed communication looked something like, *YES. ME MOVE FAR FAR FAR OUT DIFFERENT STATE LIKE GRANDMA GRANDPA 'M,'* while my voice was saying, ***Yes, I'm moving to a state*** *that's far, far away like Grandma and Grandpa Medina.* Henry looked at me, obviously puzzled. I realized that the combination of my speech and signs made my signed utterances difficult to understand. He paused for a moment and then checked his understanding by using an ASL phrase that means VERY-FAR-AWAY. He used a PRO-1 classifier (his pointed index finger) moving his hand in a slight left to right wiggling motion away from his body until he was pointing "very far away." At the same time, his face, particularly his eyebrows asked a question, as he wagged his tongue silently in his slightly open mouth. I blushed at my ignorance and responded this time using the same ASL phrase, *YES. PRO-1 (going away from the body with tongue wag).* Meaning, *Yes, I'm moving very far away* (FN:186:9:8).

I have been fortunate to maintain my relationship with the Camillo family and was able to conduct a return visit to the field in February 1998. Mark was promoted and the family transferred to a new PCS (permanent change of station) in the southwestern region of the country. I conducted brief fieldwork and a lengthy final interview over the course of my 4-day visit (February 12-15, 1998).

Returning to the Field for a Retrospective Interview

Returning to the field is an another strategy for conducting member checks. Mark and Sara agreed to a final interview in February 1998 that allowed us to reflect upon the collaborative and dynamic research process we shared. In order to stimulate memories of our 14 months together during the final interview, I developed a videotape that included clips from Henry's infancy and early intervention experiences, as well as clips recorded during my fieldwork. Video clips were chosen systematically to reflect particular categories and themes that were identified in preliminary analysis. The video clips ranged from Sara's days in the hospital on bed rest with the triplets, to the final summer vacations we shared with their extended family members. This strategy is one used and recommended by Erting (C. Erting, personal communication, September 21, 1996). She has witnessed how the strategy of presenting pictures and video clips to informants stimulates memories and facilitates their recall of events. Erting also states that the use of video clips during an interview

> *allows both the researcher and "members" to view a common stimulus [scene] and compare interpretation. This strategy is another way to elicit member interpretations and has the added advantage of allowing the researcher to see how much or how little she is "seeing through the eyes of the member."*
> *(C. Erting, personal communication, June 21, 1998)*

Writing the Story

Ethnographies are stories about culture (Agar, 1980). The final step of the analysis process involved combining and blending short stories, interview and fieldnote narrative, and description into an interpretive representation of the Camillos' family life and understandings as they relate to Henry's deafness.

Agar's Building Schema Strategy: What Does "Deaf" Mean?

I chose Agar's "Building Schema" strategy as a way to understand and systematically document the processes the Camillo family went through to make sense of their changing perceptions and understandings of the concepts of deafness (Agar, 1986). By analyzing the data using this "building" strategy, I was able to unpack the specific steps that the family took to develop some of their understandings of deafness. As I conducted my analysis, I followed Agar's three steps in the building process: (1) coherence, (2) breakdown, and (3) resolution. Agar calls this sequence of events (coherence, breakdown, and resolution), schema. When the sequence or schema is complete, the field worker draws or writes a description of it called a strip. A strip, like a memo, is a written part of the database that contains information about specific human interactions.

Determining coherence involved identifying and describing the family members' existing understandings of deafness. I learned by living with the Camillos that their understandings of deafness were more fluid in nature, rather than established and fully matured. Individuals in the family demonstrated that their understandings were constantly in a state of development. In addition, the family possessed both individual and collective understandings of deafness. For example, Henry's understanding about his own hearing status in the family was very different from his mother's or the babies'. Henry was not born as a culturally Deaf individual. Many of the strips identified were helpful in documenting shifts in Henry's behavior over time as he developed visual ways of viewing the world while interacting in auditory environments.

Second, through a process of negative case analysis, I identified what family members did not understand, or the situations or meanings they were trying to make sense of, termed breakdown (Agar, 1986). It is important for the reader to understand my initial perceptions of what the family members understood as challenges shifted as I conducted my final, in-depth analysis. The challenges identified by the family and the answers to their questions also seemed to vary depending upon the environmental context or "outside system" in which the family was embedded at any given point in time.

Lastly, each strip had a resolution. In some cases, the family's resolutions were complex, and in other situations lucid. While family members developed their own particular understandings of deafness, the resolution of information was also shared and developed into a group awareness which was reflected in, and in subtle ways, agreed upon through their social interactions and behaviors. For example, when I first encountered the term "resolution," I expected the family's resolutions about deafness to reflect the clear end of a puzzle or problem, or the finite answer to one of their many questions. The lesson that the Camillo family taught me was that resolution for them does not mean that the issue has a decided close. Resolutions for the Camillos meant that sometimes it is simply time to stop applying energy to a given situation or to accept a situation "as-is."

Agar's approach to analysis was helpful because of the many questions and confusions the Camillos addressed on a regular basis. Their questions ranged from understanding why Henry is deaf, to puzzling over why Henry's grandparents haven't learned to sign, to planning for and thinking about Henry's future.

The Camillos and I conferred about the strips I had identified during our final interview (February 13 and 14, 1998). I came to the interview with a set of themes and categories from the database that I hoped to address, and the video containing various interactive clips (see Appendix I for the video clip schedule). I also had my list of potential strips embedded within the interview protocol and among the video clips address (see Appendix D for the final interview protocol dated February 13 and 14, 1998). Without directly presenting the strips I had identified, I asked Mark and Sara to independently identify situations that they perceived as particularly significant or challenging to their family while Henry attended the Parkwood school. Together, we defined five themes resulting from strip analysis that will organize the findings in the next chapter.

Erickson's Ethnographic Microanalysis of Interaction

Ethnographic microanalysis is considered a more precise method of data analysis than the contextual methods associated with fieldwork. The microanalysis of selected videotaped interactions is a way to look at individual social interactions. Erickson (1992) states that the environments where social interactions occur are rich with information. My goal of using microanalysis techniques was to conduct a systematic search for patterns of social behavior. Microanalysis allowed me to organize and identify overall patterns of social organization and to look at how the members of the Camillo family influenced each other. Finally, by focusing on individual informants and their social activities, microanalysis highlighted cultural differences that were exhibited in customary ways by the group. In other words, microanalysis helped me to capture how the Camillos organized and symbolized social and cultural interaction (Erickson, 1992).

I followed Erickson's (1992) suggestion to conduct microanalysis in five stages: (1) search for patterns of social behavior by reviewing the selected videotaped event; (2) identify major segments of the videotaped event by determining boundaries around specific social actions and interactions; (3) examine how group members influence one another by defining strips of activity and conversation; (4) focus on individual actors; and (5) compare the specific analyses of interactive episodes across the database to identify typical and atypical events.

Searching for General Patterns of Social Behavior

I viewed each videotaped event in its entirely during stage one. I watched, listened, and systematically indexed the activities on each tape. Indexing is a strategy similar to the coding of fieldnotes. As I watched each tape, I summarized the action that I observed in a concise statement (see Appendix J for a sample page of indexed interaction). I also noted approximate locations in time and major shifts in activity during my general survey of field activities. I made note of activity shifts because they often indicated boundaries that exist between major events (Erickson, 1992).

Partitioning Events into Specific Social Segments: Looking for Cultural Boundaries

The goal of stage two was to develop an overall framework for how the social activity of the Camillo family should be organized. I formatted the indexed data to include wide margins (1.25 inches left and right), and numbered lines. I drew a box around broad phases of activity with a yellow highlighter, using Erickson's three stages of activity as a guide. In order to identify each phase of activity, I determined where the interaction began, where it developed its focus, and, finally where the interaction wound up or came to a close (Erickson, 1992).

Examining group member influence

Stage three had two parts: defining strips of activity and conversation, and analyzing those strips to determine specifically how the social actors influence one another. During the first part, I documented strips of activity and conversation defined by spoken and signed events, discourse routines, and sequences of nonverbal action. In part two, I broke down the identified strips of activity and conversation so that the amount and content of social interactions among dyads and triads of social actors could be specified.

Focus on Individual Actors: Looking at Cultural Intersections

Stage four required that the strips of interaction (verbal and nonverbal) be transcribed. This portion of microanalysis was the most detailed and relevant to the identification of cultural intersections. Erickson (1992) states, "At this level of detail, cultural differences in customary ways of organizing and symbolizing interaction become most fully apparent" (p. 219). I found that the intersections of cultural behavior were easiest to identify during episodes of social interaction where the participants became confused about or questioned one another's behavior. Questioning the language use and behavior of others indicates that the informants did not know the cultural rules and mores for particular social contexts.

Categorize typical and atypical events. During stage five, the researcher decides what strips are typical or atypical, depending on the data that were gathered throughout the entire study (October 1996 to February 1998). These comparisons can be made and frequencies documented in the form of charts or frequency tables (Erickson, 1992).

Validity and Credibility Issues

The Influence of My Presence on the Family.

Kirk and Miller (1986) describe how validity is built into fieldwork that is conducted via face-to-face contact with informants for a prolonged engagement (Ely et. al., 1991). The field worker aims to conduct persistent observations over time, of a variety of activities as a participant and observer, in order to learn how informants make sense of their day-to-day lives. As the field worker gathers data as part of a prolonged engagement of face-to-face social interactions with informants, it is important to consciously acknowledge and document biases and beliefs about the community of people being studied. I conducted the fieldwork for this investigation over a 14-month period (May 1996 to July 1997). During 10 months of this time (October 1996 to July 1997), I collected data from within the Camillos' home. In addition to maintaining prolonged engagement and persistent observation, I used the following methods to check for validity and credibility during the in-depth analysis of the study (Ely, et al., 1991): (a) peer debriefer, (b) member checks, and (c) negative case analysis.

Peer Debriefer and Peer Support

Over the course of data collection and preliminary analysis, I learned that my peer debriefer relationship (Ely et al., 1991) with Deirdre, a research associate in the LLCD lab, was the key to the success of my project. Theoretically, my weekly conversations with Deirdre helped me to recognize, document, and intellectually move back and forth from subjective to objective postures (Wolcott, 1992). Deirdre identifies herself as a culturally Deaf individual and was especially insightful concerning the feelings and perceptions Henry might have as a developing Deaf person. Because I had an excellent rapport with Sara, it was often difficult for me to change my lens to perceive how Henry or his siblings might view their world. Deirdre possesses a worldview that I cannot begin to create or understand because I am hearing. Finally, Deirdre provided me with support, support, and then more support. She was always available to discuss my feelings and attitudes towards the project and the family members. When I became frustrated with writing, or needed direction in my fieldnotes, she acted as a reader. Most importantly, Deirdre was always quick to recognize and hold up a red flag when she recognized I needed some distance from the family.

Member Checks

Member checks are a validity strategy I used with Mark and Sara Camillo during data collection and the final field visits. To conduct member checks means to share fieldnotes and interview transcripts with the people who are studied (Ely, et al., 1991; Evans, 1998). Member checks are a way of determining the integrity of fieldnotes (such as transcripts and narrative data) used to document the informants' daily-lived experiences. During data collection, the use of member check strategies gave Mark and Sara an opportunity to reflect upon and discuss the type and direction of data I gathered. Sara and Mark also participated in member check activities by sharing written and verbal conversations with me about what I documented in the field. Their help was immeasurable as I followed their leads and direction. Most frequently, it was Mark or Sara who told me I was "on the right path" or leading myself "out to pasture." Mark and Sara were also very helpful and sensitive in providing me with opportunities to observe and participate in their lives. Often after reading my notes or a transcript, they were reminded of yet another setting or situation where they could include me as a participant observer.

Sara acted as my key informant and was typically the person who provided me with input on word choice or direction. For example, during the first months that I lived in the Camillo home, Sara let me know that she felt uncomfortable with the pseudonym I had chosen for her 2-year-old daughter (Natalie). Sara admitted that she did not like the name Natalie for her daughter. At that point, Sara suggested using the pseudonym "Madeline" instead. While this may seem like trivial information, it was actually critical in the member check process. If informants are not comfortable reading observations and transcripts, they may be resistant to providing data or verifying future information.

Sara, Mark, and I continued to use member check strategies during the in-depth analysis of the data in the following ways. First, I continued to provide Mark and Sara with transcripts of interviews and fieldnotes that documented and described their day-to-day interactions. Second, I provided Mark and Sara with copies of all videotaped interviews and interactions. During data collection, Mark and Sara found it easier and more enjoyable to watch videotaped recordings of our interviews and interactions rather than read through print versions of the data only. Videotapes were something they could easily view together after the children were asleep. I also believe that the typewritten nature of my fieldnotes made Mark and Sara less apt to make corrections or revisions. The typewritten format seemed to present the appearance of an official document that could not be changed or altered.

Several times during data collection, Sara asked to compare interview transcripts with the videotaped version. For example, during her videotaped interview, Sara used "um" frequently while telling stories about her family. When she read the transcript of the pilot interview, she was embarrassed. She felt that because of the "ums," she was difficult to understand. Sara asked to view the videotape to check the accuracy of my transcription. After she made this comparison, she asked that I remove the "ums" from the transcribed document.

Negative Case Analysis

Ely et al. (1991, p. 98) describes the act of conducting a negative case analysis as "looking for data that sticks out like a sore thumb," or the exception to a well-defined cultural rule. As I read and re-read the narrative data, I coded the accounts and interview transcripts to indicate the presence of odd or incongruent interactions or behaviors. I asked about incongruent data linked to particular themes during member check meetings with Mark and Sara.

Ethical Issues

The core expectations concerning ethnographic methods and the protection of human informants from psychological or physical risk are <u>confidentiality</u>, <u>fair exchange agreements</u>, and <u>informed consent</u> (Agar, 1980, p. 183). My methods of data collection and preliminary analysis were chosen to enhance and contribute to the Camillos' household. In order to ensure confidentiality, I used pseudonyms in place of the informants' real names on all written documents and during debriefing sessions when family members and home situations were discussed. Both Sara and Mark expressed a flexible stance concerning how I explained my presence in the home to "outsiders." However, we agreed that family members were free to describe my presence and role in the household in any way that was comfortable to them. If Mark and Sara chose to reveal that I was in the home as a researcher, they had that privilege. However, to respect the family's privacy and freedom of choice, I agreed not to disclose their names or the reason for my presence in their home to anyone other than individuals who work as part of the larger research project. To "outsiders," I have framed my presence in the family's home as an invited "mother's helper" during the babies' first year of life. When questioned, I explained that I was invited to join the family because I could communicate with all of their children, and was willing to provide additional assistance in their home such as cooking, laundry, and cleaning. During the time I lived in the Camillo home, I made it a practice to seek out household chores and duties that I could complete in order to contribute to their household by making the work load lighter for Sara and Mark. Spradley (1979) defines this arrangement as a fair exchange agreement. Without contributing to the maintenance of the household, my presence in the home would not have been ethical (see Appendix F for a copy of ethics approved by the American Anthropological Association [AAA]).

Gathering Consent

I informed the Camillo family members at the onset of this project (May 14, 1996), and throughout the time I lived in their home (July 15, 1997) that their participation was always voluntary. All consent forms, including forms designed for children under the age of 18, were signed, with the exception of one extended family member who chose not to participate. A second extended family member chose to participate but opted not to be videotaped. I honored these requests without question. Participants were also informed that they could withdraw their participation or revoke use of data collected at any time. Specific consent forms were created for family members' participation in the LLCD Project. Consent forms were also created for extended family members and professionals who volunteered to be interviewed (see Appendix K for consent forms).

Changes in environmental contexts required the collection of consent forms from research informants beyond the scope of the immediate family. As I moved to physical settings outside the Camillo home, a change occurred regarding the support I received from Sara as my key informant. The phenomenon of gathering initial information about a new environment as well as gathering consent forms felt to me like learning a new dance. I knew I had to "dance" and I had a general idea of the direction to head. In the home setting, I had learned to rely on Sara to take the lead. However, it happened that when data collection occurred in other environments, Sara was typically not physically available, or seemed to take a subtle step back from her key informant role. Returning to the dance analogy, when changing environments I learned to change dance partners, sense "the beat of the music," (or the cultural rules of the new setting), and trust that a lead person would step forward to guide my efforts.

When I traveled to interview Henry's first teacher and audiologist, Sara's brother Francis stepped forward as my key informant. He and his daughters gave me shelter, helped to orient me geographically, and made sure I found my way to the informants for interviews. Francis attended both interviews and introduced the topic of signing consent forms. He also served as a source of family information and background knowledge. His quiet but consistent presence helped to "break the ice" between informants and myself. Also, his experience and contributions from a father's perspective, and as Sara's brother, made the interview setting seem less contrived.

During the trips to visit extended family members, both grandmothers assumed the role of key informant. Mrs. Medina (Sara's mother) made several visits over the course of the year I lived with the family. During that year, we had many conversations about her children and grandchildren. Because of the conversations I had with Mrs. Medina, I felt as though I had met many of her children and grandchildren before our formal introductions. Mrs. Medina determinedly helped to gather consent forms and worked effectively to recruit people to participate in the interview portion of the investigation. During our week together, she frequently asked various members of the family, "Did you sign the forms for Laura's project?" and "Have you [been] interviewed yet?"

Mrs. Camillo's style as a key informant was more structured. On the first day of data collection, she sat down with me at a picnic table and helped to organize the 27 consent forms that needed to be distributed, signed, and re-gathered. She drew a picture of her family, and helped me understand the ages of her children, as well as the order of their marriages, and births of her grandchildren. Mrs. Camillo also gave me "tips" about how to gather the forms efficiently like, "Don't write formal names on the consent forms," and "You can ask Lila to participate, but it's likely her husband won't be interested in interviewing." This information helped to subtly guide me as I interacted with and documented events over the course of the next several days.

CHAPTER IV

A DESCRIPTION OF THE CAMILLO FAMILY AND RESEARCH CONTEXT

This chapter presents Henry Camillo and his family, as well as the people and places that made up their social world during the 10-month period that I lived with them. Several years ago, I wrote a paper with the mother of a hard of hearing child (Blackburn & Everton, 1994). Within the context of that paper, we puzzled over how parents and teachers can learn to negotiate the barriers to their efforts to communicate and collaborate. Little did I know that my experience living with Henry and his family would teach me in a "hands-on" way what communication, collaboration, and "real life" meant to them. As a result, this family's story begins in their home rather than the school setting. Mark and Sara Camillo and their six children consider their home the primary setting for their social interactions and growth as a group.

Henry Camillo

Henry, who is the deaf member of the Camillo family, was four years old at the time of this investigation. He had a devilish sense of humor and a keen imagination. Henry's eyes twinkled when he laughed and he frequently winked to make a point. His favorite article of clothing was his cowboy boots--a gift from Sara's parents. Like all of the Camillo children, Henry sweats when he sleeps. As a result, when he and his older brother Daniel tumbled out of the top bunk each morning, they had what their mother Sara called *the Camillo sweaty head*. At the end of the day, most often in the warmer seasons, Sara commented as the children got ready for their bath. *Ugh!* She protested, holding her nose and signing with one hand, *You kids smell like wet puppies*! (FN:175:5:4).

Henry loved to play with vehicles--his tractors, fire trucks, double trailers, and matchbox cars frequently littered the living room floor. Sometimes they were parked in a neat row and on other occasions, he navigated them in elaborate "crash-and-burn chicken fights." When I asked Henry about what was happening as he played, he always had an elaborate action-adventure story about what was happening in the world of his vehicles.

Henry's favorite movie was "Spacejam"--a movie about a professional basketball player (Michael Jordan), who teamed up with Warner Brother's cartoons (Bugs Bunny, Daffy Duck) to overcome evil cosmic forces. The moral of Spacejam bears a striking resemblance to a common theme that was believed and demonstrated by Henry's family: *Think positively and work together as a team and the good guys will always win in the end* (FN:156:6:20). During periods of lengthy dialogue in the film, Henry usually took a break from watching the movie and pretended to slam dunk baskets in slow motion all around the living room--and then waited for and responded to the imaginary crowd who applauded his efforts.

Sometimes Henry was deemed "nosy" by members of his family (FN:87:2:17). He asked repeated questions and always seemed to want to know what was happening next. It was characteristic of Henry to interrupt his mother's telephone conversations to ask who she was talking to and why. There was also an unspoken understanding among Henry and the older, mobile members of the family (Mark, Sara, and Daniel). Before anyone left the room, they were expected to tell Henry where they were going, and if they planned to return. The scenario of "report before leaving" played out consistently, and none of the family members seemed to question or even recognize how or why this family ritual developed.

Henry took responsibility for maintaining the ritual and held family members accountable to the "report-before-leaving" rule. If they neglected to explain their departure from the room or the house, he voiced to get their attention and asked, *WHY?* meaning, *Where are you going?* or *Why are you leaving the room*? (FN:72:1:22). I saw this routine played out most often when we were in the living room, the central gathering space for family activity and interaction (see Figure 4.1 for a diagram of the Camillo's living room/formal dining room area).

My current perception of Henry was in stark contrast to my first impression. When I first saw Henry on the LLCD project's videotapes of classroom interaction, I was unaffected. In the 2-dimensional format of videotape, he appeared to be an average child. At the age of 3, he seemed to wander aimlessly around the classroom, grinding his teeth and moving his jaw absent-mindedly. As I looked further, I realized he was missing his right outer ear, and he seemed to be a left-handed signer. Something about his quiet meandering told me he was from a hearing family--he did not initiate conversations during this video clip, and his physical differences, in my eyes, set him apart as a child with potential for "cognitive delays" or "additional developmental delays."

The Medical Description of Henry

I was not the first to view Henry from a medical or deficient perspective. The medical and educational records that Sara allowed me to copy for the LLCD project's database were filled with descriptions of his physical "deformities," and his potential for further "complications." At 13 months of age, Henry was referred to a Neurodevelopmental Clinic because he wasn't walking independently. The neurologist who examined Henry described him as

> A 13-month-old white male, diagnosed with O.A.V. (Oculo-Auriculo-Vertebral) Disorder (profound hearing loss in left ear, no right ear, small right jaw, several spinal anomalies, and hypoplastic right thumb) referred here because...ENG determined that there may not be an equilibrium.
> (Artifact: 12-16-93)

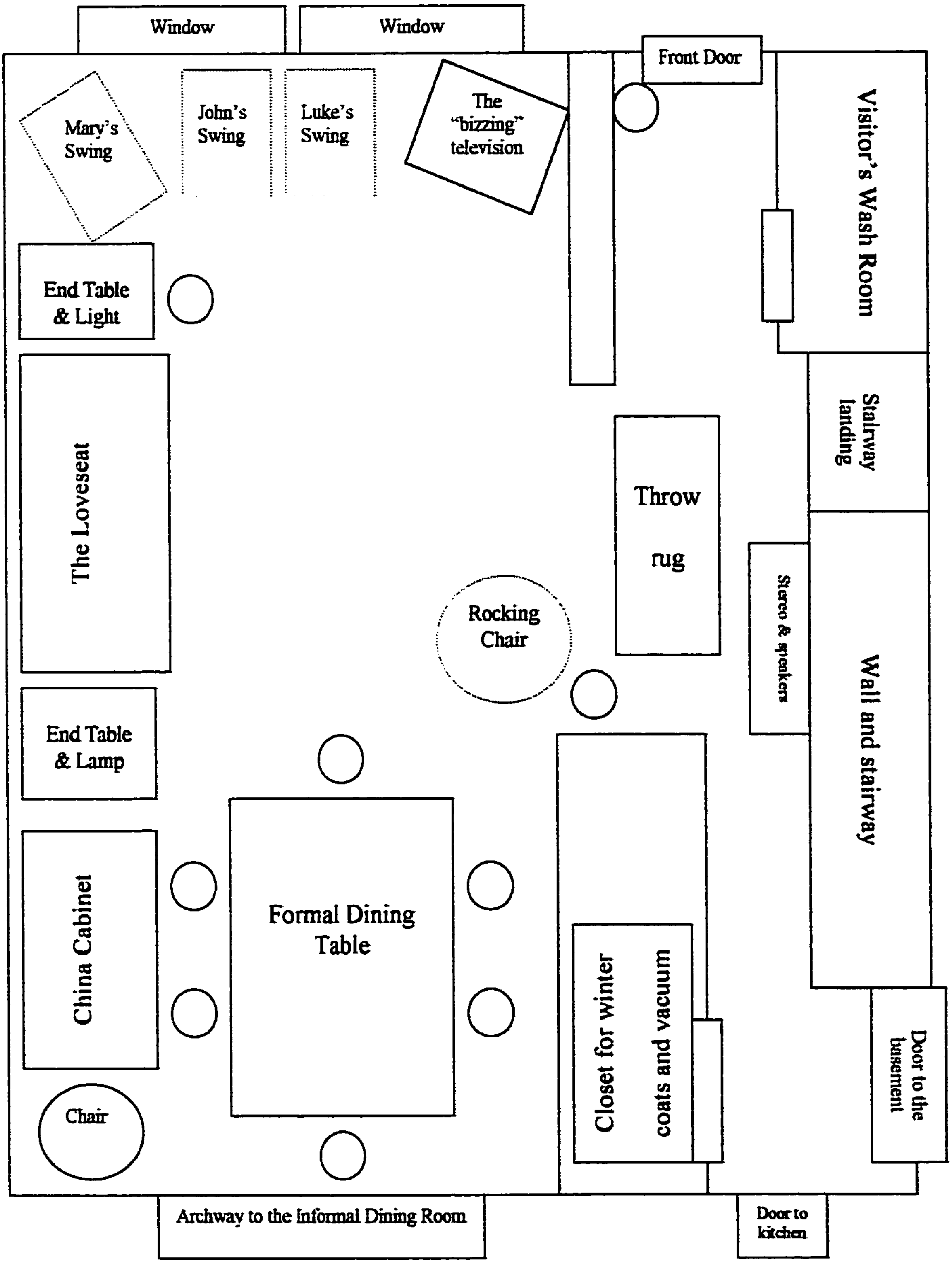
The report also included descriptors such as "dysmorphic features," "facial asymmetry," and "ill defined right ear with skin tag (microtia)."

Early Educational Descriptions of Henry

While educational assessment reports were framed in a more positive light, they also presented a child who, at best, had a lot of work to do before he could be viewed as "normal." The first educational assessment, conducted in January 1994, was typical of others that followed. The outlooks forecasted were worded in a way that suggested Henry was doing the best with the cards he was dealt. For example, observations at 13 months that warranted an appointment with a neurologist noted, "He demonstrated equilibrium responses in sitting although these were mildly sluggish." When Sara, Mark, and I viewed the videotape of this evaluation during the final interview (February 1998), the first comment they made was, *Oh, look at how tired he was! He was missing his nap during this test--that used to happen all the time* (INT: 19:4:6).

Henry was also presented as a child who had potential for later social and emotional complications. Another educational report stated:

Figure 4.1. The Camillo living room/formal dining room.



> Henry was shy and was not comfortable separating from parents. The diagnostician attempted to engage him in playing with toys, but he resisted most requests and clung to his parents....Eventually Henry warmed up to the examiners present in the room. (Artifact: 1/26-28/94)

The issue of communicative competence was also addressed in one of Henry's evaluations. Henry was applauded for "most developmental skill areas are age-appropriate," and his use of sign language to "compensate...for his profound hearing loss." The author of this report not only suggested that sign language should be used to compensate, rather than communicate, she also made the following statement indicating that one should not expect more from a deaf child:

> Communication is below age level which would be expected of a child with a profound hearing loss. However, he is compensating very well with sign language and is acquiring new signs very quickly. (Artifact: 1/26-28/94)

Finally, the diagnostician recommended that Total Communication (TC) be used as Henry's "mode of communication." The differentiation between using TC as a philosophy and as a modality is a delicate, but critical distinction. In brief, Lane, et al. (1996) elaborated on the evolution of meaning related to the term Total Communication:

> In principle, subscribing to TC meant using all the means of communication with Deaf people at your disposal, including ASL, spoken and written English, fingerspelling, mime, etc. In practice, TC came to mean accompanying one's speech with a certain amount of signing. (p. 214)

In order to consider which Total Communication meaning was the diagnostician's intent, it is helpful to consult her definition of the "dominant language" used by Henry and his family.

> English is the dominant language in the home and the language to which Henry has had greatest exposure. Testing was conducted in English with the parent as informant. Henry was present while the parent was interviewed. (Artifact: 1/26-28/94)

Based on the above definition, it appears that the report writer's definition of TC is in alignment with the practice of "accompanying one's speech with a certain amount of signing" rather than the acquisition of American Sign Language.

The above excerpt also serves as a pertinent example of how written reports about children are used to implicitly establish the worldview of a particular educator or program, rather than the true communication of the child. In turn, these messages or assertions become part of the way society, including how hearing parents and family members, come to understand the deaf experience. When we consider messages like these, that originate at the macro-level of society, it clearly demonstrates how the view of mainstream society may influence and teach Henry's family members about deafness, and how eventually, Henry may view himself.

A Brief Description of Henry Through His Mother's Eyes

The description that Henry's mother Sara provides for others of him is mixed with emotional words that reflect pride and love and other terms that mirror Henry's medical conditions and deafness. In March 1997, Sara decided to join a parent listserv for parents of deaf children. This is how she described Henry and her family:

> Hi, my name is Sara Camillo and my husband's name is Mark. We have six children under the age of six. Our oldest son is 6 years old and hearing; our second son is 4 years old and is profoundly deaf; we have a 2-year-old hearing daughter and 7-month-old triplets [one girl and two boys] all who are hearing. Our deaf son's name is Henry and, like all of our children, he is the joy of our life. He was born with Golden Hars Syndrome, which included an absent right ear, a smaller right jaw, and extra digit on his right hand, scoliosis, and a left ear that has a profound hearing loss.
>
> We have experienced many medical as well as educational "ups and downs" and being that we are a military family we move every 2-4 years, which involves extensive research of schools in all areas of the world that have

> a hearing impaired program to fit our child's needs as well as a military base within the same county. We are actively involved in the deaf community and are the coordinators of the Silent Suppers of [their state of residence].
>
> Henry has been in school since he was 3 weeks old. He started an oral Program in [Sara's home state where Henry was identified] and within a year we moved to a TC program. Once we moved to [their current state of residence] we continued the TC program until Henry was accepted at the Parkwood Elementary School on the campus of [a university]. The ASL program there was awesome and we are still there. Although it is far from home, we have a bus pick up point, which is nice.
>
> I am happy to be a part of this [listserv] because (1) I love to hear about other people and their stories and (2) I feel I have so much to offer and so much to share. Our life is wonderful, our family ALL signs, including grandparents, aunts, uncles, cousins. It is so beautiful to see Henry interact with his infant siblings grabbing their little hands and showing them how to sign. I know my little deaf son is just the "tip of the iceberg" in our relationship with the deaf community and we are anxious and excited to see what the future brings (FN:105:7:10).

The Story of Henry's Birth Through His Father's Eyes

During the interview with Henry's father, Mark described how his understanding of Henry began at the time of his birth (INT:18:9:3). Mark spoke most candidly of the feelings he experienced the day that Henry was born and in the days to follow. Mark currently shares a particularly close relationship with Henry and requested several times during the course of his interview that the story of Henry's birth be worded with the understanding that the event was a shocking experience. However, the disappointment that Mark conveys concerning the event should not be confused with his feelings toward Henry as a person. As the reader will see, the shock that Mark conveys during the context of his interview faded rapidly and turned to a strong, loving bond that he shares with Henry today.

Near the beginning of Mark's interview, I asked him to tell me about some significant events that have happened to the family. This question prompted him to tell me about a variety of events that centered on his marriage to Sara, the birth of their children, and his 8-month deployment to serve in "Desert Shield/Desert Storm." His relationship with his eldest son Daniel was affected because Mark was deployed only one month after Daniel's birth. He sees, "that whole 8-month period right in-between there" as particularly challenging. He elaborated:

> That whole thing was like, "I just wanna be home." That was because at first, I was afraid that I wasn't going to come back. But then, after awhile that [feeling] dissipated. Then you're like okay, is he going to know me? Is he going to want me? That type of thing. (INT:18:8:2)

Mark continued with other significant family events that preceded Henry's birth:

> The others events would be Sara's miscarriages after I came home. [For] one of them, I was TDY[10] to Portugal. And she called me on the phone and said, "I miscarried." (INT:18:8:6)

Mark described feeling as though someone had punched him in the stomach when he received word from Sara about the miscarriages.

> It's just you never expect that to happen, even though it's a common everyday thing. It's just something that happens to other people. Everything happens to other people, not to you. What's significant about both those times was they happened when I was TDY. The second time she miscarried when I was in San Antonio. She happened to be in San Antonio with me. So luckily I was there and she was at a good hospital. (INT:18:8:15)

He arrived at the day Henry was born:

> Then of course Henry came, and that's something I'll have to live with the rest of my life. Which is--that's not bad. That's not bad at all. But well, gosh, first the labor situation was totally different from Daniel. It was so much harder for Sara--a different ball game. Just seeing her go through that, gosh. (INT:18:8:16)

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[10] TDY is a military acronym that means "temporary duty," meaning Mark was away from home.

I asked Mark to elaborate on the story. I reminded him that he had shared the story with me earlier in the year, but for the purposes of the interview, I asked him to tell it again.

> Oh, okay. She had him in the hallway. They were going from [the hallway to] the labor room and he came out head first, but face-up--which was not a good thing because they didn't have a chance to turn him around coming out of the birth canal. So she had him in the hallway and he was just kind of there [not entirely conscious] when they put him in the delivery room. It was funny because I'm trying to get all my blue stuff on--my scrubs. And by the time I get them on, the baby's already gone and on the table about 15 feet away from her.
>
> I was like, "Where the heck's the baby?" There were people working on him. The first thing the nurse said was, "And we don't know if that's just a lazy lip or something else." Because his lip was like that, [Mark makes a face resembling Henry's mild paralysis on the right side of his mouth]. I heard her say, "some sort of palsy." I mean palsy! I thought, "Gosh, what do you mean palsy?" So, that just put me on edge from the beginning.
>
> And so, I'm just looking at him and nobody noticed anything. I noticed on his left ear, he had a little skin tag. I turned his head over thinking, "What's on his right ear?" I looked on the right side of his head, and he didn't have a right ear! I must have turned 10 shades of white at that point. Sara said, "Well Mark, how is he?" I'm like, "I can't believe what I'm seeing." And she said, "What do you mean?" And I said, "He's missing an ear." And she said, "Well, let's count his fingers and toes."
>
> So we started counting them and he has an extra thumb! They had him on a table away from Sara Jane, so Sara didn't get to see him at that point. In fact, she didn't get to hold him except for maybe five seconds before they took him away. So I thought, well what do I do? Well nobody in there cared because they were Labor and Delivery folks. You know, once the baby's out, the baby's care is in the hands of the Pediatric folks. They were like, "Well, don't worry about it. We'll take care of him." And everybody took him away. (INT:18:10:9)

I interrupted his story at this point and asked, "Did they do that with Daniel? Did they take Daniel away right after he was born?" Mark responded,

> No, no. Because I was allowed to hold Daniel. I was allowed to go into the nursery. I was there when they measured Daniel and weighed him, and did all of that stuff. (INT:18:10:12)

He compared the birth of Daniel, his first child, to the experience at Henry's birth:

> But with Henry they said, "Okay we're just going to take him now." And they did other tests. And they did some x-rays on him. But at this time, we didn't know anything. (INT:18:10:20)

Mark also noted that the attitudes of individuals attending to them in the hospital made a negative impression of their ability to process and make sense of what was happening. There was a large component of interaction with hospital personnel who were behaving as if "they had everything under control," while not involving Mark and Sara in their discussions, or the decision-making process:

> I didn't like the lady who delivered the baby because she was real crass. She wasn't really mean, but she just didn't care. She just didn't care what we were thinking. At that point, you want answers. You know nobody can you give you answers, but you just want somebody to say it's going to be all right. Nobody was there to console us. So for whatever reason, you're left hanging. You just don't know what to think or what to do. (INT:18:11:2)

Because support was not readily available to the family within the hospital system, their stories started to reflect their family's level of cohesion, and the steps they took to adapt and make sense of the experience. Mark continued his story at the point immediately following Henry's removal from the delivery room:

> So Sara and I look at each other and we said, "Okay, he appears to be healthy." I remember looking at each other going, "God." And I don't know if you can scratch this off the tape, but it's like when I first saw him, the first thing in my mind was "put him back." I even think of that now and how painful it was to have those thoughts, but I thought, "Put him back--give me another one." (INT:18:11:10)

Mark paused to collect his thoughts.

> I remember talking to Sara Jane. I asked her, "Are you going to be okay with this?" I can always look to her and see if she can be okay with it. That's a constant I rely on in our marriage. I know that if she can be okay with it, I can be okay with it. I knew at that point that it was going to be all right--whatever's going to happen in our future, we'll be all right. (INT:18:11:24)

Mark described how extended family members were attempting to be positive in order to show support.

> After a while I was allowed to be with Henry in the nursery. Daniel was with Sara's family and they were all on the other side of the [nursery] window going, "Yeah, yeah!" [Mark shows me the "thumbs up" sign they were making through the window] the whole time. I just couldn't be happy because I just didn't know at that point. (INT:18:11:22)

Mark remembered a consultation that he and Sara had with a Genetic Counselor the day after Henry's birth. The genetic counselor was the first person to answer their questions. Mark remembered him well:

> He [the doctor] was just fantastic. A nurse came in with him and they were both very positive. He said, "Okay, this is what your child has, and it's a cousin to Golden Hars [Syndrome] called Oculo-Auriculo-Vertebral Disorder (OAV)." They just said, "Okay, this is the deal." (INT:18:13:17)

Mark briefly digressed from his story and told me that he and Sara had particular concerns about his involvement in the Persian Gulf War. The family had always wondered if Mark had ingested chemicals during the war that somehow related to Sara's miscarriages, and later Henry's physical complications. Mark continued his story:

> I thought, "Okay, I know I need to tell somebody this, because this might be a reason why he was born like this." So, I told him. He says, "Well, this has nothing to do with that. There's no reason for it to happen--it just happens." And he said, "Don't even consider that it's part of Desert Shield/Desert Storm." I said, "Okay." So I just scooted it aside. (INT:18:14:13)

Mark took both hands at this point and smoothly pushed an invisible pile of guilt and anxiety off the kitchen table where we were sitting. A smile spread across his face for the first time since he began the story of Henry's birth, and he continued.

> He gave us some books that showed us what OAV is, the history of it, and how many times it happens--so many out of so many births. And Henry was, gosh, just the mildest case that you could ever see. Because most of the cases it's

> indicated by a missing eye or a totally deformed eye too. It's ocular for other people and it involves the ear, and vertebra problems. But thank God Henry doesn't have those problems--thank God. So we finally knew that Henry has a very mild case of OAV, or a few people call it a very mild case of Golden Harrs. (INT:18:14:23)

I clarified, "So they don't know what caused it, but out of so many births it just happens." Mark responded, "Yes, and our numbers happened to fall into that. It's like the triplets, it just happened--boom." Again, a broad smile crept across his face, "I need to play the lottery" (INT:18:15:5). After the meeting with the geneticist, Mark felt no more explanations were needed and he was "ready to deal with it." Then he realized that it was the first full day of Henry's life, and he still hadn't held him.

> I didn't want to hold him. I was kind of embarrassed because all the other babies in the nursery were normal babies. By "normal" I mean, God, Henry's as normal as any other 4-year-old child. Please frame this as my perspective at the time. Everybody was so happy with their little bundle of joy, and then there's Henry. That's what was going on in my mind. (INT:18:15:20)

Mark remarked that Sara handled the situation very differently:

> Sara accepts things totally--she's so positive about everything. That day when we were coming home, she said, "Henry's the most beautiful child in the nursery." And gosh, I was thinking, "No, he's not Sara!" You know but, in my heart, he is. But I didn't think so at the time, even though I accepted everything. But Sara just went way beyond that. She sees a silver lining in every cloud, to coin a cliché. When we were leaving she said, "The Camillo family is leaving with the most beautiful baby in the nursery!" She's always seen him that way. He came from her womb--that's her child. (INT:18:17:17)

Mark returned to the point in the story when he and Henry experienced a moment in the nursery that transformed their relationship.

> That night I held him. He was awake just kind of looking at me? And this part was really neat, it was like a transformation of what's going to happen in the future to now. There's still a strong bond between Henry and I. If you could get it on video you could just see the whole transformation. After I was done holding him, I thought, "Okay, this kid's gonna be fine. I'm gonna be fine. The family's gonna be fine." I had a feeling like, "He's okay." So, it

> was kind of neat at that particular moment. And I should have done that earlier in the day but I just--I just didn't want to. After that it was neat. And then, luckily he was only in there [the hospital] a full three days. He came home on Saturday. (INT:18:17:3)

Something in Mark's story echoed the sentiments I saw when the triplets came home from the hospital. One by one, each body physically crossing over the threshold of their home was a celebration, and demonstrated one of the first steps that each Camillo child took in their journey to becoming a member of the family. Henry's homecoming was just as precious and normal as Daniel's had been, and set the stage for the siblings who would follow.

The Meaning of Henry's Birth: An Extended Family Description

Extended family members had perceptions of Henry that incorporate intimate understandings of deafness as well as views held true by general society. During interviews, grandparents, uncles, and aunts recalled Henry's birth as a significant moment in their family's history. In the weeks following the event, family members felt plagued by nagging doubts about his progress and conveyed the common theme, "We didn't know anything" (INT:18:10:20). Some even went so far as to view Henry's health complications, and later the identification of his hearing loss, as easier for the family to accept than "not knowing" the nature of Henry's condition at birth. Their story consistently indicates that they were provided minimal information about Henry's condition at birth, leaving nothing for them to make sense of except a lack of information and support.

Extended family members also shared a concern that Henry was not going to live, based on the inordinate amount of inaccurate, pathological, absent, and conflicting information presented about his condition. Mark's brother Harry and his wife Maura shared their perspective:

> Maura: I remember when he was born, we feared he was not going to make it.
>
> Harry: [nodding] Oh yes, I remember that.
>
> Maura: I remember them telling us there were all these things wrong with him. And then all of a sudden they said, "No, that's not wrong." They said he had all these intestinal problems.
>
> Harry: And then, they found out that there wasn't an intestinal problem. (INT:9:3:8)

Sara's sister Nannette echoed Harry and Maura's sentiments when she shared her own story about Henry's birth. Nannette most clearly recalls the confusion and feelings of disbelief she experienced at the time of Henry's birth:

> I was with Sara on the side of the bed [in the hallway]. And then it got to the point where they were rolling her down to the delivery room. They still didn't think she was ready. But by the time they wheeled her down, it was time. I went and got Mom and Dad--they were sitting in the waiting room. Mark comes up almost right away and he says, "It's a boy, uh, he's fine. He has an extra thumb, and he doesn't have an ear." Just like that, you know? It hit Mom and Dad hard. I mean, Mark and I drove home that night together at about 2:00 in the morning and we were crying because we didn't know anything. (INT:16:1:17)

The family seemed to glean some understanding of Henry's condition by where he was housed within the hospital. Nannette continued:

> We knew he never entered the ICU for critical care. We felt good because he stayed in the regular nursery with all the rest of the children. But at the same time, Sara never got to see him. They tested him and poked him all over. I mean--we didn't know if he was gonna die. That was the only thing. We didn't know anything. I can remember driving on highway 90 and being with Mark. And just not knowing--we just didn't know. (INT:16:2:17)

Sara's sister Bobbie was living in a distant state and received the news of Henry's birth from Nannette. Bobbie used a private journal to prepare herself mentally and emotionally for her first meeting with Henry. Bobbie provided the following entry from her journal to be included in my fieldnotes:

> These last couple of days have been a total nightmare. Tuesday night, my Older sister went into labor. We are very close. When she left a message on my machine Tuesday afternoon saying she was going into labor, I was so excited! Anyway, she had a very difficult labor. At 3-something in the morning my younger sister phoned and said that Sara had had another boy! Henry Lawrence Camillo, 7 lbs., 2 oz., very fair like his father. Nannette also told me the baby had a few problems. What I was to hear next was unreal. That's the only word that can describe it. Never, ever has anything like this happened in our family.
>
> My nephew, who I will meet at Christmas time, has no right ear, an extra right thumb, and some spinal problems. He's not in ICU or respiratory machines--just an IV for feeding purposes. The doctors are testing everything genetically possible. Mark and Sara think there is a possibility that Mark ingested chemicals when he was serving in the Gulf War. My whole family has been in shock for the last couple of days. We've all noted a coming to grips with the situation. We all trust God--I know He knows what He's doing. But nonetheless, it's still a shock. All I can think about is my airline ticket that sits on my dresser. On December 19, I'll meet Henry. (FN:76:1:2)

The Members of the Immediate Camillo Family

The Camillo family consists of eight members who are considered immediate family. Sara and Mark Camillo, Henry's parents, recently celebrated their tenth year of marriage. Both Mark and Sara are Roman Catholics. Their faith in the traditions and beliefs of the church are what they consider as part of the glue that maintains their relationship and enables it to grow. There are six Camillo children under the age of seven. Each child has made their mark and created their position within the family in his or her individual way.

Mark and Sara Camillo: Henry's Parents

During the return-to-the-field interview (2/98), Mark and Sara collapsed on the couch in peals of laughter when I told them how I planned to describe them in my dissertation. I explained to them that I came up with the descriptions by going through my fieldnotes and interview transcripts, coding sections that described their typical behavior with the labels, "Markism" and "Saraism."

Mark commented on Sara's assertiveness and she teased back, "How will you describe Mark? ' He always has that pissed off look?'" (INT:19:111:8). Mark continued, "Will you write about how I was always tripping on thin air and falling down the steps?" (INT:19:110:16). I admitted and joked in response that Mark's facial expressions were something I frequently noticed and described. In spite of these light-hearted exchanges, there is much more information about Mark Camillo and other hearing fathers of deaf children than deaf education literature currently offers.

Mark Camillo: Henry's Father

I mistakenly offended Mark during one of our initial conversations. During my early fieldwork with the family, I arranged with Sara to make a casserole and join the family for dinner (FN:3:3:27). By the time the scheduled date arrived, Sara had been ordered to bed rest in the hospital, but she encouraged me to join the family at their home for dinner anyway.

The house was filled with people when I arrived but with Sara missing, the environment lacked a certain hustle and bustle. In addition to Daniel, Henry, and Madeline, Sara's mother, Peggy Medina, and Mark's brother, Steve, were both living and helping at the house for the summer. Dinner conversation was stilted and slightly uncomfortable for me. I didn't know the family very well at this point, and as a cast of characters we seemed rather miss-matched and lost without Sara present.

After dinner, we walked as a group to a wooded area near the family's home. A tree had fallen across the path and we took a moment to sit on it and have a conversation while the children scampered around looking for bugs. Mark confessed that he had been having problems managing the childrens' behavior. *They just won't listen to me!* He puzzled, *I guess they just really miss Sara and don't feel like listening.* I responded with a pat answer that personifies what I believed at the time about father involvement. *Well, it's like when there's a substitute in the classroom – kids will only listen to the teacher and when the cat's away*! (FN:3:4:22).

Mark's expression and body language changed immediately to a startled posture and he interrupted me, *I am <u>not</u> a substitute for my children! I am their <u>father</u>*! (FN:3:4:27). I apologized and attempted to stammer my way out of the hole that I had dug. I respected Mark even more because he seemed quick to recognize my error and continue with his explanation. I learned a great deal from that one response about my misperception of the father's role as well as Mark's high level of commitment and involvement with his children.

Mark can be described as a candid, down-to-earth man who wears his heart on his sleeve--particularly where his wife and children are involved. His reactions and responses were always clear-cut and black-and-white--there was never any question about his mood or state of mind. Sara shared that she loves Mark for his "what-you-see-is-what-you-get" qualities (INT:1:19:43). Mark was an avid runner and highly committed to physical fitness and living a healthy lifestyle, so committed, in fact, that he and Sara frequently juggled their already overwhelmingly busy schedules so that he could train and compete in running marathons.

When I lived with the Camillos, I was always amazed at the difference between Mark "at home" and "on the job." At the house when he was tired, Mark could fall asleep in the middle of a holiday parade--typically with at least one child in his arms. On the job, Mark's rank of Major, and role as Service Commander, afforded him a great deal of responsibility.

Responsibility and commitment are two words that describe Mark Camillo well. A classic phrase used by him in a variety of situations is, *Somebody's got to be accountable*! (INT:1:35:7). When I brought this expression to his attention, we discussed the combined influence of his upbringing in a large family and his military background. Mark explained that his interaction in both groups taught him the basic understanding that, "things work better when you work as a team and let the strongest one lead" (INT:19:88:25).

Mark's commitment to and involvement with all of his children is strong, demonstrated in his particularly close relationship with Henry. Like Sara, Mark is a fluent signer and when communicating with Henry, he most often signs and speaks at the same time. He patiently fielded Henry's questions and frequently took time to "chat" with his son. Mark seemed to take fascination in all of his children's achievements and expressed his praise and admiration of them easily. Mark's conversations with Henry were punctuated with comments like, *Well, isn't that neat! Did you see what he just said?* and *Sara, you won't believe what he just told me*! (FN:31:4:30).

Sara Camillo: Henry's Mother

Sara saw and conducted herself as a classic maternal figure. Her demeanor was ultra-feminine, while her communication style was direct, assertive, and sometimes sharp. The only time I found Sara without her hair and make-up in perfect order was when she awoke in the morning or at the gym during her regular workouts. Sara shared with me that she "keeps up" her appearance as a reminder to herself and to others that full-time motherhood is not a burdensome task.

Sara was meticulously organized and hates to have *things hanging over her head* (FN:117:4:16). As a classroom parent, she was typically one of the few mothers who remembered teacher appreciation day. Daniel and Henry's birthdays were always honored and celebrated at school. For special occasions Sara sent cupcakes to school (with vanilla and chocolate icing) that were baked from scratch. Sara also participated actively in several mothers groups (Mothers of Preschool Children, and Mothers of Multiples).

As a single person, she worked as a bank officer for a large national bank where her co-workers jokingly referred to her as "The General." I saw "The General" in action many times at the house. The scenes that come to mind are during bath time when she gracefully bathed, towel dried, and dressed all six (screaming and chattering) children for bed in 15 minutes or less.

"Loading everyone in the truck" for a family outing or to run errands was also an operation that worked like a well-oiled machine. Sara's job before travel was to organize the group and pull together last-minute details. While Mark or I assumed the role of changing diapers and wiping faces, Sara packed bottles for the babies and snacks for the older children. She could also be found making last-minute phone calls, throwing yet another load of laundry in the dryer and checking to make sure the windows were opened or closed, or the furnace was set at the right temperature for our return. Sara typically gave a two-minute warning before departure asking, *How are things coming with the babies? Do you need anything?*

Mark described Sara as his *beacon*, and treasured her ability to move and organize their family (FN:156:4:5). He understood that behind every family activity, Sara was the person who puts each plan in motion. Sara spent most of her life planning and preparing for her role as wife and mother. When she was on bed rest at home with the triplets, she told me a story that exemplifies her understanding of motherhood.

It was mid-afternoon on a Saturday, and Sara had just been ordered to strict bed rest the previous Thursday--she was only permitted to leave her bed and go downstairs twice a day for breakfast and dinner. Mark's brother Steve was living at the house for the summer to help keep up the house and to entertain the children. Evidently, both Mark and Steve fell asleep at one point in the afternoon, Mark next to Sara in bed and Steve in the basement. Sara told me this motherhood story during her interview:

> Mark and Steve just got really pooped out. So anyway, it was Saturday. They fell asleep--I mean they were <u>out</u>. The doorbells were ringing, the phone was ringing off the hook, Madeline was screaming in her crib 'cause she'd just woke up. And what was I gonna do? I <u>could not</u> wake up my husband--he was out, just <u>out</u>! And Steve--I don't know where he was!
>
> So I had Daniel help me get Madeline and we went downstairs, opened the door and it was a family bringing us dinner. They said, "We thought you were supposed to be asleep?" and I said, "All my HELPERS are asleep!" (INT:1:6:14)

Sara was concerned that the three older children would wander around the house and "get into trouble" without supervision, so after the casserole was dropped off, she brought her children back to her bedroom.

> What was I supposed to do? I said, 'You guys [the children], I have to lie down. Do you want to paint?' and they said, "Yeah!" So I got these face paints I bought. I picked up my shirt, pulled down my pants and they colored all over my tummy, colored all over my legs. I mean, look at my toenails--they're still black! They painted my toenails and Henry was doing his letters on my leg. (INT:1:6:38)

Sara often told people the story of our first meeting at the Parkwood school, where I saw both her nurturing feminine side and the person that others describe as "The General" in the course of one afternoon (INT:3:20:4). I met Sara in person for the first time in the receiving area outside of Henry's preschool classroom at Parkwood. A variety of issues were on Sara's mind that day. She had just learned she was carrying triplets, and she had end-of-the-school-year issues to wrap up with Henry's teacher as she anticipated bed rest with the babies.

On that first day, Sara entered through Parkwood's automatic front doors and strolled smoothly into the lobby with Daniel and Madeline to either side of her, holding her hands. Her appearance was meticulous--she wore make-up and her brown skin glowed from the humid spring air. Her dark brown hair breezed away from her face and fell behind her to the middle of her back. Although we had never been formally introduced, I recognized her immediately because of her pregnancy. Several teachers walking by stopped and asked about her pregnancy and Sara jokingly said, *You won't believe the latest news! No one has a life like mine*! (FN:1:1:25). Sara began to share with them the news about her multiple pregnancy, and I decided to wait for her in the smaller lobby outside of Henry's classroom.

The story that Sara tells begins as she enters the smaller lobby, engrossed in conversation with Linda Sheffield, one of Henry's classroom teachers. Sara was upset about something that had happened on the bus that morning and was complaining about the bus assistant:

> She told me that for legal reasons that I wasn't allowed to get on the bus in the morning and buckle up my baby [Henry]! It's bad enough that he has to ride all that way by himself and he's only 3 years old! (FN:1:1:15)

I thought, "There's a parent who isn't going to let the special education system run her life! Good for her!" Sara continued her conversation with Linda for another few minutes. They discussed a variety of issues including arrangements for Henry to attend summer school, and the changes that were happening at home because of Sara's quickly advancing pregnancy. She also shared her concerns that Mark was feeling stressed because of the different and additional roles he had recently assumed in the house because of her pregnancy.

Sara abruptly looked at her watch, becoming aware of the time and said, *I'm supposed to meet a woman here named Laura Blackburn to talk about a research project* (FN:1:2:27). Linda pointed in my direction and Sara blushed as she realized I had overheard their conversation. She said, *Oh my goodness, what you must think of me! You must be thinking, "Get that witch away from me! I don't want to interview her!"* (FN:1:2:30). Sara was embarrassed because she had shown me a side of her personality reserved for "getting things done." I assured her that my thoughts were actually the contrary and that she shouldn't be embarrassed, but I wasn't sure throughout the course of our relationship if she ever believed me.

Henry's Siblings: Daniel, Madeline, Mary, Luke, and John

Daniel Camillo: Henry's Older Brother

Daniel is the Camillo's oldest son, and he is hearing. During data collection he was six years old and in the first grade. Daniel was a sensitive child who was especially responsive to and shared a close relationship with his mother. In fact, Daniel bore such a strong physical resemblance to his mother that when they pulled back their hair from their foreheads, their likeness was close to identical. Daniel held the distinction of being the child who prayed for and was granted each of his brothers and sisters. He told family and friends the story of asking Jesus for baby after baby, and then added jokingly, *But man! After the triplets, I won't do that again*! (FN:31:4:23).

Daniel had a husky build, dark brown hair, and soulful brown eyes. He experienced bouts of muscle cramps from growing pains in the fall, and during the winter months, lost numerous "baby" teeth. At one point, visits from the Tooth Fairy and Daniel's toothless grin became a form of social status around the house. Henry and Madeline couldn't wait to lose their teeth as well and often commented, *My teeth are loose too*! They would wiggle their teeth forcefully to make their point and say/sign, *See? I'm losing my teeth--same as Daniel* (FN:77:2:2)!

Because Daniel was the only Camillo child able to voice his questions and concerns about Henry and deafness in spoken English, his queries seemed to hauntingly foreshadow the concepts the other children might eventually address. Sara told me some of Daniel's inner reflections that he shared with her shortly after the births of Madeline and then the triplets. On both occasions, Daniel tentatively sought out his mother and asked, *Will these babies sing? Will she hear me? Will he talk to me or use sign language like Henry*? (INT:1:21:33).

Daniel and Henry shared a unique and informal "sibling style" sign language that they used most often during play between themselves. Daniel was a fluent "sibling signer"--his signing with Henry was done in stuttering movements with chubby hands and a whispery voice. Despite his fluency, Daniel was resistant to and sometimes resentful of using sign language for many reasons.

As evidenced from the early videotapes of Henry's first home visits, and more recent video clips from the summer family vacations, Daniel spent many years in the background, patiently and persistently vying for attention and recognition. Daniel managed his unique role by projecting a "devil-may-care" and sometimes-angry attitude about Henry's deafness and sign language. My fieldnotes indicated numerous incidents of Sara interpreting for Daniel at the dinner table, or Daniel asking, *Why do we have to sign? Henry's not looking anyway*! (FN:31:4:24).

However, Daniel's actions also demonstrated a quiet resolution, as he shouldered the responsibility of leading his younger siblings in their pursuit of making sense of deafness from the perspective of developing children. Daniel assumed responsibilities that one would not expect of a 6-year-old child. For example, once when Sara and I were discussing the development of evacuation procedures in the house in case of a fire, Daniel interjected, to his mother's dismay, *Don't worry Mom. I'll get Henry and you can get the other kids* (FN:77:3:4).

Daniel's loyalties to Henry were also evident during the family vacations. At different points when large groups of family gathered, Daniel could be overheard watching out for and interpreting Henry's wants and needs to aunts and uncles, *My brother Henry says he doesn't want chocolate syrup on his ice cream! Sprinkles only! He hates chocolate*! (FN:185:4:21). Many times in the pool he fended off cousins who stole Henry's underwater goggles, saying, *Hey! It's Henry's turn to play with those*! (FN:183:4:2). And then mediated to Henry, "HENRY SHARE, O-K? CAN HAVE GOGGLES FIVE MORE MINUTES, O-K"?" (VC:6:6:21).

Madeline Camillo: Henry's Younger Sister

Madeline's middle-child role and gender allowed her to be both a nurturer and a *scrapper*. She cared for the babies and played with them *as a big sister should*, and at the same time was regularly put in the position of defending herself against the playful *rough and tumble* antics of her older brothers (FN:93:1:16).

Madeline had a petite frame to house her feisty 2-year-old nature. After her first "beauty shop" haircut, her baby-textured, fuzzy hair blossomed into a dark brown mane of loopy curls. Her eyes are a deep, moist brown, and her lips are red like candy. Sara described Madeline's personality as "spicy." (FN:106:1:20). "Spicy" meaning that Madeline was learning to assert her own authority, and was at a point in her life where she protested even the choices that she approved of. If caught in a spicy mood, Madeline was likely to respond with a fervent, "NO!" regardless of the question.

As mentioned previously, Madeline had the advantage of exposure from infancy to both American Sign Language (ASL), spoken English, and a combination of spoken English and signs when they are used simultaneously. She used both ASL and English comfortably and separated their use, depending on the person or persons involved in the social interaction.

Madeline was also learning the role of Henry's interpreter. In the interactive video clips, she demonstrated a consistent behavior I called the "Madeline eye shift." When she and Henry were playing together or side by side, and were approached by a nonsigning or minimal-signing person, for a split second Madeline's eyes shifted from Henry to the nonsigning participant to assess the communication situation. In a seemingly subconscious manner, and in the blink of an eye, one could see her survey the environment and determine if she would be required to interpret. At the dinner table, Madeline could also be overheard voice interpreting for Henry in second person, "He likes his soda!" or "Henry wants more chicken!" (VC:3:2:25). Madeline's assumption of the role of interpreter was so natural that I didn't notice it during my day-to-day living with the family. Her repeated behavior of voicing and mediating and voicing for Henry in communication situations only became apparent when I reviewed and systematically indexed the interactive video clips I had collected during the extended family vacations.

In return, Henry enjoyed his interactions with Madeline and often audibly snickered at her "baby" signs--signs that she used that were not formed with the correct handshape or articulated in the correct location. With the raise of an eyebrow and a wave of his hand, Henry good-naturedly pointed to Madeline and signed, *BABY SIGNS!* as if to say, *Did you see how she said that?* (FN:10:5:26).

Before the triplets developed mobility, it was typical for Madeline to go to great lengths to play with three dolls, rather than one. The "taking care of triplets" play scenario involved lengthy preparation--she brought the babies down the stairs from her bedroom, one at a time, gathered enough blankets and "binkies" for each of them, changed diapers, and heated an endless supply of bottles in her Tyco microwave oven. When Sara ran errands and Madeline and I stayed home, I could always count on caring for six infants, rather than three. It seemed as soon as I settled on the couch with a "real" baby in my arms, Madeline handed me one of her babies as if to say, *Here Laura, I need your help with this one too* (FN:164:6:16).

Mary, Luke, and John Camillo: The Triplets

The triplets weren't born when I met Henry Camillo and his family. I was introduced to the babies for the first time by listening to their heartbeats while Sara was in the hospital on bed rest during the latter part of her pregnancy. In utero, Mary was positioned facedown and laid horizontally over her mother's cervix. The two boys stayed in breech position above Mary. John typically was found curled in a tight fetal position on the left side, while Luke was *deep inside* his mother on the right. When the nurses came to take their vital signs, Sara slapped her swollen stomach and said, *Wake up Luke! Time to rise and shine*! (FN:11:2:26). Sara and Mark often referred to Luke as *our little stowaway*. Luke's arms and legs were often fully extended, as though he were stretching or lounging. In order to monitor the babies' positions, the nurses drew the letters A, B, and C on Sara's heavy mid-section. The nurses referred to them by letter; Sara always called them by name.

Mary, Luke, and John were born in August 1996. The family story for the triplets' delivery was that there was a slight delay because Sara could not reach Mark at work. He was taking his daily run and had to be chased down by one of his office mates. A team of obstetrician surgeons and residents delivered the babies by Cesarean section within two minutes: first Mary (11:08 AM at 18 inches; 4 pounds, 9 ounces); then John (11:09 AM at 17 inches; 3 pounds, 9 ounces); and finally Luke (11:09 AM at 16 & 7/8 inches; 3 pounds, 12 ounces).

A great deal of my time during data collection for this project was spent tending to the triplets during their first year of life. My last field notes in the Camillo home described the unique experience of lying on the living room floor and being crawled on by these three simultaneously. By the time I returned for the final interview (February 1998), the babies were 17 months old--a gang of three who toddled around their home with the nipples of their bottles clenched between their teeth, and their arms outstretched to be held.

"Camilloville"

My fieldnotes describe the Camillo home as a "hub of activity," filled with "extremely organized chaos." While it was an active environment, their home was also a warm, comfortable place to set up this research project. Their home seemed to contain just enough square footage to house the eight who reside there, in addition to any researcher or extended family member who set up residence in the basement (see Figures 4.1 and 5.2 of this dissertation for drawings of the living room and dining room floor plans in the Camillo home).

A Description of the Camillo Home

Regardless of the approach made to enter the cul-de-sac where the Camillo family lives, a yellow sign marks the neighborhood on both sides of the street as a DEAF CHILD AREA. Sara, my key informant, mother, and wife was responsible for requesting the placement of these signs from the state. She re-requested them three times since the family was transferred; someone kept taking down or stealing the signs. When giving visitors directions to the house, Mark and Sara used the Deaf Child sign as a landmark to indicate, *you're on the right street* (FN:31:1:4).

Outside their 3-story town home, the family's nine-seat, *Suburban all-terrain vehicle and the red truck* were parked in their town house's assigned parking places. From time to time, the front lawn looked slightly overgrown, as they waited for the new grass seed to take root. Over the course of the time that I lived with the Camillos, plastic Easter eggs, jack-o-lanterns, and holiday lights were used to decorate the tree in the front yard. Often when I came back to the home on Sunday nights, I mused at the hieroglyphic chalk messages left by the young "natives" that resided within. Near the front curb there was also a slightly bent "No Parking" sign. When Mark and his three older children were outside riding bikes, he often pointed to the top of the sign and said/signed, *Remember? Remember when the snow was ALL the way up at the top? Remember we rode our sleds ALL the way down to the bottom*? (FN:59:1:24).

The front door of the family's home represented the challenge that they experience on a daily basis. As one walked up the stairs to ring the bell, an embroidered sign was hung on the door that read, QUIET! The sign was hung to indicate to visitors that there may be sleeping babies inside. At the same time, there was a sticker on the screen door depicting the symbol of an ear with a line through it; an indicator for fire fighters that an individual who was deaf lived inside.

Depending on the season, multiple sets of boots, sneakers, galoshes, or sandals could be found in the entrance way by the potted plant. This planter also often contained Henry's favorite red truck--its wheels caked with mud from outside. The scents of banana bread and diaper ointment, when I walked through the front door into the living room, were regular reminders to me that this was a dwelling for six young children. Every week, Sara and I diligently dusted an array of family portraits and individual snapshots that were hung on the walls and propped on the end tables and stereo speakers. The gift basket of wine and cheese that adorned the middle of the formal dining room table was often a catchall for stray Legos, crayons, hair bows, and baby socks.

As you walked in the front door, the small kitchen was straight ahead. The living room was the area in the home where one is most likely to find the family gathered, was to the immediate right. Three bedrooms were upstairs, and the fourth bedroom where I stayed was in the finished basement.

Superficially, the Camillo's townhouse was like any other house in their neighborhood. However, their home possessed several structural idiosyncrasies, unique to a home that sheltered six young children, deaf and hearing. First, many of the doorknobs had been reversed so that the locks were located outside the door, rather than inside. All the bathroom doors and the door that led to the basement were examples of these alterations. Mark and Sara decided to reverse the doorknobs after Henry locked himself in the bathroom several times, and Madeline locked herself in the basement.

The Camillo home also possessed several artifacts that are specific to the needs of individuals who are deaf: a TTY for telephone conversations, a visual smoke alarm, a visual telephone alert system in Mark and Sara's bedroom, and a television decoder.

Sara either purchased or borrowed those items and used some of them regularly in her interactions with Henry and deaf people outside their home.

Discussion

This chapter has provided an introductory description of "Camilloville" and members of the immediate Camillo family in order to familiarize the reader with their home environment as well as the individuals who live there. These accounts of the Camillos' lived experiences, within their distinct home environment, are not uncommon when compared to other families who have mixed deaf and hearing membership. Specifically, the scenes and activities that played out among the members of the Camillo family were surprisingly similar to Lynn Finton's (1996) description of living in a bilingual-bicultural family.

Finton (1996) makes the same observations and describes her family using the same words that were frequently used by Sara Camillo. Sara Camillo's mantra, "We treat everyone the same" (INT: 1:65:7) is comparable to how Finton and her children "identify Deaf people as 'normal' people who do 'normal' things" (p. 271). Both the Camillo children and Finton's children share the same common perception of Deaf people: "Deaf people can't hear but the essence of being Deaf isn't the lack of hearing" (p. 271). In other words, this isn't a story about Henry Camillo's lack of hearing ability and how his hearing family members coped to habilitate him. Instead, the next two chapters provide greater evidence and discussion of various deaf and hearing worldviews possessed by members of the same family. The worldviews documented here also demonstrate that Henry Camillo and his family members were growing and developing as members of a bilingual-bicultural household.

CHAPTER V

ANALYSIS

George Spindler (G. Spindler, personal communication, March 6, 1998) suggests that the most valuable presentation of analysis speak to the reader about the main views and interests of the informants. This dissertation takes the theoretical position that Henry Camillo and each of the members of his large family constellation view the world as individuals, but make meaning of their experiences in collective ways during their social interactions (Blumer, 1969; Mead, 1934). The Camillo family interactions contribute to the creation of various worldviews among young siblings (ages birth to 6), adults who participate in the roles of parent, wife, and husband, and extended family (i.e., cousins, aunts, uncles, and grandparents), who have both naïve and experienced perceptions of individuals who are deaf.

Consequently, the systematic description of how Henry and his family members, immediate and extended, make sense of deafness results in a complex story filled with multiplicity and contradiction of thought and action. When I use the term make sense I am describing the way that human beings interpret life events by attaching meaning to them, as they would objects and persons who are part of their day-to-day lives (Blumer, 1969; Mead, 1934). The term deaf and the expression deaf experience hold different meanings for different people in society, as well as Henry Camillo and his family members. Groups of people view deafness as a medical condition, while others see deafness as symbolizing a particular group of people who share the same language (American Sign Language) and ethnicity (Erting, 1982/1994; Jacobs, 1974; Johnson & Erting, 1989).

One might conceptualize these divergent understandings of deafness as two separate roads, one deemed medical and the other cultural. Individuals traveling either road would expect to meet different types of people sharing similar information about the medical or cultural perspective during their interactions. Their constructions of deafness would be distinct and clear-cut because the travelers on either road could not be in two places at once, and would have little or no opportunity to interact with others traveling a different road. While these two worldviews of deafness may seem as distinct in theory as two roads that branch off, the lived experience of hearing families with deaf children confines them to a real-life road that mixes and confuses the medical and cultural perspectives. This third road can be viewed as the deaf education perspective, and it can be a risky place to travel.

In part, what makes the deaf education road uncertain for families members are the differing understandings of deafness that are presented and developed during their interactions there. Legislation assures parents that they have the right to choose what education and communication options are best for their child. In turn, the understanding of deafness that deaf educators, audiologists, and medical experts present to parents often influences their understanding of deafness and the ensuing choices they make. However, one important lesson that can be learned from Henry Camillo and his family members is that they do not learn an accurate representation of deafness on the deaf education road because the system does not allow them to interact regularly with all the necessary players and information. In order for them to be peripherally influenced by interactions with individuals outside the family, they must live their day-to-day lives in environments that provide passive opportunities to mirror the behaviors and actions of others. In contrast, this research found the predominant influence of sense-making for hearing members of the family seem to occur primarily among their own family members as they interact with each other as social beings.

As described earlier in this dissertation, Erting (1982/1994) developed various models of individual social actors that demonstrate how biological and social environments, as well as personal and interactional influences, structure the development of each person's unique worldview. Erting recognizes and this research adds evidence to the position that, it is possible for individuals to live in the same physical environment or space but perceive and understand the world in totally different ways (Blumer, 1969). Identity is developed and demonstrated by each person's biological and experiential contributions to interaction. For example, one person may make sense of deafness in a different way than another because of their relational position in the family to Henry (i.e., younger sibling versus older cousin), biological characteristics (i.e., intelligence or hearing status), and the quality and quantity of interactions they had with Henry and/or other deaf individuals throughout their life span.

Among the four conceptual models I used to describe the Camillo family member's views of deafness, I borrowed two models from Erting (1982, pp. 16, 21): Figure 5.1: Model of the Hearing Parent; and Figure 5.6: Model of the Deaf Child of Hearing Parents, and developed two new models to represent other members of

Henry's family: Figure 5.3: Model of the Hearing Sibling of Deaf Child, and Figure 5.4: Model of the Hearing Extended Family Members of Deaf Child. Each model allows for the consideration of three aspects that influence how individuals construct their worldviews of deafness: Opportunity structure, personal characteristics, and interactional spheres. Figure 5.1 provides a schematic representation depicting all three aspects of the model of the hearing parent. The information in the first section (The Parents' View) corresponds to Figure 5.1 and describes Mark and Sara Camillo's worldviews related to deafness, and how their views inform their actions.

The component that grounds all aspects of the model is called the individual's opportunity structure. Erting borrowed the term opportunity structure from Barth (1981) to refer to characteristics of the larger macrostructure of society, and represents the opportunities available to the social actor within that society. Using Figure 5.1: Model of the Hearing Parent as an example, the Camillo family's socio-economic status, Mark's career as an officer in the armed forces and their religious affiliations and practices are examples of specific components that build the framework of their individual "hearing parent" models. The second component of the hearing parent model looks at the personal characteristics of the individual. This center portion schematically represents information regarding the person's biological characteristics (e.g., hearing person, avid runner), the parent's personal history with deafness (e.g., knowledge of medical or cultural aspects of deafness, sign language fluency), and the values, decisions, and choices they have made as they relate to Henry and deafness. Finally, the model schematically represents the interactional spheres that are available to hearing parents, represented by the arrows and small squares.

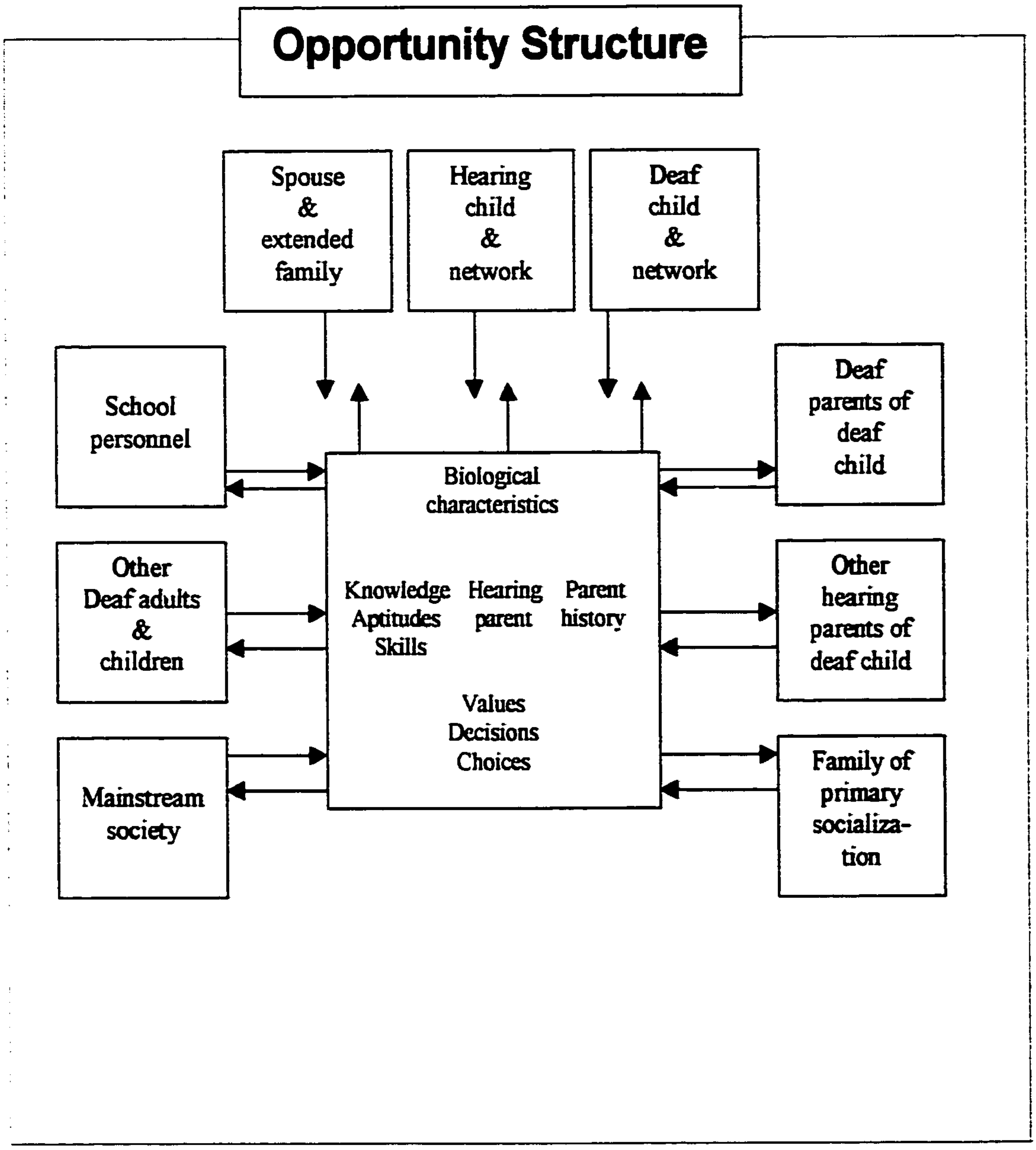
The analysis presented in this chapter reveals four views of deafness that emerged, in part, from the interactions among various family members, immediate and extended: (1) The Parents' View, (2) The View of the Hearing Children, (3) The View of Extended Family Members, and (4) Henry's View. I used Erting's Models as a framework for understanding how Henry and his family made sense of deafness. The themes that are described within each view reveal that individuals portray their understandings of deafness in unique ways. This individuality is developed and demonstrated by each person's biological and experiential contributions.

Section 1: The Parents' View

Henry Camillo's family is large by modern standards. His parents Mark and Sara made sense of deafness in ways that intertwine the information they gather about the deaf experience and their responsibilities and perceptions associated with the task of parenting their six children. Therefore, the issues and understandings that were most important to Mark and Sara related to making sure <u>all</u> of their children's needs were met on a day-to-day and often moment-to-moment basis. Mark and Sara were particular to point out that they love all of their children equally, considered them blessings from God, and made special efforts to "treat everyone the same." The Camillo home was filled with conversation about the incredible beauty of their children, and the high expectations Mark and Sara set for them and expected them to achieve.

Keeping in mind the components of the various models for individual social actors, my fieldnotes, and interactions with the Camillo family also shaped the content of questions I asked Mark and Sara during our individual and collective interviews. I

Figure 5.1. Model of the hearing parent.



Note. From "Deafness, Communication, Social Identity: Ethnography in a Preschool for Deaf Children," by C. J. Erting, 1994, p. 16. Copyright 1994 by Linstok Press. Reprinted with permission of the author.

asked questions like, what is important for me to know about your family? What major changes (positive or negative) has your family experienced since it was first established, and tell me some of the challenges you've encountered related to deafness (see interview protocols assembled in Appendices C and D)? Mark and Sara's responses and stories defined the themes that were important to them concerning adult, parent interactions with their son Henry. Consequently, this section is organized by the themes that they defined: (1) Creating a fair communication environment for all the children, (2) Parenting a deaf child, (3) The issue of structural dependency, (4) Home-school interactions, and (5) Why doesn't Henry make sense of sound?

Theme 1: Creating a Fair Communication Environment for All the Children

Starting with the pilot interview with Sara, the theme of "treating everyone the same" and "fairness" was a consistent understanding among family members that helped them make sense of the deaf experience. Sara explained that the family's concept of fairness was grounded in her understanding of the different communication needs of her deaf and hearing children:

> Everybody's treated fair, and fairness is a hard thing. I try to explain that to Daniel [and he responds] "That's not fair!" I said, "But son, what's fair for you and what's fair for Henry are two different things. I will be fair to you because you're the older brother and it's fair for you to stay up 30 minutes longer. But, it's fair for Henry if I read to him 30 minutes longer because it takes longer for me to read and sign and for him to understand what's happening--and that's fair. It doesn't mean I love you less if I spend 30 minutes less with you. (INT:1:42:38)

Sara experienced feelings of conflict about the communication compromises she made with her children. She admitted that making the compromises was not always a clear-cut, easy task:

> It's a hard call because I recognize that every time we talk to Henry, we have

> to use direct eye-to-eye communication. But when I talk to the rest of my children, I can holler at them saying, "Could you go do this for me?" It takes a toll on them. Then they either ask, "Why didn't you ask me?" or "Why didn't I have that one-on-one attention? So sometimes they feel, that Henry gets more attention. (INT:1:43:8)

Sara and Mark used simultaneous communication (the simultaneous use of spoken English supported with signs) in their home in an effort to compromise or blend interaction among their deaf and hearing children. They also monitored the modality and quality of communication used by visitors. For example, when I initially moved into the Camillo's home, Sara sometimes reminded me to add my voice when I was signing to Henry in the presence of the hearing children or hearing visitors who did not sign. She also regularly interpreted for Daniel when he did not sign.

As the year progressed, we had numerous conversations about signing and speaking at the same time. These discussions seemed to shape our understanding of how Henry might have perceived, and often misunderstood, information that was signed and spoken at the same time. Many of our discussions occurred at family dinner hour, a regular part of the Camillo family experience. Mark and Sara took special care during dinner hour to ensure that the communication interactions among family members were "fair."

The Family Dinner Interactive Context

I paid close attention to family interactions at meals because of my advisor's previous research (Bodner-Johnson, 1985; 1988; 1991). Bodner-Johnson's work is particularly focused on interactions among family members who are deaf and hearing. She considered the conversations occurring at the family dinner table as a focal point for several of her studies (1988, 1991). Bodner-Johnson's research helped me to focus on the types of interactions I looked for initially and documented at the dinner table. Her work began with the premise that effective family interactions in general were positively correlated with increased achievement in academics (i.e., reading and mathematics) (Bodner-Johnson, 1985). Her eventual focus on conversations at the dinner table yielded an understanding of how a small sample of deaf children responded to questions and statements or expressions of ideas when conversing with their hearing family members.

In some ways, Henry's dinner experiences resembled the deaf children investigated by Bodner-Johnson (1991), while in other circumstances Henry's interactions among his family members generated new experiences and understandings. Dinner hour was the time in each day when Henry had the advantage of almost complete access to family conversation. When one considers the different settings available in a typical American home, "around the dinner table" is a logical place to choose as an effective site for accessible visual communication.

Two other locations were analogous to the dining room table as prime communication areas in the Camillo home: the living room floor and Mark and Sara's bed. The frequent interactions and type of human "traffic patterns" in each of these three areas is what set them apart in terms of visual communication accessibility. In other words, the living room floor and Mark and Sara's bed were highly trafficked areas, where the dining room area was distinct because it was designed for family members to come and stay for a set period of time. Considering the intent of each area, the dining room was used as a space where everyone was invited and encouraged to stay. In contrast, the living room floor and Mark and Sara's bed were used as family meeting areas, but the interactions occurring there were typically unplanned and random. Therefore, as Bodner-Johnson (1988) recommends, it is important for family members to possess an overt intent to provide "equal" communication opportunities for all family members. Mark and Sara focused on creating a pleasant environment in the dining room and used different strategies for communication (i.e., sign only, voice only, simultaneous voice and sign, and interpreting strategies), that were responsive to the communication needs of all their children. The family members made a regular, conscious, and overt effort at the dinner table to include everyone in conversation. Furthermore, the types of interactions that occurred at the dining room table were unique in that the focused environment created more opportunities to concentrate on a variety of communication needs.

By the Spring season of 1997, I acquired a year's worth of experience at the Camillo dinner table, as both a visiting and live-in researcher. My long-term engagement in this routine family activity helped me to extend Bodner-Johnson's work as well as further my understanding of the patterns and meanings of this family's specific interactions. Categorical data analysis (Ely et al, 1991) revealed that the dinner hour served four major socio-cultural purposes for the Camillos': (1) sharing the events of the days and discussing upcoming family events; (2) sharing social opportunities with invited guests (individuals outside the immediate family); (3) learning and discussing sign language; and (4) discussing certain understandings related to Henry and deafness.

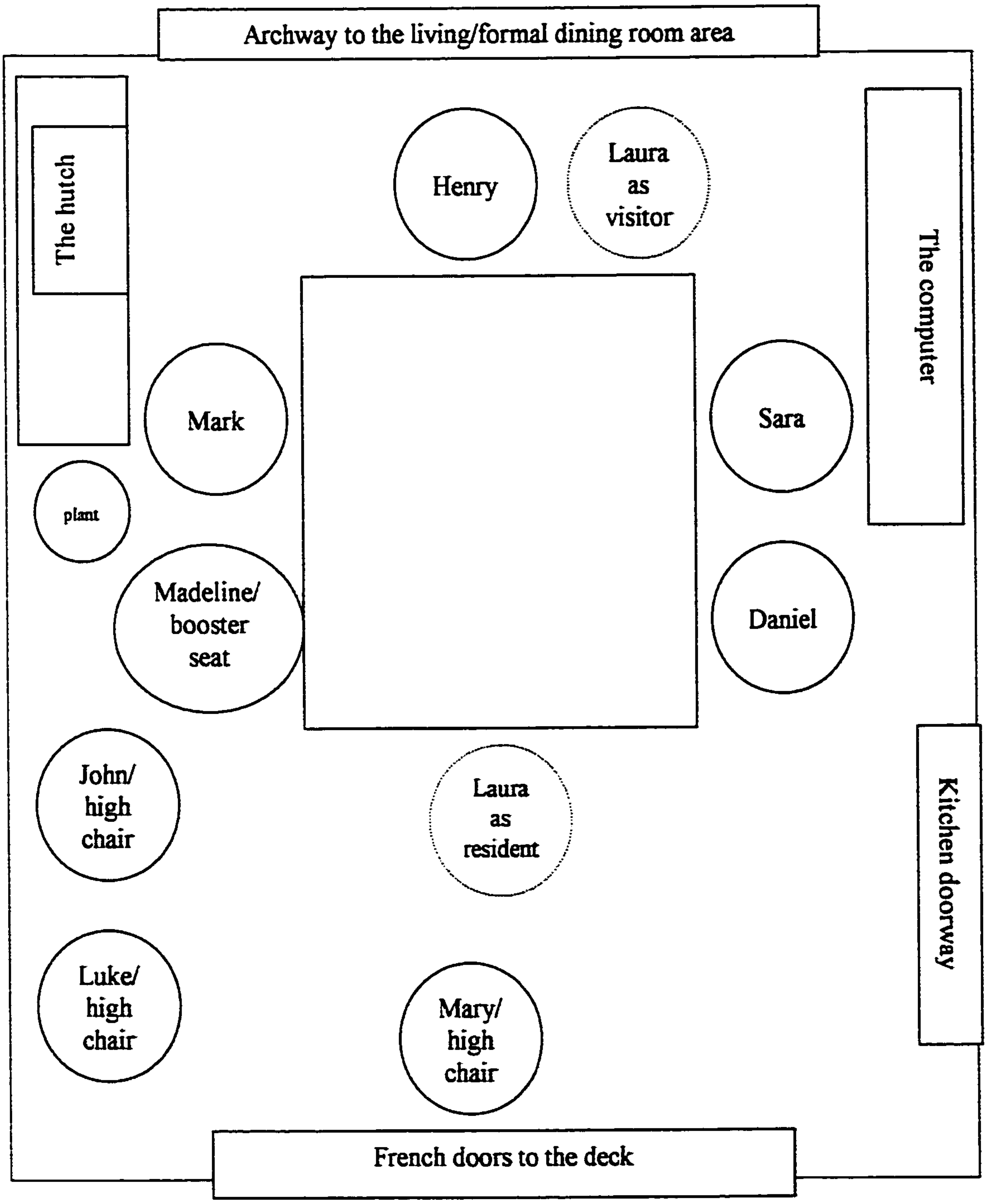
How was your day? Meal preparation and getting everyone to the table was conducted in an organized flurry of activity. Typically, I started to feed the babies before we sat down at the table. Feeding the triplets early always worked well because it meant I could eat dinner with the rest of the family and the babies were somewhat quiet but still able to join the group. Henry was responsible for gathering silverware from the kitchen drawer and dishwasher and it was Daniel's chore to set the table. As Mark walked in the door and changed out of his uniform, Sara moved hot food from the oven to the table. When the children were expected to gather at the table, someone turned on the overhead dining room light. After a chorus of prayer, simultaneously spoken and signed (*THANK-YOU JESUS FOR [the] FOOD*), the children ate while Sara served Mark. Finally, Sara and I took our portions from the normally generous amount of food in the middle of the table.

My fieldnotes documented (42) "sit-down" meals occurring in the Camillo dining room area from May 1996 to July 1997. Data were collected at sit-down meals with a particularly high concentration in the Spring (13/42; 31%) and Summer (15/42, 36%), compared to meals documented in the Fall (6/42; 14%) and Winter (8/42; 19%) seasons. As stated previously, mealtime also served the social purposes of gathering and sharing information within the immediate family. Using spoken and signed languages simultaneously, Mark and Sara took the lead in conducting more formal, predictable dinner conversations with each other, Henry, and Daniel. They asked standard, predictable questions, *How was work?* and *What did you do at school today?* Henry and Daniel responded with similar responses (i.e., *school was fine, Johnny was absent*) but used different languages (e.g., Henry used ASL and Daniel used spoken English). Henry liked to elaborate on the behavior of other children at school, *JAMES TIME-OUT FOR HITTING*, and *SHERRI ABSENT*. Daniel told first grader jokes and talked about homework and class projects. Sara's position at the table was between Daniel and Henry (see Figure 5.2). Henry did not use his voice when he signed and Daniel rarely signed at the dinner table. Consequently, Sara mediated communication between the two children by sign or voice interpreting for both the boys. Sometimes rather than interpret she encouraged Daniel to sign and Henry to pay attention to the visual communication at the table.

While communication at the dinner table began purposefully with adult-directed questions, interactions became multilayered and complex by dinner's end. In other words, pathways of interaction (Blumer, 1969) and topics of conversation were multiple and information was exchanged simultaneously among dyads and triads of individuals using gestures, ASL, spoken English, and combinations of signs and speech. For example, my observations yielded multiple and overlapping interactive scenarios: (1) Madeline using ASL with Luke, waving and encouraging him to eat; (2) Mark and Daniel using spoken English; (3) Sara and Henry using a combination of signs and spoken English; (4) John babbling "ba-ba-ba" to get his mother's attention; and (5) Mary watching Henry intently, mirroring his signs.

Dinner guests. Dinner guests beyond extended family were frequently individuals who were deaf. During the 10 months that I lived with the Camillo family, their invited dinner guests outside the immediate and extended family were always deaf or in some way connected to the Deaf community or Parkwood. My fieldnotes document a total of 29 dinners (from October 1996 to June 1997) attended by at least one deaf person--I sat at the table for 14 of the meals. The family's reading mentor Justin came every Monday night for dinner, followed by practice reading sessions with

Figure 5.2. Diagram of the Camillos' dining room floor plan



the family. Dinner hour was important to Mark and Sara Camillo--it was a time when all family members are expected to attend and interact. Interactions with Deaf guests frequently sparked conversations revolving around deaf-related topics. In addition, I noted a relationship between the number of Deaf dinner guests and the texture of the communication environment. In other words, the more Deaf guests who attended, particularly Deaf adults, the greater the likelihood that ASL would be the language of choice around the table, rather than spoken English. The selected stories that follow occurred when at least one deaf visitor was present at the table.

TRAIN HEAR ENVISION BLUE. At one point during dinner in mid-March, Madeline heard a train in the distance and told us all (signing and speaking simultaneously), *Choo choo train! TRAIN HEAR (points to her ear) TRAIN!* Sara and Mark responded to Madeline, *Oh really? Good girl! Wow! You heard a train!* Henry observed their interaction and signed, *HENRY HEAR (Pro-1 point to ear) TRAIN SAME!* which we translated to mean, *I heard the train too!* Sara turned to Henry and asked, *Tell Mommy what the train sounds like?* Henry paused and scratched his chin thoughtfully and then proceeded to describe the train's sound, *TRAIN HEAR (PRO-1, pointing at his ear) ENVISION BLUE* (FN:105:4:4).

I was surprised and felt disoriented by Henry's remark and voiced the my translation of the meaning of his signs in English in an effort to make sense of them, *The train sounds blue?* Sara looked at me with a confused expression and said, *That's not what he said! That's crazy! I've never heard of such a thing!* She turned to Henry and asked, *Henry, what sound does the train make? Make a train sound.* Henry didn't respond to Sara's question. He was already discussing a different topic with Mark about vehicles – trucks, cars, and trains. In an attempt to mediate the tension, Mark redirected their conversation with Henry using a reminder, *If Henry hears a train again, he should tell Mommy and Daddy as soon as he hears it, okay?* Sara added, *Yes, sometimes Mommy is busy and doesn't notice, so if Henry hears the train, please come and tell Mommy!* Henry nodded, *YES-YES* to both and dinner conversation continued on a more typical path (FN:105:4:12).

The "blue-sounding train" dinner conversation seemed to mark a turning point in my understanding of Henry's different worldview, particularly how he understands, or doesn't have access to the world of sound. In that instant, I understood his perspective with clarity. Trains make noises and sounds that are different than how they are expressed in spoken English or American Sign Language. Children's literature depicts trains as "saying," squeak-squeak, toot-toot, chug-chug, or choo-choo. In contrast, ASL users represent a train by showing the steam puffing out of the smokestack. I realized that it was logical for Henry to describe the train "sounding blue" because he had never <u>heard</u> a train. He may have seen trains or felt the vibrations of a train while it passed by, but he is not audiologically capable of <u>hearing</u> the true sound of a train or train whistle. Nor has Henry been exposed to the hearing representation of trains that his sister Madeline learned passively in her interactions (e.g., "choo-choo") with people and written English literature. I pondered that it only makes sense that he would describe "hearing" a train using his experience base – which is visually oriented. At the same time, I could understand Sara and Mark's reaction – Henry's remark was almost inconceivable to me as a hearing person.

The "blue train" dinner conversation was an important conversation for the family, because it occurred during a period when Sara and Mark were puzzling about Henry's ability or nonability to recognize environmental sounds. Parkwood's speech teacher had recently sent home a videotape of Henry responding to environmental sounds in isolated speech sessions, and their private audiologist was insisting that Henry should be capable of recognizing environmental sounds that include human voices in the lower ranges. The information provided by the speech and audition individuals conflicted with Henry's behavior at home--we didn't see any evidence of Henry recognizing or responding to train sounds or other environmental sounds at home. Sara and Mark frequently asked the questions, *Is Henry truly hearing environmental sounds at school?* and *If so, how do we carry those "skills" over so that he demonstrates recognition at home*? (FN:105:4:15).

How do you sign? A week later the Camillos' reading mentor, Justin, and a deaf friend of Henry's who I call Peter, were visiting for dinner. During Justin's visits, the use and meaning of particular signs was often the topic of conversation. One evening, a conversation emerged at the table related to sign choice and the development and use of "home signs."

That evening we had hamburgers and french fries for dinner with a variety of condiments set up buffet style in the center of the table. As the adults prepared sandwiches for the children, Peter corrected a sign that Mark used when he asked Justin to pass the ketchup (*KETCHUP PLEASE*) (FN:111:1:10). The Camillos use a "home sign" for KETCHUP that is articulated with the left hand held in a fist or S handshape, and the right, open palm strikes against the inside of the fist (as though you are beating the ketchup out of a bottle). As soon as Mark asked Justin to pass the ketchup, Peter's eyes popped open in surprise. Peter chastised Mark, telling him not to use that sign for KETCHUP because it was considered "bad" language. Mark and Sara questioned Peter about the sign's meaning, but Peter didn't want to share the meaning of the sign with the family. Justin turned his body and had a side conversation with Peter at the table. If we had wanted to, we could have watched the exchange between Justin and Peter, but Justin's body shift was an indication that we understood meant he wanted to discuss the sign with Peter privately. In a few moments, Justin turned back to the table and expressed his confusion because he had never seen the sign Mark used in a negative context. Justin encouraged Peter, *Tell us, what does that sign mean*? (FN:111:1:17). After some encouragement, Peter admitted that the students at Parkwood use the family's sign for KETCHUP to mean SEX. Justin rolled his eyes and suggested that the students had probably made the sign up to use among themselves at the residential school. He suggested that Peter wasn't aware that sometimes "home signs" used in an environment with one meaning might have alternative meanings in another environment.

We all spent a few minutes discussing the Camillo's sign for KETCHUP. Mark asked Justin, *Well, what should we use?* Sara commented, *Don't tell me I have to fingerspell it!* Justin suggested using a sign that looks like a classifier with a C handshape--shaking the ketchup out of the bottle. I suggested that I had seen KETCHUP signed by shaking a K up and down in the air. Sara and Justin both said, *That's a Signed English sign*, meaning my suggestion was unacceptable. The discussion came to a close when Sara stated that they would continue to use their family's sign for KETCHUP but would avoid using it around Peter.

The dining room table was a central meeting place for members of the Camillo family and invited guests to share cultural information using the vehicle of two languages. Mark and Sara felt successful in navigating cultural and linguistic differences at the dining room table because there was a "level communication field" among all family members. At the table, strategies or "rules" for managing differences in communication were either in place (i.e., first we pray, then we eat, and conversation is expected because this is a special time set aside for family interaction), or were explicitly discussed and defined (i.e., deciding what signs to use at home, "the train sounds blue"). The next section describes some of Mark and Sara's experiences that created frustration because the situations challenged their ability to create a "fair" communication environment in their home. Their frustrations resulted from communication circumstances that did not appear to have a solution at the time.

Theme 2: Parenting a Deaf Child

When Mark and Sara asked other parents questions about how to be better parents to Henry, they were not seeking information about how to parent Henry, but rather they were asking for strategies to communicate more effectively. Mark and Sara actually had a strong understanding of their role as parents for all their children, which Mark shared with me during his interview:

> We actually want to be active parents, not reactive-type parents. We want to make sure that every child has the opportunity to develop the same morals, the same ethics, and the same values that I grew up with and I think Sara grew up with too. The way I see our role as a parent, we're responsible for our own kid. Nobody else is going to do it. Nobody else is going to take care of him like we are. (INT:18:37:9)

However, as Henry's ability to express himself developed, Sara and Mark recurrently voiced concern about setting up more effective communication practices in their home. The next section details Sara's concerns related to being Henry's parent, and grappling with feelings and fears of not being able to keep up with his maturing ability to communicate in American Sign Language.

The Camillo Dilemma

The first evidence of Sara's puzzling about special skills for parenting a deaf child occurred within the context of the story I call "The Camillo Dilemma." At the beginning of data collection for the pilot study, during the summer of 1996, I was also teaching class at the university about families with deaf children. My class consisted of an equal mix of deaf and hearing women, some single, and others were married with children. Two of the class participants were hearing mothers with deaf children. Some of our class discussions were pertinent to Sara's experience and I frequently shared class anecdotes with Sara during my field visits.

Parenting issues naturally came up in class and one day a discussion developed between the classmates who were deaf mothers with deaf children and hearing mothers with deaf children. The hearing mothers asked, *How do you keep an eye on your kids and have a conversation at the same time? and How do you teach them all they need to know if you can't hear everything in your environment?* The deaf mothers responded, *You just do it--there isn't any special trick involved--you just watch your kids and talk at the same time! You just live with them and teach them*! (FN:15:5:34).

The following morning during a field visit with Sara, I shared the class discussion with her. Sara became excited to hear there were other mothers who had similar questions and expanded on the problem she and Mark had recently been experiencing. *We've been having some of the same problems! Henry gets angry with us because something will happen to Madeline—crash! And we look away when we're talking to him! Then when we turn back to Henry he says, "Just forget it Mom! You are rude!"* (FN:15:5:8).

I explained to Sara that members of the class were having the same experience and asked her to videotape her dilemma for me to share with the class. I told her I would give the class an impromptu assignment and ask them to write out some possible solutions to her problem that we could share during my next field visit.

Sara began the video clip by telling the class about her family's composition. Henry was 3 years old at this time, Madeline was 18 months old, and Daniel had just turned 6. Sara continued to explain her experience by describing their educational placement choices for Henry (An Oral program for the first year and then Total Communication). She ended her description of Henry by detailing his syndrome (Ocular Auricular Vertebral Syndrome--OAV), and how it presents itself, "Henry has an absent right ear, was born with an extra digit on his right hand, and he is profoundly deaf (VC:15:1:14). Sara proceeded to explain the recent problem she and Mark were experiencing:

> Henry is brilliant, and this is my question. He has a lot of language now, to the point where he signs so much that my husband and I are missing some of it. Because we have other children, I cannot always pay attention to his lengthy conversations. So, when I turn my head to watch my 18-month-old or to correct something else that's happening in the house, Henry gets very frustrated with me and tells me not to interrupt him--to pay attention! Then when I tell him I'm sorry, that [I had to look away because] your sister was falling. He doesn't understand. He wants me just to look at him the whole time. I can understand that [I need to look at him] because I don't want to be rude, but I don't know how to explain it to him. (VC:15:2:21)

During the recording of this video clip, Sara was interrupted by a telephone call. When she returned to the taping and her story, Sara decided to describe what communication was like at home before she was expecting three additional children:

> When Henry was first signing, we would pay very close attention to him, so that we could feed him more language and he could communicate back with us. I'm wondering what I'm going to do when the babies are born [and] I won't be able to sit there and hold these all day, lengthy conversations with my son. I don't want to be rude and I don't want to hurt his feelings but if I tell him "Wait a minute" or "Excuse me," he gets upset with me. He tells me, "Quit interrupting." Then if I lose part of the conversation and I ask him to, "Please tell me again," he tells me, "Just forget it." (VC:15:3:13)

Sara expressed guilt and concern about the heavy responsibility of "feeding" Henry "language." Sara continued to explain that she and Mark were frustrated and somewnat intimidated by Henry's blossoming communicative abilities. Expressively, Henry was beginning to convey and use more complex forms of communication. Rather than stringing several signs together, he was using fully grammatical ASL utterances. Also, Henry's expectations of communication situations at home were becoming more sophisticated at a time when his parents were distracted with new children and additional responsibilities.

> My husband is feeling the same feelings that I'm feeling because Henry has so much language now. He's not just signing five- or six-word sentences. He's signing paragraphs and stories to us. This little boy loves conversation. We have a lot of conversation! (VC:15:5:3)

Sara continued to describe her perception of communication in the home. She also described the difficulties of <u>parenting</u>, which she defined as "paying each child a 'fair' amount of attention." Sara was referring to the challenges of trying to address the diverse communication needs of both deaf and hearing children in the same home.

> We sign--our whole family signs. My 6-year-old signs and my little 18-month-old signs, and these babies will sign. It's just I need to help him understand that now with the new babies coming and with his little sister, I can't always just watch everything that he says.
>
> I can understand what my hearing son was feeling when Henry was first growing up and learning to sign. [My oldest son] would get upset because we would always look directly at Henry, and sign, and pay attention to him. And my hearing son would feel left out because we could go and talk to him when we were in the kitchen and he would be in the living room, or he'd be upstairs and we could be downstairs and we could still talk. We changed our living so that whenever we talked to our 6-year-old, our hearing child, we would go directly to him and say, you know, "Mommy would like you to do this," so that he could feel that same attention that we gave Henry. Henry has always had this attention when he's talking to us, undivided attention. Now that there's more children in the house, I cannot provide that undivided attention all the time. Henry doesn't understand that. He becomes frustrated--he quits--he tells me "forget it." (VC:15:3:17)

Sara was perceiving the communication tensions between Daniel and Henry as unbalanced and "unfair." She interpreted the time that family members spent looking at Henry to communicate as additional attention, rather than as a visual communication strategy that was necessary for Henry to gain access to what is happening in the home. If the truth be told, it is very likely that since his birth, Henry has received an inordinate amount of attention, compared to Daniel, because of the special services he was receiving beginning at his third week of life. Videotapes from Henry's first year of life showed Daniel making repeated bids for his mother's attention that were left unmet because she was focused on the directions of the early interventionist, learning to sign with Henry.

Sara concluded the description of her dilemma by asking for help from the deaf members of my class. At this point, she was trying to make sense of something that went beyond parenting skills and communication strategies--she was trying to resolve a cultural tension within herself. She identified the central tension she was experiencing when she asked the next series of questions.

> So, that's where I need your help. How do you handle that? How does a hearing person handle everything else that's going on when the deaf people can't hear that somebody, something just crashed and burned? Or that the phone just rang? How do I help my deaf son understand? Or, what do I need to do to change, or help my husband to change?
>
> Henry tells me, "I'm not telling you. I'm angry at you. You don't pay attention. You interrupt Henry! That's not acceptable behavior." And it's like my heart is broken! He won't tell me! He won't even tell me later! He just tells me, "Forget it." And I feel like, "No. I want to know what you're thinking. I want to know what's on your mind!" And, I can't get that time back. But, I can't let my daughter walk around with a glass cup! So, help me, please. I'm open to anything! (VC:15:6:3)

The term <u>cultural tension</u> can be defined as something that exists during interactive episodes when one or more of the participants responds in a manner that indicates they have encountered a cultural boundary. When interactive participants encounter cultural tension, they demonstrate the tension in behavioral and linguistic ways. People expressing cultural tensions tend to appear uneasy, uncomfortable, confused, angry, or disoriented about the actions or words of another.

Portions of Sara's "dilemma" revealed cultural tensions that she repeatedly voiced and attempted to understand during the course of time that I lived with her family. Based on Henry's reactions to Sara's requests for clarification, it is possible that Henry was also encountering cultural boundaries that produced tension. During the final interview with Mark and Sara 20 months later, we sat in the family's living room and watched the video of Sara in the hospital conveying The Camillo Dilemma to the class. Mark and Sara made the following comments as they watched the video clip.

Mark: It's still that way.

Sara: But the pressure's not there any more.

Mark: I really don't think it's that much of an issue. You just do it. I don't really think it's that much of an issue any more.
Sara: No, not at all.

Laura: Oh really? Well, what do you think happened?

Sara: It's definitely not the conversations that have changed.

Mark: The conversations are still the same. I think Henry just adapts and we adapt.

Sara: I think different needs changed. This one's [points to Madeline, who is semi-sleeping on Mark's lap] needs changed. The babies' needs changed.

Mark: Yeah.

Sara: I don't know. Even now, we [she and Henry] have long, long conversations. I kind of forgot about that actually. Because it kind of just solved itself. He [Henry] wasn't as frustrated either any more. He wasn't angry at us. At first, maybe it was me being in the hospital. I don't know; maybe it was just the time and the place. It all just corrected. Because I remember you giving me the feedback saying well, just make time for him. It's like, I'm not going to say, "Save all your conversations 'til the end of the day!" But, Camillo[11] and I discussed it and we didn't like any of those things. I don't know how we changed!

Mark: I think we just said, "Okay, we'll just take the time." I really think we just took the time, right then and there. Because [points to Madeline] we figured, it's not fair for Daniel to have that conversation right when he wants it. For her [Madeline] to have that conversation right when she wants it. He's [Henry] not gonna have the conversation right when he wants it. I just don't think it became that much of an issue. We just took the time and we dealt with it.

Sara: We listened to his [Henry's] frustrations too, because he would explain it to us too. (INT:19:43:20)

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[11] "Camillo" was Sara's pet name for Mark.

Mark, Sara, and Henry were experiencing what it might feel like to be a traveler attempting to assimilate into the cultural atmosphere of a foreign land. When one first arrives, interactions may seem strange and challenging if one does not speak the language. As time goes on, and the traveler has opportunities to encounter and interact with cultural boundaries, the tension reduces. The situation unfolds just as Mark and Sara explain it in the final interview--our situation hasn't changed, but the pressure isn't there any more (Rosaldo, 1989; Turner, 1994).

Staying with the "travel" analogy, the particular problem faced by the Camillos' was that no one in the education system told them about the cultural tensions to anticipate and identify while on their journey. As a result, they internalized the problem as, "something's not right here," "this isn't working," and "we must be doing something wrong." In the meantime, Henry's behavior was evidence that he was experiencing his own cultural tensions.

Henry Darts Away from Conversation

At the time Sara came home from the hospital with the babies, Henry began to repeatedly disengage from conversation, particularly when people were making efforts to engage him in conversation. For example, he tended to leave the dinner table right after someone asked him a question, or when it was expected of him to proceed with a conversation. At various points throughout the year, Sara and Mark puzzled over Henry's "dart-away" behavior. At first, we debated over whether or not he was bored with the conversation. I also suggested that perhaps he was frustrated and didn't have full access to the group's communication.

During the family vacations (June/July 1997), I saw evidence of Henry's frustration or avoidance of communication with family members on video clips, particularly when it seemed he did not want to do something or answer a particular question. Some examples of this occurred when Henry met his Uncle Ernest for the first time. The scene unfolded as Sara asked Henry to speak or use his voice for Uncle Ernest, and Henry looked down, passively refusing (VC:7:1:33). In another circumstance that same day, Sara asked Henry to fingerspell Uncle Ernest's name and again Henry looked down and passively refused to comply with her request (VC:7:1:34). I don't want to provide the impression that Henry was being "naughty" in this circumstance, but for one reason or another, he was choosing not to participate. This example also marks the type of uncertainty Mark and Sara experienced regularly as they questioned, *Is Henry behaving like a 4-year-old or is he behaving this way because he's deaf?* The communication barrier and cultural tensions that were present between Mark, Sara, and Henry added ambiguity to the parenting process--a situation that would not have occurred in their interactions with Daniel, Madeline, or the other hearing children. Cultural differences also made Henry appear to be more inquisitive than the other Camillo children.

WHY TALK TALK?

Henry's inquisitive behavior (which existed in part because he did not hear the interactions going on around him) set him apart from his brothers and sisters in a way that caused Mark and Sara to believe "parenting Henry" involved a different set of skills than parenting their other five children. For example, at several points in every day I lived in the Camillo home, Henry asked Sara and me what we were talking about. He asked, *WHY TALK TALK?* His question puzzled me because at some points when he asked us what we were talking about, we were signing and talking simultaneously. I wondered about the clarity of our communication. We discussed Henry's repeated question, *WHY TALK TALK?* later at dinner and decided that there were two times when Henry used this phrase, which resulted in two different meanings (FN:72:3:20).

Mark uses the example of when Daniel didn't sign, and Henry asks, *WHY TALK TALK?* to mean, *What is he saying?* In the situation where two people are voicing and signing to each another, we hypothesized that Henry could mean, *What are you talking about? I'm missing the gist of this conversation.* We questioned if the use of simultaneous communication was unclear for Henry. We debated, perhaps Henry asks for clarification because we are not using the most accessible form of communication for him.

Because I am a hearing adult, it was easy for me to understand and experience the same cultural tensions that Mark and Sara encountered. Cultural tensions and communication differences were particularly evident on the days when Daniel and Henry were home from school. I noticed how easily I could call Madeline to tell her that her toast was ready, and noted how much I depended on hearing her feet pad against the floor as she headed towards the dining room. The sound of her feet told me she was coming to eat her toast and that I wouldn't need to repeat my request. During my interactions with Henry, I was particularly aware of taking a different approach. Sometimes I was cognizant that my interactions with him felt like they took extra energy to seek him out in the house for face-to-face communication. I noticed myself waiting for him to look up so we could converse when he was eating. When I heard his footfalls coming towards me, I didn't know what he wanted or why he was approaching until he stood in front of me.

Theme 3: The Issue of Structural Dependency

The Camillo home was filled with high levels of energy, activity, and growth. It seemed that the busier we were, the more intense and serious the conversations were between Sara and me. One sunny, crisp day in March, in the midst of our morning routine, we began discussing the issue of structural dependency that deaf people inevitably experience throughout their lives when they must live in a world structured by and for hearing people (Erting, 1982/1994). What follows is a description of one conversation Sara and I shared about the issue of structural dependency that is part of each individual's opportunity structure. My data contain multiple instances of the notion of structural dependency in the family member's interactions and remarks as they were making sense of deafness. The issue of structural dependency was presented on such a multifaceted level that the family's understandings of deafness as they relate to dependency issues were embedded and deeply interwoven into the fabrics of day-to-day living.

My conversation with Sara about dependency issues began with a discussion that stemmed from our recent family experiences with parents and older relatives in need of care and medical attention. At the time (March 1997), my mother's health was unstable, and Sara's parents were experiencing health difficulties. Sara commented on the strength one can draw from sibling relationships when a parent's health begins to fail, and I was reminded of the reverse circumstances that led to my Deaf uncle's death. That morning the babies and Madeline were occupied with toys and books on the floor, and Sara sat down with me at the dining room table, as I unexpectedly began to tell her the private and disagreeable details of my Uncle's death. I explained that my Uncle's life did not truly end with his natural regression into a coma. I realized Bill's life was cut short because of the issue of dependency.

I began the story by telling Sara the same details of my uncle's death that I mentioned in Chapter II of this dissertation. I explained that in the end, my uncle experienced kidney failure that presented itself as a heart attack in the emergency room. Coincidentally, our immediate family was gathered that evening to celebrate my mother's birthday, so we all met him at the emergency room. After I shared the details of the illness that led to his death, I found myself telling the part of the story that still seems unspeakable: My Aunt Martha and the primary care physician euthanized Bill because he was deaf and had physical disabilities.

The issue of dependency for Bill became apparent to me during my father's illness. In the eyes of his family members, Bill had never been an independent person. Bill shared a particularly close relationship with his mother (my grandmother) Ella. Ella's relationship with Bill was different than what she shared with her other children. She and my grandfather (William J. Blackburn) saw Bill as a dependent, rather than an independent person because of his deafness and physical disabilities.[12]

After Ella's death, Bill's siblings (Martha, Robert, and my father John) initially rotated the role of Bill's caretaker. By the time I was born in 1962, my father assumed full power of attorney and Bill moved in with our family. Throughout my childhood,

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[12] Bill's birth was traumatic. A drunken doctor using forceps during the birth, delivered Bill with excessive force. The damage to Bill's brain resulted in a spastic form of Cerebral Palsy and deafness. Later in his childhood Bill contracted polio which further complicated his physical mobility.

Bill stayed with us for the majority of the year, using the summer months to visit Martha, Bob, and their families, as well as his Deaf friends from the residential school.

I believe that my mother, Ann, who has minimal signing skills, shared the closest emotional and familial relationship with Bill throughout his adult life. My mother and Bill's relationship resembled a mother-son dyad, rather than one of sister and brother-in-law. Ann made suggestions that led the family toward glimpses of seeing Bill as a capable, independent, and productive human being. As my immediate family expanded, the need for space and privacy became a more pressing issue in our home. My mother eventually suggested that the family find a near-by apartment where Bill could develop an independent lifestyle. She proposed that we provide Bill with a carpentry shop in our back yard and extend him an open invitation to dinner with the family. Consequently, Bill's siblings decided to use his social security income to secure an apartment where he could retreat from the bustle of our family and entertain friends in privacy.

My father John's role with Bill during my early childhood was different than my mother's. John was consumed with work responsibilities outside our home. He signed fluently with Bill using their "siblingese" to discuss events of the day over dinner, handling the paper work, and making the decisions. In contrast, my mother and Bill shared day-to-day interactions. Ironically, after my father died, Aunt Martha became Bill's legal guardian because she was considered his only "blood relative" (Bob died of Hodgkin's' Disease in 1971). Following the bloodline and family tradition, I was designated next in line as Bill's caretaker if Martha should die before

Bill. Because my mother was not a consanguineous family member, her input was rejected after my father's death.

When I told the story of Bill's death to Sara, I emphasized the "blood relative" component. She commented, *Yes, we have to remember that Henry is going to be deaf for <u>his</u> lifetime, not just while Mark and I are alive.* Sara added that they do not see Henry as a dependent person among their immediate family. I reminded her that there are people in society who will interact with Henry, always viewing deafness as a disability, and deaf people as dependent citizens. I told her that one of the driving philanthropic forces for my research and work in deaf education is to ensure that there are no more deaf people who live--or die--the way that my uncle did. We discussed the challenge that parents of deaf children face. Parents need to teach and instill independent values about deafness in <u>all</u> of their children (deaf and hearing) because sibling relationships hold the power of life-long interaction and influence, while parent-child relationships typically do not.

I told Sara that I believed my uncle died an untimely death because the doctor and my aunt viewed deaf people as disabled and therefore dependent. Sara mentioned that even teaching the other children in the family to advocate for him is not a good option if one considers that Henry could be the last person in the family alive. Sara reasoned that one would like to think that he will marry and have a wife and children of his own to look after his best interests (and vice-versa), but now, not everyone gets married or has children! Sara concluded that there are no guarantees except to teach Henry independence and how to cope in this world--and from there, *He has to run with that ball.*

I continued telling the story to Sara, starting at the afternoon they made the decision to end Bill's life. My mother, Martha, the doctor, and I stood in Bill's sunny hospital room and discussed his prognosis as his coma deepened. We knew his condition was critical because his kidney failure had been a persistent, long-term condition. For the past year, my mother had been trying to convince the doctors at the nursing home, and Martha, that Bill's physical health was deteriorating. She noticed that Bill had stopped drinking water and complained frequently of pain in his mid-section. Bill also shared his health concerns with us--he thought he was dying of cancer like my father John and his mother Ella. Eventually Bill developed an "adult acne" problem. We also noticed that Bill's spirit for living was diminished. With greater frequency, his daily newspaper stayed creased and folded neatly on his bedside table. The new television with a built-in caption decoder sat cold in the corner.

Despite our efforts to get proper care for Bill's puzzling symptoms, our concerns were left unattended. The nursing home and my aunt decided to treat his acne condition topically, never questioning why a 71-year-old man would suddenly have fiery pustules on his face. Treatment from the dermatologist was not effective, but the decision-making process was delayed further because medical specialists did not make "house calls" to the nursing home without additional expense. Consequently, in some regard, I initially saw Bill's trip to the emergency room and hospitalization as a wake-up call for his caregivers. I thought, "Maybe now he'll get the medical attention that he needs."

I reminisced with Sara about the life he led as a younger man. I was shocked by the realization of dependency because the Bill I remember from my childhood was quite independent. Some summer mornings my mother asked me to run notes to Bill at his apartment asking, "Please pick up milk for mashed potatoes when you come for dinner," and "What kind of jello do you want for dinner?" Most mornings, I found him in his kitchen, polishing off a bowl of cereal and typing letters to his friends from the residential school on an old typewriter. Bill was a "saver." His typewriter was propped on his kitchen table amid stacks of books, newspapers, and magazines. Coffee cans holding up the window usually held an assortment of nuts and bolts or a collection of spare change. Frequently in the afternoon he took long walks with my dog or refinished pieces of furniture in his woodshed in the back yard. At dinner hour, he showed up like clockwork. When the windows were open we could hear his staggered step coming down the sidewalk and my brothers would call out, "Uncle Bill's here!" With extraordinary regularity, Bill entered the house with a slam of the screen door voicing "Hello" to my brothers and me as we lay sprawled in front of the television. Sniffing the air and smiling, Bill would proceed to the kitchen to peer over my mother's shoulder to see the contents of pots and pans on the stove.

On the day they made the decision to end Bill's life, I found myself standing at the foot of his bed, thinking about the man he was in my childhood. I took comfort that he at least looked like he was resting peacefully. I was looking forward to talking to the doctor to determine what was happening next. I remember not being able to make sense of what the doctor was saying. "Well, Martha and I discussed Bill's situation and his prognosis is not good. There's really not much we can do for a man his age, in his physical condition, and Martha has decided to let things run their course." I looked back at Bill and heard myself asking, "What course? What's the course of action? What's the plan? Dialysis?" Martha responded, "Laura, consider the life that he's led. Just look at him. Dialysis will be too difficult and painful for Bill. We're doing the most humane thing--we're going to let him go."

I wanted to lift the lids of Bill's eyes, peer inside and tell him, "Can I please tell you what they're planning to do?" Hospice workers say that people in a coma can still hear what is happening around them. For the first time I could ever remember, I wanted Bill to be a hearing person. I wanted him to at least be aware that he was going to die. I wanted to show them that Bill could make the decision to live or die. I wanted to see his head nod yes or no.

The last words I had signed to him in the emergency room were words of reassurance, and I wanted to take them back. I felt compelled to apologize to him. I had contributed to the mistaken belief that he was safe in the care of his family members and medical professionals, but I was wrong. I prayed that he would wake up for just a moment. I sat and watched the stillness of his face, waiting for his eyes to open for even a second, but that glimmer of consciousness never came.

The issue of structural dependency is the most difficult for deaf people and their family members to manage because it is intangible--a pervasive, implicit worldview of Deaf people, held by persons with an auditory orientation, who represent the majority of society. I was struck by the irony of Henry's situation. Unlike my uncle's experience, Henry's family members appeared well on their way to viewing him as a whole being with linguistic and cultural differences. However, the contexts where Mark and Sara gathered information about the Deaf experience (i.e., medical and educational professionals, extended family members, mass media) seemed to cloud their vision, and in some ways, delay their progress towards achieving cross-cultural understanding and competence. I noted that when the family's interactions occurred primarily within their home and with extended family, their ability to work around issues of structural dependency was good. However, interactions with certain school personnel--interactions with the macrostructure--tended to exacerbate their progress and understanding.

Theme 4: Home-School Interactions

This section requires a brief preface that explains the environmental context of Parkwood elementary school and my position as a researcher in relation to that context. It is also important to understand the political position of individuals (teachers) who worked at Parkwood and the history of recent changes that occurred at this school for deaf children. Understanding both of these perspectives is critical when making sense of the stories that follow, because they actually provide an embedded view that is part of the interactional sphere of parents: the view of the teacher.

The Teacher's View

First, it is important to recognize that my presence in the Camillo's home was explained and simplified for practical reasons. The Camillo family members told others that I was a nanny or high-tech mother's helper, and viewed me as a researcher assigned to study their lives. As I will discuss later, the children grew to see me as a maid and caretaker. I viewed myself as a researcher and family ally. However, interwoven among all those simplistic roles and perceptions, my previous experience as a classroom teacher for deaf children and my connections with the university made me a symbol of the deaf education system. I was a "resident expert" living in the Camillo's basement who helped them with day-to-day living. At a different level, I also provided them with knowledge and expertise from a teacher's perspective concerning IFSP development, how to manage the deaf education system, and how to gather resources and make acquaintances with people who could teach them about Deaf ways of viewing the world. Consequently, when my fieldwork left the safe abode of the Camillo family's home and ventured into the school environment, I frequently encountered the dynamic tensions that existed between parents and teachers. The stories that follow are included because they demonstrate those tensions, but not necessarily the particular worldviews of Mark and Sara Camillo as parents.

The Influence of Restructuring Efforts at Parkwood on Home-School Interactions

Henry Camillo attended the Parkwood school as a full-time day student. Parkwood is an elementary lab school that is located on the campus of a university. The same group of administrators oversees Parkwood and the university, and many of the same resources fund both organizations. As one example, the LLCD Project is a shared link between the university and Parkwood.

Up until the point of my first participant observation at Henry's bus stop, my understanding of the school's restructuring efforts were almost entirely framed from a researcher and graduate student perspective. I did not have access to a parent's view of the changes at Parkwood. As a researcher, I visited the halls and classrooms occasionally to gather data for the LLCD Project. I learned through second-hand information shared in my graduate classes and among Parkwood teachers that the teaching team's summer training focused on moving from a traditional teaching model to a collaborative, team-teaching approach. Parkwood's traditional structure was comprised of several components that typify traditional, self-contained classrooms: small group instruction, small class size with a low teacher-to-student ratio, support services provided on a "pull-out" basis, and grouping of students by academic and communicative ability (Friend & Bursuck, 1999).

Daily instruction at Parkwood the previous year occurred in small groups of 8 to 10 students assigned to one teacher and sometimes a classroom aide. The students were grouped by their chronological age, academic, and communicative achievement levels. Because of ability grouping, the traditional curriculum structure also contained a special separate educational program for students who had mental or physical disabilities. The special needs classrooms were physically separate from other programs in the school. Finally, the previous Parkwood curriculum structure provided students with "pull-out" services. Students left the classroom to receive specialized support services from teachers prepared in the areas of speech and language pathology, occupational therapy, and physical therapy.

Parent-to-Parent Interactions

My first understanding of the connections and dynamic tensions that existed between Henry's home and school life began at his bus stop. A few weeks before I moved into the Camillo home, I made several full-day field visits to the home (FN:31:1:7). During those visits, Sara and her mother acclimated me to their daily schedule and taught me about the particular needs of the children. These early visits made me feel a lot like an apprentice learning a trade. One of my "apprentice" duties included riding alongside Sara in the truck during her afternoon errands. These tasks normally included a quick stop at the food store or gas station and then we went on to pick up Henry at the bus stop.

Henry's bus stop was located at a strip mall located about 10 minutes from the Camillo home. The meeting spot was directly outside a Giant food store, and Sara pulled into a wide parking spot in front of the store when we arrived. Sara explained to me that she often tries to arrive early so she can do some food shopping before Henry's bus arrives. The weather still felt like summer that day, and both Daniel and Madeline asked to get out of the truck to romp as soon as we pulled up. Sara released Madeline's car seat buckle and allowed her to join Daniel, who was waiting for her on the wide sidewalk area in front of the store. Sara explained, *Let them burn off some steam* (FN:31:1:20).

As Sara unloaded Daniel and Madeline from the truck, a woman named Patty Richmond, approached her and struck up a conversation. It became apparent to me that Sara knew Patty as another parent of a child who attended Parkwood. Sara asked immediately about Patty's son, James, who was in the third grade. Patty was angry and began to share with Sara her latest frustrations concerning the restructuring efforts that began at Parkwood at the beginning of the school year.

Sara opened her conversation with Patty by asking, *How's the school year going for James?* Sara's question had the effect of opening Pandora's box. Patty explained to Sara that she was frustrated because James was supposed to be following the third-grade curriculum this year, but instead, he was placed on this team where students were still doing first- and second-grade work. Patty elaborated,

> *Deaf Education stinks. I can't get over the run-around we've had! They can never give you a straight answer, and there is no curriculum! I had a meeting recently with the acting principal, and I was trying to explain to him where James should be [third grade]. I told the principal how hard we worked to get James to that point last year. I told him that he [James] had had passing grades last year, and was really doing well. Then I asked him, "Why aren't you promoting him to third grade where he should be?"* (FN:31:2:18)

The acting principal's response to Patty's concerns was, *I'll decide where your child will go.* Patty continued to her second frustration,

> *I knew all the people who worked with James last year! Why did they have to go and change things! Now I don't even know who to go and talk to if I have a problem! There is no one to trust! I don't have a relationship with anyone!* (FN:31:2:26)

Sara agreed with Patty and mentioned that she felt Henry's behavior has taken a turn for the worse lately. She said he seemed to be much more aggressive. Sara thought Henry's behavior changes were because he was frustrated with the changes that were happening at the school (i.e., larger class sizes, his placement with older children or children with disabilities, etc.). Patty asked Sara if she had similar complaints about what was happening at the preschool level. Sara confessed to feeling slightly "out of the loop." She explained to Patty that the babies had only been home for three weeks, and she was still trying to get the house in order. She told Patty that she and Mark planned to attend the preschool Open House meeting with parents that was scheduled for October.

As I listened to Sara's conversation at the bus stop, I realized that the restructuring efforts that originally influenced only teachers and administrators were now making an impression on the children and families of Parkwood. Watching Sara interact with other parents of deaf children also made me realize how differently parents and teachers communicate and develop relationships with one another. In

Sara's world, the exchange of experiences partially built her knowledge about parenting. Among her circle of friends and acquaintances, she considered practical experience just as valuable as formal training or earned credentials. In the case of Mark and Sara Camillo, the practical application of information they acquired was one of the keys to their family's success. They discarded or ignore information that could not be applied in practical ways for the family. It became apparent to me that families who make decisions that are not aligned with the services or suggestions of educators, they were often labeled as uncooperative or disinterested.

At this point, James and Henry's bus arrived, and Sara started to gather Madeline and Daniel – trying to get everyone back in the truck. Henry was surprised to see me. He surveyed me from head to toe with his eyes while we are standing at the bus stop. I suspected he was still not sure why I was spending time with his mother, and I wasn't sure how to explain my role to him. I knew that Daniel and Madeline may have overheard some of the conversations among Sara, Mark and me about my research and plans to move into the house, but I wondered, "What does Henry know?"

Henry gave his mother a big kiss and waved hello to Daniel and Madeline; he seemed very excited to go home from school. We all boarded the truck and said our good-byes to Patty and James. Sara and Patty's conversation ended abruptly--presumably left hanging until they resumed it at the bus stop later. As we drove away, Sara called out, *Good luck Patty*! (FN:31:3:2).

On the way back to the house, Sara told me that Patty and her husband were vocal parent advocates at Parkwood. Patty's husband held an office in the parent-teacher organization. Sara shared that they've always had problems with James at

Parkwood because school officials tried to label him mentally retarded. I commented that Patty seemed very angry. Sara agreed,

> *Oh yes--they've gotten the run-around. We are so fortunate that that hasn't happened with Henry. We've always been so happy with Parkwood, and Patty and her husband have only had problems from the very beginning. She's very angry and very upset. But James has really made a lot of progress*!
> (FN:31:3:24)

Sara paused to sign and speak to Henry who was buckled in his car seat two seats behind her. Henry's regular seat was on the far right side of the truck, next to the window. In order for Henry to see her signs, Sara raised her arms and hands up, to the right of the steering wheel. When the truck was in motion, she signed with one hand. Sara had a round, rear-view mirror attached to the back of the sun visor and alternated watching the road and the mirror for Henry's responses. She asked him, *HOW SCHOOL?* Henry replied, *FINE*. Henry also asked for a drink and wanted to open his lunch box to eat leftovers as a snack. Sara told him that he could have a snack when he got home and asked, *WHAT-DO SCHOOL?* Henry responded, *PLAY PLAY* (FN:31:3:28).

Sara shared with me her frustrations because she was having trouble establishing regular communication with Henry's teachers this year. Sara said that in the past she had daily contact with Henry's teacher using his communication book--a notebook that passed back and forth between Sara and the classroom teacher as a form of daily written communication. She wondered why she and the teachers were not able to keep up with writing to each other regularly this year. Sara explained,

> *I understand that they're busy, but I'm not able to get much information out of Henry about what he did at school. Because I don't communicate with the teachers, I feel like I know less about Henry's day than any of my kids! It*

> *makes me so sad not knowing what my Henry is doing during the day!* (FN:31:4:2)

One might argue that teachers share information and build their understandings with each other in very much the same way. Teachers share student stories and give advice to each other during their break in the teacher's lounge, during bus duty, and at formal meetings. However, the story of parent-to-parent interactions at Henry's bus stop, supported by statements Sara made when I lived in her home, illustrate for me the source of the inherent difference between the lived experiences of parents and teachers. By analyzing the pathways of interaction created by parents and teachers, my analysis indicated that the intent of parent interaction concentrated on seeking information about deafness, while the purpose of teacher interaction was to impart or share knowledge. I recognized an imbalance of power between home and school players.

Educational legislation passed within the last 10 years explicitly addresses the imbalance of power between family members and school officials (citations: P.L. 99-457, IDEA-97). However, the behavior of individual actors within an age-old social scenario (e.g., teacher knows best) is far more ingrained in human consciousness than the intent or interpretation of legislation. In order for parents and teachers to take the step beyond merely acting their part in a redundant cycle of school-centered, rather than family-centered practice, both sides of the interaction must be aware that their role exists. The examples of home-school interaction in this section demonstrate that merely balking at one's role, without cooperation and conscious efforts from opposing actors in the system, results in frustration, social labeling, and an unsuccessful resolution to the communication or collaboration obstacle.

Two weeks later, Sara looked forward to the opportunity to share some of her concerns when she would have the opportunity to make a formal visit to Henry's school in order to meet with the acting principal and other concerned parents of preschool-age children attending Parkwood.

Parent-to-School Interactions

During the Fall semester, feelings of increasing anxiety felt common to me when I crossed the threshold of the Parkwood school. My fieldnotes reflected that as I considered my role as a participant-observer in the Camillo home, I was able to identify the source of my anxiety by considering who I was not. I was a researcher, an onlooker, a baby-sitter, and family ally. Once again, the concept of power inequity between actors in home and school environments became apparent. I realized the part I played at the nucleus of the power dynamic: For the first time in my career, I was not in a position of power--I was not a teacher.

Mark and Sara were unable to attend the scheduled parent meeting at Parkwood in early October. However, the morning after the meeting the telephone began to ring at the Camillo home. Sara's accounts of conversations at the bus stop with other parents also increased in intensity. Parkwood parents were gathering support for a follow-up meeting that would address the concerns that had been left unanswered at the Open House.

The preschool follow-up meeting was scheduled for October 11, and Sara invited me to attend with the family, take notes, and help her look after the children. I sent an E-mail message to the team leader, Karen Turner, asking her permission to attend and gather data for the LLCD Project. I told her in the message that I wanted to be able to observe a parent meeting and document the interactive behaviors of Mark and Sara Camillo among other parents of deaf children. I also wanted to give Karen an opportunity to contact other parents of preschool children to inform them that I would attend as an observer. I closed the E-mail by thanking Karen for considering the request, and told her that I would watch my messages for her confirmation. Karen Turner never responded in writing to my request.

October 11th arrived and I drove to the Camillo's home so that we could ride to Parkwood in one vehicle and brief for the meeting on the way. Mark left work early and planned to meet us at the school. When I arrived, Sara's mother Peggy seemed anxious about the meeting. She commented to me, *I don't know what's going to happen tonight at this meeting darlin'! Other parents have been calling Sara all week*! (FN:35:1:23). Sara seemed less concerned. I remembered her comment to Patty about feeling "out of the loop" because of her involvement with the babies, and I assumed incorrectly that Sara didn't realize the heated nature of the upcoming meeting.

The meeting was scheduled to start at 4:00 PM with the arrival of the acting principal, Anthony Salins, who is deaf. Sara, Grandmother, and the children were in good spirits as we packed into the truck and headed for Parkwood around 2:30. Sara wanted to allow time before the meeting to set the babies up comfortably, and she hoped to have a chance to chat with Henry's classroom teachers. We arrived at 3:15 in time for Henry's dismissal and we met Mark in front of Parkwood, parked the vehicles, and headed into the building.

We made our way to Henry's classroom, a glass-enclosed and open environment. Because the classroom is enclosed by glass, I often have the feeling of being a fish in a fish-tank when I am inside. The classroom has a geometric flavor to its design. Floor space is not a flat plane, but rather is arranged on multiple tiers throughout the room. Much of the open space of the classroom is broken up with room dividers, stairways, and platforms.

The family settled into a small niche that is elevated by six steps off the main floor. The niche was developed into a reading area and decorated with beanbag chairs and child-size bookshelves. The beanbag area was partially obscured from hallway activity outside the classroom by wall hangings of children's art. We spread the babies out on the floor in their "bouncy seats," engaged the older children with classroom toys and books, and gave the babies "nibbler" bottles. Sara and Mark settled into beanbag chairs to chat with one of Henry's teachers Donna, and the classroom aid, Tommy. Donna and Tommy are both deaf.

Tommy opened the conversation by telling Mark and Sara about the negative effect of Parkwood's restructuring on his role in the classroom and on the children's learning. He confessed that he was beginning to reach his limit with the changes that were being implemented. He felt that the teachers and staff members were particularly frustrated because they had no control or "say" concerning any of the changes that were being implemented.

As an example, Tommy explained that without consulting any of the preschool teachers, Parkwood administrators had recently hired an outside educational consultant to assess the effectiveness of the daily curriculum used by the preschool team. The administrators evidently presented the consultant to teachers in light of the restructuring efforts as a "perk" that would enable them to evaluate their teaching practices. Tommy said that the consultant arrived the week prior and conducted about one hour of observation. The following day, first thing in the morning, a Parkwood administrator came to the preschool classroom and informed the team that their daily schedule was unacceptable because it didn't include enough play opportunities for the children.

Tommy paused and looked to Mark and Sara, shaking his head in disbelief and frustration. Sara offered, *What can we do to help? Is there anything we can do to support you? What should we ask from Mr. Salins that would help you*? (FN:35:2:14). Donna interjected that they just wanted to have enough resources and teachers to educate the children. *We want to be left alone to do our jobs without being pulled and pushed in all directions.* Sara responded, *Okay, so you need more bodies in here--you need more teachers. I love the teachers here and don't want you to be criticized any more. How are you supposed to do your jobs when you're being criticized all the time*? (FN:35:2:18).

Donna commented that they were not only being criticized. *We're being told, if you don't like it, leave*! (FN:35:2:19). She held up her finger to indicate she was leaving the area briefly. She retrieved what appeared to be a newsletter from her work area. Donna returned, pointing out an interview with Salins, that had been conducted and published in Parkwood's newspaper. Sara and Mark silently read the article and Mark commented, *seems like the emphasis for parents and teachers is, 'If you're not happy, please feel free to leave!' Right*, Donna responded, *I'm wondering if they're trying to dissolve the school so they can start again from scratch? My question is, are* *they trying to dismantle the program*? (FN:35:2:32).

The conversation ended abruptly as other parents began to trickle in to the meeting. Sara waved energetically to Penny and James Hanson and motioned for them to join our group. Sara said to Mark and I as they approached, *They have two kids here at Parkwood* (FN:35:3:2). At the same time an interpreter came over to the area where were sitting and said, *I'm here to interpret for Spanish-speaking parents--are there any here yet*? (FN:35:3:6). Sara shook her head and told the interpreter that we were the first ones to arrive to the meeting. Sara continued, *We might need a sign language interpreter but no one Spanish-speaking has shown up yet!* The interpreter commented, *Yeah, who knows if any of them will show up*! (FN:35:3:8).

James and Penny came over and introductions went around the group. Communication shifted from a combination of signing and speaking used with Tommy and Donna to using ASL only with James and his wife. James suggested that we organize the chairs in a circle and have a brief discussion before Salins arrived. James wanted to discuss and organize a game plan that would allow everyone to "get on board" with a few common goals. We started to gather chairs, and Tommy said his good-byes to Mark and Sara. Teachers and classroom aides were not invited to this meeting--it was for preschool parents and Salins only.

As we finished setting up the circle of chairs, a Hispanic couple arrived and began conversing with the interpreter. Another mother, who I called Belinda, stood at the perimeter of the chair arranging activity with her arms folded across her chest. In May, I had attempted unsuccessfully to recruit Belinda and her family for my pilot study. Her facial expression indicated to me that she was struggling to remember where she has seen me before. She moved into the circle of parents who were beginning to introduce themselves and shook my hand asking, *Do I know you?* I reminded her where we met and asked about her son. Belinda responded, *Oh! He's fine! It's good to see you again*! (FN:35:4:15).

James and Penny motioned everyone to sit and as we settled into our seats, James began to share his concerns with the group. James is a culturally Deaf individual, and although he was using sign language alone, his signs were clear and produced mostly in English word order. He noticed that some of the parents in the group were perplexed, struggling to understand what he was saying. He asked, *Would it be helpful for me to use my voice*? (FN:35:4:24). Heads nodded, *YES-YES* around the room and some parents said, *Yes please, that would help.* He turned to me and asked, *Until the interpreter arrives, would you be willing to voice for us*? (FN:35:4:29). I agreed to interpret but reminded the group that I was not an interpreter. My mouth went dry and I shifted and leaned forward in my chair, thinking that if I repositioned my body, I could make a smoother mental transition from the role of caretaker/observer to spoken English interpreter.

James Hanson continued, laying out the historical foundation of the problems to be addressed at this meeting:

> *There is a history of excellence in the preschool at Parkwood. The quality of this program is demonstrated in the fact that as children graduate from the younger grades of Parkwood and go to the high school program at Meadowbrook (another school for the deaf nearby), where they are academically ranked ahead of Meadowbrook students. We are here today because we are concerned that the academic integrity of this program is at risk for several reasons.*
>
> *One of the problems that Penny and I want to address today is the room where We are seated–the preschool classroom. When Parkwood was built in the*

> *'70s, this room was created to be a classroom. However, over time the idea of using it as a classroom was discarded because the room was considered "visually noisy" for deaf students. Teachers moved away from the idea of open classrooms, and turned this classroom into an indoor recess area.*
>
> *During the restructuring efforts this summer, someone erroneously made the decision to use this area as classroom space again. People say, "I feel sorry for you because your kids are back in that room." Penny and I discussed this situation, and decided that it would be a better idea to use the motor room space that is connected to the art room. There is concern at this point in the year that it would be impractical to change classrooms, but we think it could be done.* (FN:35:5:2)

The parents' heads were nodding, and James stopped, asking if they were in agreement with him and Penny's observations. Penny added that she thought moving the preschool children to a self-contained, less visually noisy environment (i.e., the movement classroom), would solve some of the behavior problems they had planned to discuss at this meeting with Salins. She explained that a more contained classroom environment would provide more structure, and students would have a better idea of the visual and physical boundaries of their classroom--an effect she felt was not possible in an open classroom.

The parents discussed the difference between open- and closed-classroom environments. The Spanish interpreter and I reminded everyone to talk one at a time so we could keep up with communication needs. Sara added that she didn't particularly have a problem with the open classroom, but offered her and Mark's support in their efforts. She suggested that the parents "pitch in" and help teachers prepare the movement classroom on an upcoming Saturday afternoon. She continued, posing the problem presented by Tommy and Donna--teachers and aides were leaving, and they were not being replaced. Sara posed the question, *If this is supposed to be a* *state-of-the-art restructuring, why don't they have the money to hire new staff and support the ones they already have*? (FN:35:6:7).

James responded, *If things don't start to improve around here, the problem of too many students and not enough teachers won't be an issue. There has already been a mass exodus of students in the upper grades. Yes, teachers are also resigning left and right. I know several Deaf families who have children in the preschool program who are also considering sending their children to another near-by residential school until Parkwood can get its act together.*

It is interesting to note that the reason the parents called the meeting, to discuss behavioral problems (i.e., aggressive behavior) among the preschool children, was being expanded. Instead of maintaining a narrow focus, this dynamic group was attempting to address more extensive issues related to the restructuring efforts at Parkwood. From my perspective as a bystander, it appeared that this small group of parents, representing four families (two hearing, English families; one Deaf, ASL family; and one hearing, Spanish-speaking family) had brainstormed collaboratively and then identified several key restructuring issues in a matter of minutes. I considered the meeting they were about to have with the acting principal. I thought about the collective blessing encompassed in this diverse group of parents, who offered suggestions for improvement plus hands-on support to help with the change process.

James summarized the important points that the parent group wanted to make during their meeting with Salins:

1. Problem: The current "open" classroom was filled with visual noise that

distracted the children and negatively affected their behavior. Solution: The children in the preschool team should be moved to a more confined classroom space to prevent visual overstimulation, and prevent related problem behaviors.

2. Problem: Teachers and aides were resigning because they felt constricted and controlled by the restructuring process. Solution: Stop managing restructuring efforts from a "top-down" position and gives staff members more support, control, and "say" about what happens in their work environment.

3. Problem: The quality of the education program was suffering because teachers and aides who were resigning were not being replaced. Solution: In order to maintain a state-of-the-art educational program, individuals who resign should be replaced as soon as a proper replacement is located (FN:35:5:28).

While James wrapped up their list of problems and solutions, anchoring them on the fingers of his left hand, I felt a tap on my left shoulder. Karen Turner, the preschool team leader, had arrived at the meeting and asked me to step out into the hallway. Sign language interpreters arrived at the same time. I happily relinquished my voicing role and removed myself from the circle. Karen was out of breath and spoke to me hurriedly, *Laura--I am really sorry I didn't get back to you about attending this meeting. I want you to know this isn't anything personal, but you won't be able to stay in the room for the meeting. The content of the meeting is going to be too confidential for just anyone to sit in, and I'm afraid you'll have to stay outside* (FN:35:7:3).

I only had time to explain briefly to Sara that I wasn't permitted to stay in the room and reminded her to get me if she needed help with the babies. Before I knew it, I scooped up my notepad, gave my apologies to the group for my abrupt departure, and moved quickly out of the classroom. The English expression, "Here's your hat, what's your hurry?" popped into my mind as I looked over my shoulder at the meeting's official start.

The meeting lasted for well over 90 minutes. I spent the time writing up fieldnotes and chatting occasionally with teachers I knew as they straggled out of the school. Everyone asked the same question--What are you doing here on a Friday afternoon? *Helping out with some babysitting for one of the preschool families* was the response I was accustomed to giving these days. The Camillos had the option of sharing my research presence with people outside the immediate family. However, my ethical responsibility to Henry and his family did not permit me to disclose the research portion of our relationship.

As the meeting ended, I was in the midst of a long conversation with a fellow doctoral student, who was also a teacher in the upper grades at Parkwood. Salins was the first to leave the classroom. He bustled through the double doors and walked over to where the Parkwood teacher and I were talking. Before the teacher could introduce us, he commented, *Those people in there don't have the first idea what's going on* (FN:35:7:23).

I struggled to hide my shock. I thought to myself, *Did he have a meeting with the same group of people?* Salins continued to disclose privileged information about the preschool parent meeting to us as if he had known both of us for years. As James

Hanson had done, Salins listed the parents' suggestions on the fingers of his left hand and bluntly dismissed each one as ridiculous. *If they would just focus on parenting and let these school issues up to the people who know what they're doing, we'd be a lot better off!* (FN:35:7:27). Salins' casual comments about the preschool parents broke every basic rule of confidentiality I had ever been taught. As he talked, I puzzled to myself about why it had been so critical for me to leave the meeting if he was permitted to broadcast the meeting's contents in an open hallway to virtual strangers.

Eventually the Parkwood teacher was able to introduce us. Salins said, *Laura Blackburn. Your name sounds familiar.* Then he made the connection, *Oh! Karen Turner said you wanted to sit in on the meeting to do some kind of research?* My friend questioned me, *I thought you were babysitting?* I explained, *I'm collecting data for the home and family component of a research project at the university. One of the families I am investigating invited me to that meeting. As a form of fair exchange for data collected, it is my ethical responsibility to make some contribution to their family–so I help take care of their children when I'm doing fieldwork.* Salins asked, *Which family is it?* (FN:35:7:29).

I blinked again, startled by the boldness of his question as well as his total disregard for confidentiality. I responded, *I'm sorry. For reasons of confidentiality I'm not permitted to tell you which families are participating in the research project.* Now it was Salins' turn to be startled. He raised his voice and leaned towards me. His response seemed angry, *What is this, some kind of game? We'll see you leave with the family and make the connection!* He took a step back, and folded his hands across his chest. I said, *Yes, you may see me with different families, but that's no guarantee they are involved in the research project. The way it works is, the family members have the option of sharing information about our research relationship. However, in order to protect their privacy, I don't have that right. Ultimately, it's their decision, not mine* (FN:35:8:6). Salins dismissed our conversation and said, *I need to get back to my office*, and hastily walked away (FN:35:8:12).

I did not immediately share Salins' post-meeting remarks with Mark and Sara. I wasn't certain if conveying his message would be helpful to the family's position or the outcome of the decisions they needed to make about Henry's education. As I left Parkwood the day of the meeting with the family, I was in a very serious mood. As we walked to the truck, I considered my position as a researcher in their home. I weighed my loyalties to the research project, to Parkwood and the university, and to each of the family members. As I handed babies to Sara in the truck, I considered what I would do if the conversation I'd had with Salins came up on our ride home. As the adults in the truck snapped on their seatbelts and Sara drove the truck out of Parkwood's parking garage, I pulled out my notepad and pen, ready to record Mark and Sara's account of what had happened at the meeting. I was prepared to address my torn loyalties. On this day, the Camillos taught me that one can never fully anticipate the direction, behavior, and resilience of informants. I also learned that the topics shared at the parent meeting would be discussed another day. As we drove out of Parkwood's neighborhood and onto the freeway, Sara opened the conversation that we maintained for the rest of the ride home: *So, should we order pizza or Chinese for dinner tonight?* (FN:35:9:5).

At the time, I was surprised by Sara's response. My surprised reaction stemmed from my years as a classroom teacher. Repeatedly I witnessed parents treated in similar ways--their needs disregarded--the educational interests of their children cast aside. I became emotional because I feared this family who I was growing to rely on and trust for information might fall victim to the perils of the special education system. I assumed from my "teacher's view" that Sara and Mark were naïve to Salins' unprofessional attitude and disregard for their requests and suggestions. I even chose to withhold his remarks about them, intending to protect them or shield them from the negative parts of the school system.

As my time with the family progressed, I recognized a pattern in Sara's behavior that indicated she was far from naïve, and her response to this parent-teacher meeting was typical and aligned with the view of a parent. At some point Sara and Mark must have decided that their interactions with teachers and school personnel would be conducted solely to meet the educational needs of their children. Their position was that they would not invest in the interests or priorities of any school program that did not provide support or guidance that created a reasonable "fit" for their family. Sara summarized the position of her family and their relationship with school programs in the final interview. She and Mark view their role as a team member. They invested time and energy in home-school relationships that involved "going in the same direction" on the educational road:

> You ride with us or get off. You know, we're going up here and you're there and if we're heading in the same direction, great! You know what I'm saying? We both have to have the same interests, the same values, and the same thinking. So let's go! Let's go! We work as a team. I don't need any more dead weight. I don't need any more excess baggage. (INT:19:119:11)

Loyalty to the System

Sara expanded on the concept of being a team member a week after the parent meeting at Parkwood. She introduced the concept of loyalty in one of our conversations after she'd spent the day observing in Henry's classroom. After her observation, Sara had a private conversation with Tommy, the deaf teacher's aide working in Henry's classroom. Tommy pulled Sara aside and encouraged her to have patience with the program at Parkwood. He stressed that Mark and Sara should keep Henry at Parkwood for at least another year. Tommy explained to Sara that Parkwood was the best environment for Henry (compared to other programs in the area). *Parkwood will get better next year,* was the message that Sara received. Tommy further explained that many of the Deaf families were only pulling their children out of Parkwood until the restructuring situation had a chance to improve. Tommy told Sara, *They'll be back. You just need to be patient* (FN:90:2:30).

Sara was pleased with what she saw during her classroom observation but disturbed by her conversation with Tommy. Two days after her observation, Tommy's message was complicated by his resignation. Tommy's conversation with Sara, followed by his resignation prompted a discussion between Sara and me about loyalty. She detailed the discussion she had had recently with a group of graduate students at the university. One of the main points Sara made was concerning the concept of loyalty. Sara shared with the students that she becomes upset with parents and family members who are loyal to teachers and programs because "they've been so good to us." Sara thinks of the "they've-been-so-good-to-us" posture as helpless:

> *Those teachers wouldn't think twice about leaving our kids behind. Do you think if they got a good job offer, they'd give a second thought to the kids?*

> *No, they would change jobs in a heartbeat—any time a better offer comes around. In return, we shouldn't be expected to hold those types of loyalties to the teachers and programs.* (FN:87:1:15)

Sara's position on loyalty speaks for many parents and family members. She has identified the subtle distinction between parents participating versus leading in their child's education plan. The questions are often raised, "Who know the child best?" and "Who can best determine this child's educational needs?" Sara Camillo's position was that as his parent, she was primarily responsible for leading Henry's education for his lifetime. Teachers, administrators, and volunteers would appear for short visits along the road of Henry's education, but Sara knew it was her responsibility to be with Henry and her other children from start to finish. Because of the powerful influence of the special education system in the United States, this family-centered message is often overlooked or forgotten.

A related, but central problem concerning appropriate delivery of family-centered, rather than school-centered services, is that families are often provided a wealth of information, but are not provided a tool or framework within which they can process the information in light of what they are experiencing. The next theme described here provides an example of how Sara and Mark grappled with trying to apply particular "deaf education ideologies and methodologies," but were unable to synthesize the information so that it was applicable for Henry and their family.

Theme 5: How Can We Teach Henry to Make Sense of Sound?

The winter months marked a time in the Camillo home where social events and commitments outside the family slowed. The worries, commitments, and adjustments the family made in the fall concerning the restructuring at Parkwood and the homecoming of the babies were behind them. As Sara would say, for a brief period after the new year, they were *in their comfort zone* (FN:79:1:11).

Daniel and Henry were settling into their schools' calendar of events. The babies were removed from their heart monitors. Henry and Madeline's birthdays as well as the Thanksgiving and Christmas holidays were under their belts. Sara, Madeline, and I were even able to establish a regular morning exercise routine. We were settling into a winter routine without any big social events outside of the immediate family pending. This quiet time seemed to prompt Sara and Mark to begin "taking stock" of their immediate family circumstances. They began to evaluate and discuss the children's progress, surveyed their individual and collective duties and activities, and planned for the next flurry of activity that would arrive with the spring (i.e., IEP season, Little League games, Boy Scout outings, and excursions from the home to more frequently visit friends and family).

On the surface of activity, the winter months appeared to be a routine, quiet period. However, the time Mark and Sara took to reflect upon their day-to-day living seemed to produce new concerns and understandings of deafness. The following event took place on a Monday in January when Mark and the children had a day of vacation from work and school. We gathered on this holiday because I was asked to write an article about the family's participation in a reading program based out of Parkwood. The reading program was designed to improve the sign language abilities of hearing families and teach them how to read children's literature to their children using American Sign Language (ASL) rather than spoken English.

The Camillos had participated in this program on a weekly basis for two years, excluding summers. They were assigned a deaf mentor who I call Justin. Justin was born deaf and his family chose Cued Speech[13] as the primary communication modality for their family. Justin attended the university that is affiliated with Parkwood. He was working on a Linguistics degree, and being a deaf mentor was one of the part-time jobs he sustained to support himself as a graduate student. Like myself, Justin's attendance at the university was his first experience communicating primarily in ASL rather than spoken English. Justin and I first met in a graduate class we took at the university, and recently we both worked as research assistants for the LLCD Project.

Earlier in the week, we arranged to meet at the Camillo home for an early reading session. Typically, Justin came every Monday evening for dinner. Afterward he and Mark read books to the older children, while I cleaned the dinner dishes and Sara tended the babies. After the reading session was over, Mark took all the children upstairs for bed, and Sara spent an additional 30 to 60 minutes talking to Justin about what it was like for him growing up.

On this day, we agreed on the early meeting time because of the holiday. Unlike other reading sessions, I videotaped this reading event and our interaction afterwards. My intent to videotape was to gather both interactive and informal interview data. I also wanted to be able to look back at the tape later to clearly recall what happened for the contents of the article that I planned to write. In all other regards, the usual players (e.g., all the immediate family members and Justin) attended this reading session, with the exception of my friend Molly who I lived with on the

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[13] Cued Speech is a phonetically based communication tool that consists of eight hand shapes presented in four locations around the mouth. Each "cue" represents a different phonetic sound.

weekends. Molly attended as a photographer and friend of the family and eventually co-authored the article with me.

When Molly and I arrived at the house, we found Sara out of sorts. We'd had an ice storm the night before, and when she took the trash out early that morning, she'd slipped on the hill by the cans and landed on her thumb, spraining it. Sara was frustrated because the sprain was painful (she was waiting to go to the emergency room until after the reading session), but also because it inhibited her ability to care for the babies and communicate effectively with Henry, and now Justin.

At first, Mark led the reading session with Henry and Justin only in attendance. Sara sent Daniel and Madeline upstairs to prevent them from creating a distraction. She lingered off camera talking to Molly and me as we captured the scene on film. It was mid-morning naptime for Luke, Mary, and John. The babies watched the interaction from their swing seats in the living room, alternatively sleeping and stirring for a blanket and their "binkies" throughout the session.

At some point, I began to wonder if they were going to call Daniel and Madeline to the living room. Daniel and Madeline typically participated in the reading program along with Henry and Mark; the scene felt somehow staged to me. I was concerned that they thought I wanted a formal presentation from them. The family I was capturing was not typical or what I intended.

I asked Sara if Daniel and Madeline could participate and she called them downstairs. Daniel was shy about the cameras but Madeline didn't seem to notice. She read books to Justin in ASL, and then books to her father and Henry while signing and talking at the same time. She negotiated the group members' communication easily. Sitting on the couch with a baby in her arms, and sometimes Daniel on her lap, Sara signed and whispered to me, "She is smart-smart-smart!" and said aloud, "Mommy is so proud of her girl Madeline! You are so smart!" (VC:2:3:14).

The reading session dissolved as Henry lost interest, and the babies started to show signs of hunger. Sara and I began to put sandwich fixings on the table for lunch, and Mark changed the babies' diapers. Justin wrestled on the floor with Madeline for a short time and then joined us at the table.

I set up the video camera to capture our lunch conversation, and got drinks ready for the adults and older children. While we ate, I asked questions about the reading program pertaining to its purpose and how Justin and the Camillos were matched. Did they feel the program was beneficial? What had they learned from their regular reading sessions?

About mid-meal, Sara changed the subject, and from that point, led the conversation topic. She had come to the table with a lot on her mind and had questions ready for Justin about some current issues related to Henry. The central issue that Sara raised was the concept of cross-cultural understanding. The idea of cultural conflict resonated throughout this interaction as one could see Sara arriving at an important intersection of understanding. Her behavior and language use were symbolic of the cultural tensions she was processing. Sara expressed distress and frustration, accompanied by statements like "I just need more" and "We're missing something for Henry" (VC:4:6:8).

These behavioral and language-use examples are symbolic of a person experiencing a cultural conflict (Glickman & Harvey, 1996). Sara was in conflict about what she knew to be true as a hearing person, while trying to understand the world as Henry sees it: through deaf eyes. Another example of her processing of cultural information was her repeated questions to Justin of how to convey sounds to Henry. She understood and accepted that her son was deaf, but ironically puzzled over and justified ways and reasons why it was important for Henry to understand and use sounds in his day-to-day living.

Sara began the conversation by asking Justin about both a communication system and speech teaching tool she had been grappling with lately (e.g., Cued Speech and Visual Phonics). She asked Justin, "Have you heard about Visual Phonics?" Justin laughed and responded, "What is that?" Sara told him her story.

> I went to Henry's school this week--Parkwood--and I was telling them that we were interested in starting cueing. They said, "Okay but, we use Visual Phonics here." And I said, "What's that?" (VC:4:1:9)

Sara demonstrated what was described to her as "signs for sounds." Throughout the demonstration, she used initialized movements that she called "signs." These signs seemed to move with a rhythm that matched the prosodic features of spoken phonemes. For example, Sara demonstrated the "sign" for the phoneme /sh/. The phoneme /sh/ was articulated with a beginning S-handshape starting at a position at the mouth. The S-handshape gradually changed to an H-handshape that moved away from the mouth, seemingly to represent air that escapes when the phoneme /sh/ is produced.

Justin asked, "They're signing phonics?" "Yes," Sara replied, "They're signing phonics" and continued to provide other examples. Sara continued with her explanation of how Visual Phonics is used at the school. "They [the speech teachers] said that Parkwood had been using it for two years now.

Seeking clarification, Justin asked Sara, "Is it [Visual Phonics] an MCE?"[14] Sara didn't know and told him that she had just received written information on Friday.

> I haven't read it yet. But I wanted to talk to you about [it] because I don't know what it is. They said Parkwood has been using it for two years now and that it's a wonderful program. A deaf person developed it. They said it is a form of sign because it incorporates signing as the visual for sounds (VC:4:1:24).

Justin looked at Sara with skepticism and Sara continued. She appeared anxious about their conversation and seemed uncertain about the information she had gathered. Sara began to support her explanation by providing information about her efforts to understand Visual Phonics.

> The good part is the deaf person already knows signing so it's easier for them to learn. This is happening at the school. I don't know, I mean--I asked Laura and she's never heard of it. You know and this is the first time that I heard about it. She [the speech teacher] said that they used it last year. But Linda Sheffield [Henry's teacher from last year] never said anything to me about it. This is the first time I've heard of it [Visual Phonics] (VC:4:1:28).

Justin expressed an interest in the reading materials related to Visual Phonics and Sara left the table to retrieve the packet. While Sara was absent, I concurred that I had never heard of Visual Phonics before. Mark commented, "Maybe they only use it in speech." Justin spent a considerable amount of time looking through the materials while we continued the meal. By this time, the older children had finished eating and moved to the living room to play with trucks. The babies had finished their bottles and were dozing again. Mark held John, Mary was with my friend Molly, and Luke was asleep in my arms. Sara waited for Justin to finish reading. When he looked up, she reiterated the story that led her to the discovery of Visual Phonics. This time she included some of her reasons for pursuing alternative communication systems.

> I was telling the school that we were thinking about using cueing now to improve Henry's reading and understanding of sounds. I want Henry to understand sounds because I don't like just fingerspelling the sound M-O-O, when the cow says, "Moo." It's just not enough for me. I want more. (VC:4:2:14)

"I want more" and "I need more" were common phrases in the house at that time. Sara and Mark felt that Henry's use of ASL was "getting away" from them. They might have been experiencing a phenomenon that Kemp (1998) discusses, related to the process of second language acquisition (SLA). Kemp points out that often individuals at the intermediate to advanced level of learning ASL feel they are not making progress or that the language is "getting away from them" because they are not able to monitor or see their progress as clearly as during the beginning to intermediate stage. He compares SLA to the sensation of flying in a high-speed jet. The passengers on the jet experience a "high speed" sensation during take-off, but as the flight continues, they become less conscious of their traveling speed, even though at later stages they are flying at double the rate of take-off speeds (Kemp, 1998).

Mark and Sara also expressed frustration at not having the time to formally learn and use sign language. They had not been able to maintain their practice of taking sign language classes and attending regular social functions with deaf friends since the beginning of the summer. Their social support system, comprised primarily of interactions with hearing people, was not able to provide the information or

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[14] MCE is an acronym for Manual Codes of English.

perspective that they needed. Even weekly visits from Justin were "not enough." As this conversation progressed, I thought to myself, "Sara is sitting at the wrong table." It became apparent to me that regardless of my years of formal education about deaf people, I did not possess the answers she was seeking either. Nor could the answer be found in any printed literature for her to gather.

The conversation between Sara and Justin continued:

Justin: It looks to me like a teaching tool.

Sara: That's right! They said it was a tool because it incorporates signing with sounds.

Justin: Yes, but I want to emphasize the idea of a teaching tool--teaching. Someone would use it, like a parent, to teach the child to make the association between the sound and the word and the movement. You probably have to memorize it. (VC:4:3:1)

Then Justin promoted the use of Cued Speech instead.

Justin: Cued Speech is different than that. Cued Speech does not use signs. Cued Speech is for the purpose of communication. When you use it [Cued Speech], you use it almost as if you are talking, except you add the cues--that's all. (VC:4:3:4)

Justin switched from signing and talking at the same time to cueing and talking.

> I am cueing and using my voice. I can say whatever I want to say. The purpose of Cued Speech is to use your own language [he gestures to Mark and Sara, meaning their "own language" is English]. At home your language is English I guess? Then later you teach the child [Henry] to read the same way you would teach--Daniel. The kid incorporates all the part of phonics already. But the child does not see [cues] as individual phonics [sic]. They see it as whole. Do you understand? (VC:4:3:9)

Mark nodded and signed "YES" while Sara's expression did not change. During Justin's demonstration, she had been leaning toward him with a body posture of complete attention. Her elbows rested on the table and she held her face in her hands. She said, "No. I don't understand that at all." Justin continued,

> It's complicated. It's complicated because it's hard to explain. Let me teach you a few cues and then you'll see how to use it. (VC:4:3:18)

Justin further explained the logistics of using Cued Speech. Sara's eyes were glued to his demonstration of various handshapes and positions used to cue. Baby Mary woke up fussy during the demonstration but Sara's focus never wavered. Molly handed the baby to Mark and left the table to join the older children who were playing with a noisy toy fire truck in the living room. Justin concluded with a comparison of Visual Phonics and Cued Speech:

> Justin: Visual Phonics is phonetically based. Their approach seems to be using signs.
>
> Sara: Right.
>
> Justin: Cued Speech shows phonics in everyday conversations, and that approach [Visual Phonics] seems to be more teaching related than communication. Cued Speech is more interactive where Visual Phonics is teaching. (VC:4:4:4)

I was beginning to think that Justin's information was becoming repetitive and confusing. Sara shifted in her chair and brought up her frustration with having to educate and re-educate themselves, as well as others about deafness. She said,

> I understand that, but it still doesn't help us to decide which is best for Henry. My concern is that we're going to move to another town in two years and everything's going to be different again. We're going to have different signs for car or truck or whatever. Even just moving here we had to change all of our signing. When we moved from [name of state] to here, we had different people telling us we were signing English – you know, TRUCK, CAR, BUS, VAN. (Sara demonstrated her point by showing us those initialized signs.)
>
> People said, 'Those signs aren't accepted here. You need to change it because that's English." Then we meet a teacher who says, "That's fine! I'll just understand that that's Henry's sign." And it just changes and changes and changes. Henry knows three signs for traffic. He knows a lot of these things but what if we have to learn something different in these two years, whether it is cueing or visual phonics? Where am I going to go with that? Is that going to [be used] in our next town? Is Visual Phonics going to be the new thing to

> learn? I'm just concerned that maybe Henry will become confused. (VC:4:4:7)

On the surface, Sara considered how she would teach Henry to read and become literate if he couldn't use phonetic strategies. Sara was trying to make sense of Henry's deafness. The core of her dilemma was actually grounded in a general confusion concerning how Henry perceives and experiences his world. Within her concerns, she expressed the classic heartache experienced by many hearing parents of deaf children.

> This is a good time for him to try to learn to read. And I just don't like that they [deaf people] don't have a sound for animals, or the phone. This is what he sees [Sara demonstrates the sign for the telephone ringing]. He doesn't understand that there is a sound for that. I want him to know that the sound is R-I-N-G [she fingerspells], and I don't know how to voice that. I don't know how to give him the understanding that there's a sound for that. You know I want him to see sound--I want him to see the sound. (VC:4:5:18)

Sara asked Justin, "How do you know what things have sounds?" Justin responded with a potential solution to Sara's dilemma.

> I always knew Cued Speech growing up. And all I can say about Cued Speech is that you cue the way it sounds. When you cue, you can cue "onomatopoeia." You can cue sounds that are not words, like when you go, "KNOCK KNOCK" or "RING" or the door slamming "THUD." You can cue when there are no words. (VC:4:5:25)

Sara continued with an emphasis on how she needed a method to teach sounds to Henry:

> I just need something. I hear him running and [it sounds like], "POW! POW! POW! POW!" I say, "Stop Henry!" It's loud!" But I need to tell him that it's loud and I have no way to tell him what "loud" means. I just need more! That's what Mark and I are feeling now. We're missing something for Henry. We need more information--more signing. I don't know if it's necessarily more ASL as maybe the cueing or words for sound.

> I need a sign for things. I need signs for sound. I need to say that that's loud and what you're doing sounds like--I don't know! I just don't have enough for him right now. I have words and I can communicate and I'm fine with that but I need the signs for sound, especially now because with Madeline we talk about the animals. You know, the cow says "moo." And Henry doesn't care--he's bored. He could care less! [When I sign to him] "The dog says B-A-R-K" he looks at me like, "How ridiculous is that?" (VC:4:6:5)

Ironically, as a group of adults sitting around the table, we overlooked the world of children where they are working through a practical solution to Sara's dilemma. During the length of time that Sara was describing her need for a more effective way to teach Henry about sounds, a toy fire engine was sounding loudly in the living room. Mark interrupted the conversation and said, "Daniel, please turn that off! I can't concentrate with that blaring!" Daniel complied and the flashing lights that Henry had been attending to turned off when Daniel turned off the siren on the truck. Henry immediately protested. Off camera, Daniel and Molly explained to Henry that the truck was making too much noise and Henry's protests stopped.

At this point, Justin presented a different way of thinking about how deaf people learn and used the meanings of different sounds as suggested by Padden & Humphries (1988). He suggested, "I've met deaf adults who say, 'SOUNDS, WHAT-FOR?'" Sara stiffened and sat back in her chair. Justin continued, "They would say that. But they would also teach you that 'The cow says <u>M-O-O</u>, not <u>moo</u>.'"

When providing this example, Justin used sign language and spoken English simultaneously. When Justin fingerspelled M-O-O, he opened his mouth wide with each letter and fully opened his hand between each letter, making his hands and mouth resemble what a cow's mouth might look like when it "says moo." When providing the second example, he used his voice with small mouth movements and said, "moo."

I interjected, "I think Justin is saying that some deaf people might say, it's important for Henry to know that the cow says moo, but how will he use that [information] if he's deaf? In other words, if he can't hear it himself, why is it important for him to use that information?" Our conversation became more intense as it continued. Sara responded to my question,

Sara: Because I want him to know that. Because I don't know if he's going to have hearing or deaf kids. And he needs to know that.

Justin: Deaf people all know that cows say 'moo' because they're taught how to say the word "moo" or they fingerspell M-O-O--they know.

Sara: You know [to Justin]! You know that a cow says "moo!"

Justin: I know that because I learned it.

Sara: Well, I want Henry to learn that.

Justin: Right. The way I learned is different than the way hearing people learned. Deaf people get their information on sound--they perceive it visually.

Sara: I understand that.

Laura: Perhaps it would help to start thinking more about how Henry will access that information, like instead of saying, "moo [cueing it]" or "moo [visual phonics]"--maybe there's another way. I mean, if Henry were standing here next to a cow, and the cow said "moo," what would it look like for Henry? It would probably look like, "M-O-O!" [exaggerating my fingerspelling as Justin had demonstrated] because the cow doesn't say [voice] "moo." You know what I mean? I can really understand how that's important to you Sara. (VC:4:7:17)

Justin introduced another example for Mark and Sara to consider.

Justin: You know, like when you walk on the floor and it creaks. How could you represent that visually?

Sara: See that's what I want to know! Because Henry stomps around "bonk bonk bonk" and I say, "Stop it! That is loud! The floor moves and the babies get scared!" (VC:4:7:25)

Justin explained and demonstrated the example of a "creaking floor" as he had seen other deaf people do. He explained, "Deaf people tend to make sound visual." He provided more examples of what dogs look like when they bark, and what kittens look like when they meow. He asked Sara and Mark how they would change the bark of a dog from an auditory to a visual "sound."

> Justin: There are different ways to show it [visual sound], but it depends on how you are telling the story. Suppose you are telling a story and the dog says, "RUFF RUFF." [Justin turned to Mark] How would you show it?
>
> Mark: [laughing] I would use my face.
>
> Justin: Would you do that with Daniel too? How would you talk?
>
> Mark: For Daniel? I would say, "The dog said 'ruff ruff.'" For Henry, I'd move my mouth [he demonstrates] "RUFF RUFF."
>
> Justin: Fine! That's fine! Do you see the difference? (VC:4:8:7)

The conversation was frustrating Sara. The examples we were providing were not addressing her concerns.

> "Bark-bark" or whatever! Yeah! I want Henry to know that the animals have a sound. The crickets. The frogs. The birds. I want him to know that there's a sound associated with what that bug or what that animal makes. That's what I want him to understand.
>
> And people sounds! I know this lady--she's an older lady at Parkwood and she didn't know until last year, that voices sound different. She didn't know that on the telephone, voices sound different. She didn't know that a boy's voice is different than a man's voice. (VC:4:8:17)

Justin responded incredulously, "She didn't know that?" Sara responded,

> No! She didn't know that! And I thought, "That's terrible! That's terrible!" I want him to know that if it's an old voice or a young voice. If it's a girl voice or a boy voice, or deep or light. See, I don't know how to do this information. (VC:4:9:7)

Justin made a cultural comparison to look at this woman's knowledge base from a different perspective:

> Justin: She didn't know because no one told her.
>
> Sara: Right.
>
> Justin: You didn't know how to get a deaf person's attention because no one told you how to get a deaf person's attention.
>
> Mark: [signs] YES!
>
> Justin: So, it's a matter of what you teach him, not a matter of him learning Himself. (VC:4:9:11)

Sara's response surprised me. We had known each other for nine months, and lived together for four. During that span of time, I had only seen her become emotional once--the day she was discharged from the hospital and had to leave the triplets in the NICU. Sara took an audible breath and turned her back to the camera. She lowered her voice, leaned towards Justin, and began to cry.

> Right. I'm feeling now that Henry is 4 years old and I feel that he's still missing out on a lot. He still doesn't know at 4 years old what a cow says, and that upsets me. He doesn't know what a chicken says, whatever! He's missing out on so much information, and I'm not always going to be there to tell him. He's getting older and I don't have the information to tell him about a cow, or a horse, or a cat, or the slamming of a door. (VC:4:9:17)

Sara shared that she was especially anxious when she compared Henry's behavior and progress with his hearing siblings.

> [I notice it] especially because Madeline is 2 years old and she knows those sounds! It's not a good enough reason because he's deaf. I don't want to use that. I can really see it when we're reading to the kids. He doesn't pay attention and he's bored. I think it's because he doesn't know and I don't think that's right. (VC:4:9:22)

Sara's frustrations were heightened by poor communication between home and school.

> It just makes it hard because I want to go to school. I want to see what's happening. I'm not sure that Parkwood knows what it's doing right now. He lost two teachers and I don't know what's happening in speech. I just don't know if he's getting all the information he needs now. And I don't want time to just get away from us and we lost him. Or, he just doesn't know enough. (VC:4:9:28)

Finally, Sara was concerned for Henry's safety. She wanted him to be able to "fend for himself" when he was not in her care.

> I was trying to tell him about strangers. About cars. About crossing streets. He's at a very important age now that he needs to know these things. About strangers trying to steal him. About not letting people touch your private parts. About not opening up the doors to strangers and talking to strangers. How to call for help--9-1-1! He's supposed to know that! He's 4 years old! So, I want to know, how do I learn that? There are a lot of things he has to learn about that he doesn't know! (VC:4:10:2)

At this point, I was at a loss for words--Sara's concerns became apparent to me for the first time. I responded,

> It's a lot of responsibility. It must weigh heavy on you. There's a lot to teach him. Because so many of those things you acquired naturally. Maybe you feel like you're missing them because you take them as a natural part of your day. And then you realize, "Oh, I didn't tell him that!" (VC:4:10:9)

Sara responded by presenting yet another concern that she shares with Mark--running out of time. She agreed with my statement,

> Yes, I feel like we've lost time because we thought he was so smart-smart-smart and that we were ahead. Now I feel like we're behind! I feel like, "Oh, no! He's <u>four</u> now! He doesn't know how to call the police if Mommy gets hurt!" I mean, what if only Henry's home? He needs to know what he needs to do! What if there's a fire? How does he escape?
>
> Daniel, Henry, and I were talking about this the other day and he said, "I'll help Henry Mom. Don't worry. Don't worry. Daniel will get Henry." And it's like, that's not your responsibility! He needs to know where do I meet the family if he has to escape! Where's he going to go? I can't imagine if something happened to him. It just scares me if something should happen here [at the house]. He doesn't know and he would be so lost and it would be all my fault! It's my responsibility! I don't know how to do this! And it's hard because there are so many babies here. I can not focus on Henry all the time.

> And the time is going by so fast! I don't know what I'm going to do! I know there's not a fast way but I need to know something now. We need to incorporate it now because he's smart and we just need to do it. We need to do it for him and for me so that I can find peace--peace in my heart. I'm just so worried about him. If he gets off at the wrong bus stop? He doesn't know his phone number! He doesn't know his last name! He knows nothing! He can't even fingerspell his name! He'd just be lost – all alone! I need to know what is right. What is the best way to teach Henry these things? I want him to learn and to become independent. I just don't know! (VC:4:10:13)

The stressors that Sara shared in this story were precipitated by interactions with audiologists and speech therapists at school, leading Mark and Sara to consider a new placement for Henry in the following year. The results of the audiogram seemed to send a cycle of events into motion. First, the audiologist produced evidence about the nature of Henry's hearing loss. The audiologist told Mark and Sara that Henry should be able to use his hearing to recognize environmental sounds if he wore his hearing aids regularly. Consequently, Sara requested an update from the speech teachers at school. The speech update consisted of a hand-written report accompanied by video footage of Henry responding to animal sounds during a "booth" situation at school. These events prompted Sara to hire a private Cued Speech tutor who suggested they consider a change in Henry's educational placement.

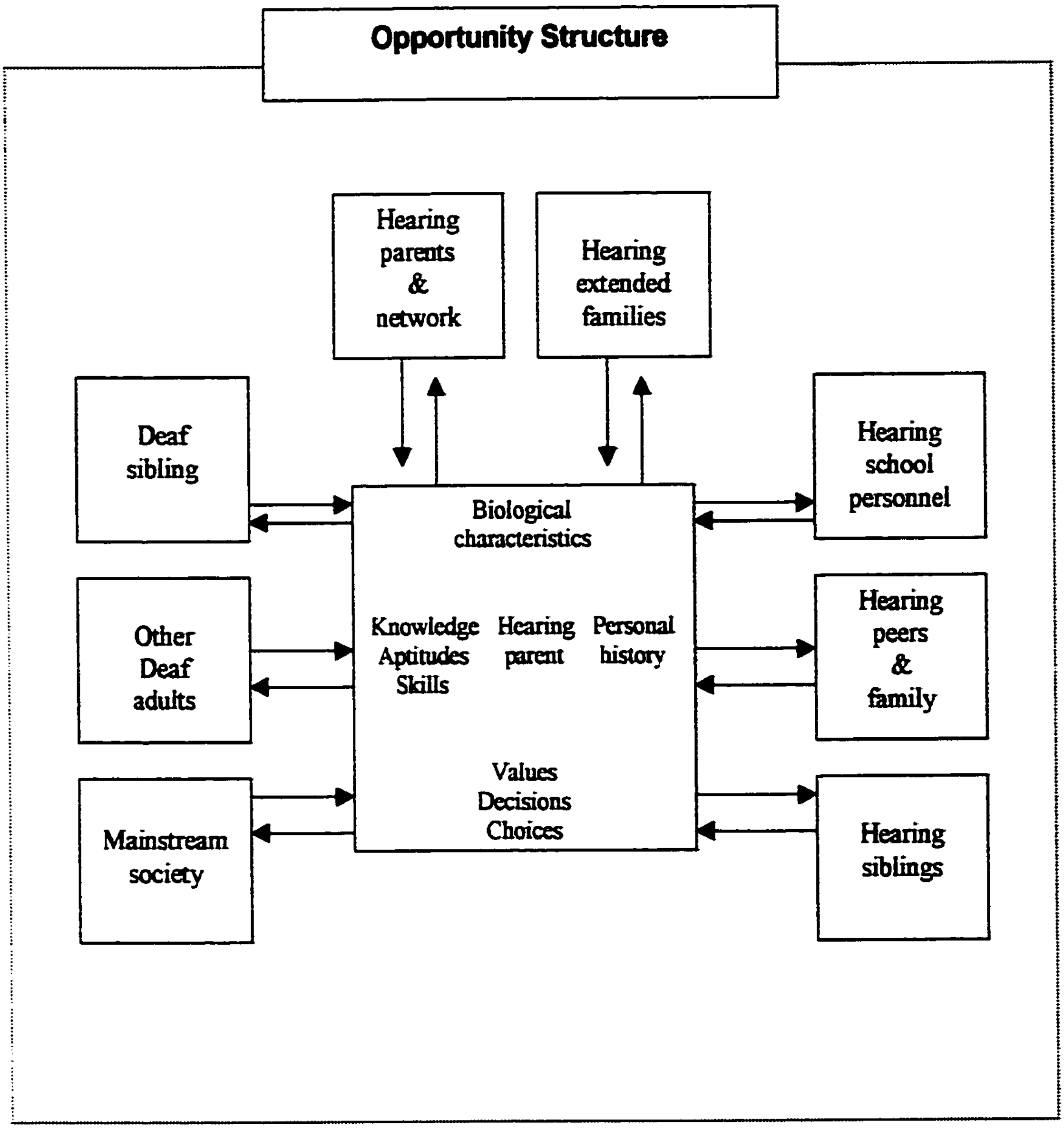
Imbedded within the context of Mark and Sara's encounters with the special education system and attempts to make meaning as parents, the Camillo children possessed worldviews and developing identities that existed apart from adult interactions. In a sense, from my vantage point among them, I recognized that the Camillo children lived in a world of their own. I also recognized that Henry's interactions with his siblings were bound to leave a deep, reciprocal influence on their developing worldviews.

Section 2: The View of the Hearing Children

A model of the hearing siblings of a deaf child is presented in Figure 5.3 on the next page. This model is similar to the hearing parent model but the content of personal history, biological characteristics, and knowledge about deafness within each of the hearing Camillo childrens' spheres is different. For example, Daniel is the oldest child and experienced the most complete history of the Camillos as a family. During the first ten months of his life, Daniel lived as the child of a single-parent with Sara, while Mark served in the Gulf war. Daniel also remembers when Henry was born, and was present at a point in Henry's life where there was a heavy emphasis on seeking medical interventions for his deafness. These interventions involved regular visits to multiple doctors, early education assessment and placement procedures, and audiological evaluations.

Madeline was born at a time in the Camillo family history when Mark, Sara, and Daniel were actively taking sign language classes and becoming involved in activities related to the Deaf community. Sara describes the perspective of Madeline and the younger children as, *They'll never know any different* (FN:15:3:20). At some point during this investigation, Madeline was observed playing with three dolls, rather than one. Her play behavior indicated that she considered the birth of triplets to be normal. It is likely that Madeline views Henry's deafness in much the same way. She has had less exposure to conversations about Henry's deafness as a medical condition. In contrast, her personal experiences indicate that she is acquiring American Sign Language and spoken English simultaneously through her interactions with Henry and other individuals who are deaf.

Figure 5.3. Model of the hearing sibling of a deaf child.



Note. From "Deafness, Communication, Social Identity: Ethnography in a Preschool for Deaf Children," by C. J. Erting, 1994. Copyright 1994 by Linstok Press. Adapted with permission of the author.

Finally, John, Luke, and Mary entered the family with three older siblings already established in the family and possessed their own unique bonds of biology as members of a multiple birth. The triplets had multiple care-givers throughout their first year of life, including adults (e.g., Mark, Sara, Grandmother Medina, and me) and their three older siblings who often pitched in to help with their care. While they were learning American Sign Language through their interactions with Henry, their exposure to other Deaf adults and children during their first year of life was more limited than Madeline's experience for reasons of practicality. Mark and Sara were overwhelmed with the responsibilities of three additional children and had less time to attend social events that would provide them with opportunities to interact with members of the Deaf community.

The Children Make Transitions

Three-year-old Henry and his siblings, Daniel (6 years old) and Madeline (18 months old), spent most of their Summer (1996) living at a distance from their mother while she was on bed rest in the hospital. Their summer adjustments, including the absence of their mother and the arrival of the triplets, were challenging in a different way for each sibling. Henry's challenges converged on issues related to communication access. Henry's mother Sara served as his interpreter--the primary conduit to interaction with individuals who are hearing. For Henry, deliberately or passively accessing the communication (spoken) and language (English) of his home in her absence became an even greater day-to-day challenge. At that time, Mark and Sara's greatest concern was that clear communication was possible between Henry and the myriad of helpers that filtered through the Camillo home (FN:10:3:1).

As the calendar page turned to September, Henry's home environment continued to bustle with new activity and people. Henry's communication access at home shifted again when Grandmother Medina, a user of basic sign language, replaced Uncle Steve--a fluent signer--as a caretaker for the children. The babies came home from the hospital one by one, and with each new addition, using sign language became more complicated. Daniel, Henry, and Madeline dutifully made faces at the babies and plucked playfully at their soft ear lobes and slobbery lips--but for the most part found them socially unresponsive. John, Luke, and Mary ate, slept, dirtied an endless supply of diapers, cried, and cried some more. John and Luke provided some excitement when their heart monitors blasted from time to time, but through the eyes of the older Camillo children, the babies served primarily to further distract their already sleep-deprived parents.

Daniel and Madeline may have had a better understanding of their parents' trials because they were able to hear Mark and Sara's early morning telephone conversations, recapping the previous night's stories with the babies. Mark typically arrived at work in time to call Sara as she made breakfast for Daniel and Henry. Sara's end of the conversation typically sounded like, *Which one was awake at 2:00? Did you give him a bottle or just change his diaper?* And, *I think Mary was awake because she was cold. We'll have to remember to wrap her better tonight.* Daniel expressed the complaint that all three older children may have been thinking, *I know I asked Jesus for another baby brother or sister, but I didn't ask for three*! (FN:104:2:7).

Communication at home became less accessible in many ways as Henry spent his daily interactions with more hearing, nonsigning [by choice or necessity] individuals. Henry's new communication situations included conversing with individuals who had a crying baby in each arm, and several "binkies" stuck between their teeth. He also found himself waiting more to express his thoughts or to ask questions. Adults in his environment, busy with babies and increased household tasks, frequently said to him, *Hold your thought Henry–I need to finish changing this diaper*, or simply, *Wait–the baby needs me* (FN:171:2:12). Henry found it took him longer to establish communication with his parents and maintain it.

The Maid in the Basement

My place as a caretaker with the children allowed me to see a different world nestled within general family activity. Similarly, many times I found myself sitting on the floor with the babies, realizing I was seeing the home interactions from the same [low] vantage point as Daniel, Henry, and Madeline. I had to look up to converse with adults. I noticed shoes and knees and dust-bunnies on the floor more often. With this child-like perspective to my participant observation efforts, I realized that the children interacted differently with one another than they did with adults.

First, the children possessed different rules about communication and interaction. Their interactions emerged as their need for communication grew. The children sometimes expressed frustration about communication breakdowns that occurred between themselves and Henry. However, their communication issues were often addressed directly and resolved immediately. Unlike Sara and Mark, the children never expressed concern that they *didn't know enough*, or *needed more information* (FN:4:8:6) in order to communicate effectively with Henry and one another. The children seemed to have little time or interest in ruminating over communication breakdowns and misunderstandings.

Second, the children's behavior at the time that I moved in seemed to indicate that they had territories, both physical and social, that they needed to protect. The children were cognizant of protecting their physical space and possessions, but their comments and behavior also showed me their understanding of and value for maintaining the status quo of family relationships. For example, when I was a visitor in the Camillo home, the children appeared quite taken with me. Daniel, Henry, and Madeline all vied for my attention by bringing me special toys to share and asked that I sit next to them at the dinner table. However, as I moved my possessions into the Camillo home, the social relationships I shared with Daniel and Madeline shifted. Both children made overt efforts to keep me "at arm's length" and protect their physical space and possessions. To my surprise, their initial warm welcome turned to guarded suspicion.

Sara's rearrangement of furniture and family possessions in the basement was one operation that validated my official move into the home for the children. As Sara made space for my possessions among Tonka toys, rocking horses, and a stockpile of disposable diapers piled to the ceiling, the physical space officially became *Laura's area* (FN:39:1:1). I decided to leave most of my possessions and furniture at Molly's house, but brought a carload of favorite books, clothing, and my stereo. The night I moved in, I left my possessions in the car until after dinner. Later, as I carried each load of boxes and bags in the front door and down to the basement, I could hear Mark and Sara at different stages of bathing and readying the children for bed. My last load was my portable-sized stereo and speakers. As I came in the front door, I spotted Daniel, oldest child and self-appointed spokesperson for the children, watching me from the stair landing leading upstairs. He had a tube of diaper rash ointment in his hands--obviously on an errand for his parents. I shifted my load which was cumbersome and said, *Good night, Daniel! See you tomorrow*! (FN:39:3:28). Daniel's response served to simultaneously surprise me and stake his territory. He stated that one of the rules of the house is <u>no loud music</u> and made it clear that he stood behind that regulation. He commented that if he was downstairs playing, he didn't expect to have to listen to my music. I tried to respond with an egalitarian approach, *You're right Daniel. This is your house and I need to follow the rules*! (FN:39:4:2). Again, Daniel surprised me by not responding. He stood on the stairway landing in the living room and watched me carry my load down to the basement. I was never certain if he was thinking about what I said, or if he was trying to make a disapproving point with his silence.

Also, during the first few weeks that I lived in the home, I had a sensation that the children perceived me as a person who was "there for Henry" only. Initially, it appeared that the children made a distinction among visitors. At first, I assumed my select status as "Henry's special friend" developed because I was associated with the university and used sign language. During the weeks immediately after I moved into the home, Daniel and Madeline's social responsiveness to me shifted from a favorable reception to interactive postures that kept me socially "at arm's length." Based on their surface behavior, it appeared that as soon as someone began to use sign language, they were socially considered as a person "visiting for Henry." However, various other scenarios can be used to support my presumption.

Sara and Mark's discussions about visitors in the home also contributed to Daniel and Madeline's understandings of my presence as a "live-in outsider," versus the intent of other visitors. Sara and Mark struggled to find individuals outside the family who knew how to sign fluently and who could also interact with all the children and not only Henry. Sara explained that visitors from the field of deafness sometimes exasperated her because they showed a particular interest in spending time with Henry and not necessarily her other children.

My efforts to contribute to the affairs of daily family life resulted in the development of my role as "maid" during the early days of fieldwork. The day after I moved in, I assumed cleaning and caretaking responsibilities in the house. It took weeks before Madeline allowed me to tie her shoes, and her initial reaction to my attempts at cleaning was a vocal, *Mommy do! Mommy do!* combined with bodily attempts to wrestle the mop or vacuum out of my hands (FN:50:2:3).

Sara introduced me to outsiders as her helper and jokingly brought visitors to my living area some evenings so they could meet "the maid in the basement." While I struggled personally and professionally with my new social label, my role as maid seemed to help the children, including Henry, make sense of my presence. None of the children were old enough to understand my research intent, and I was the first non-family member to live under their roof. Henry, more than the other children, watched what I did around the house and asked me questions about my activities. He started by asking questions like, *HELP MOM WITH TRIPLETS?* or *YOU COOK DINNER?* (FN:50:2:20). Eventually his questions stopped and his behavior demonstrated that he understood my role in the house. For example, I knew Henry had a general understanding of my role in the household the day he wrinkled his nose and handed me his dirty socks implying: *Here are my dirty socks. I've seen you do the laundry so that must mean it's your job to take care of these* (FN:54:1:28).

Navigating and Interacting in Deaf and Hearing Environments

Henry Camillo entered the Fall season of 1996--his second year of preschool--experiencing and adjusting to changes in both his home and school environment. At home, helpers outside the immediate family with various levels of sign language fluency were navigating in and out of the house, bringing food, providing childcare, and offering other means of support to the family.

In addition to changes at home, Henry's school transitions were numerous. First, his educational placement changed in design from a split part-time arrangement (mornings at Marshwood--the local public school program, and afternoons at Parkwood) to a full-time day school placement at Parkwood. Henry also made a natural transition to a new team of teachers and support staff with his change in placement and progressed to a preschool class for older children.

One of Henry's tasks in the Fall of 1996 was to make sense of his developing interactions in both home and school communities, while the social patterns of activity in those settings changed and shifted in unpredictable ways. By developing interactions, I mean that as a regular part of his day-to-day living, soon to be 4-year-old Henry made sense of his world by negotiating the complexities of interactions that occurred in different modalities and languages (e.g., auditory and visual/spoken and written English and American Sign Language), among various people (e.g., parents;

siblings with and without communicative competence; and deaf and hearing teachers and staff at school, with and without communicative competence), and in different environments (return to Table 3.4 for information regarding the social environments and actors who interacted with Henry during data collection).

Daniel

The winter months marked a time when Daniel was working to resolve some very complicated feelings of anger about his new siblings and still, Henry's deafness. The following illustrates Daniel's efforts to make sense of where deafness fit into his new family structure.

A Christmas package came to the house addressed to the triplets: Mary, John, and Luke Camillo. The three oldest children were practically dancing when the gift came to the door and were quite disappointed when they realized it wasn't for them. Henry missed a lot of the discussion about who the package was for because some of the information was signed and spoken simultaneously, while other information was only verbalized. Still other information was exchanged when Henry's back was turned or when he wasn't watching.

The story began with the ring of the telephone. Sara went upstairs to have a conversation with the doctor who wanted to take John and Luke off their apnea monitors. The package arrived and Daniel and Henry were meandering around the package for a closer look at the box as I started to feed and change the babies.

Henry looked more closely at the handwritten address. The Camillo's live on Herring Street and Henry commented to Daniel and me that the address said "Henry." Henry signed, LOOK, MOTHER WRONG! *BOX FOR TRIPLETS* _**AND**_ *HENRY!*

Meaning, *See! Mommy was wrong! This package is for the triplets* *__and__* *Henry*! Daniel signed back, *NO! HENRY WRONG! NOT FOR HENRY!* Daniel was not a fluent reader at this point and he became stressed about Henry's remark. I could almost see the wheels turning in Daniel's head. He was thinking there was a chance his mother misread the package. Daniel and Henry both became emotional and went back and forth a few times taunting, *Yes it is for Henry,"* *"No, it isn't for Henry.* Their argument reached a turning point, and Daniel grabbed Henry by the arms and pinned his back against the coffee table. Daniel screamed at Henry, *You are stupid! You are wrong! That package is not for Henry!*

I put down the baby I was feeding. I signed and said, *Okay boys--that's enough. Daniel, you are hurting Henry and hurting others is not permitted in this house. Also, Henry can't understand you or respond with his arms pinned down to the table.* Daniel didn't budge and I continued with an analogy, *It's like if I stuffed a sock in your mouth and expected you to talk to me. You need to chill out and let go*" I was very conscious of my role and didn't want to intervene as a disciplinarian. I also didn't want to resort to touch the boys in order to separate them. However, both boys were upset and crying and neither appeared to be calming down. I gave one more signed and spoken warning and then stepped in to separate them. The moment they broke physical contact Daniel ran upstairs screaming, *I hate him! I hate him! I just want to beat him up*! (FN:55:2:22). I could hear Daniel interrupt his mother's telephone call.

I started to explain to Henry that the street name started with an "H-e" like Henry, but it was really the name of the street. As Sara came downstairs Henry immediately pointed to the box, and she explained the same thing. Henry persisted in trying to make his point and Sara chastised him for interrupting her telephone call. She told Henry that if he mentioned the box one more time, she would put him in time out – and that he should never interrupt her when she was on the telephone. The entire time she was chastising Henry, Daniel hummed to himself and smiled at me.

Sara was ready to change the subject to start helping Daniel with his homework, and I said, *Daniel, are you going to tell your Mom what you did before you interrupted her telephone conversation*? (FN:55:3:4). Daniel didn't respond. I continued, *Daniel, I explained to you that when you hold Henry's arms, he is unable to understand what you are saying, or communicate back to you. You were holding him down to the coffee table, and he was very frightened and confused.* Daniel responded, *I hate having to sign to him all the time!* I said, *I know it can be frustrating Daniel, but the frustration is just as bad for Henry. Your behavior while your Mom was on the telephone was unacceptable.* Daniel looked at Sara and she said, *You need to take six minutes upstairs Daniel and chill out.* (FN:55:3:13).

Daniel and Henry's disagreement about the gift for the triplets was resolved shortly after Daniel's 6-minute time-out period, but his sense-making and adjustment continued. This was a difficult year for Daniel in almost every interactive sphere of his life (school, home, Boy Scouts, etc.). He shouldered a great deal of responsibility as the oldest sibling of six, a young child transitioning from kindergarten to first-grade academics and the marked decrease in one-on-one attention from his parents. In addition to that, Daniel was a sensitive, vibrant child who took situations to heart more readily than other children might. Mark and Sara actively sought ways to support him, and often pondered what they could do for him in order to take off some of the pressure.

While there was evidence of his growth and adaptation throughout the entire year, I caught a glimpse of an older, wiser Daniel at the end of my fieldwork when we visited Mark's side of the family. One evening while we attended a cousin's Little League game, the Camillos were approached by a family of four--the oldest, singleton girl and her three younger brothers who were a set of triplets. As the children were introduced, Sara commented to Daniel, ***She's the oldest of lots of kids too!*** (FN:177:6:16). Daniel and the oldest child of the other family made an immediate connection. Their facial expressions as they shared family stories were filled with empathy and understanding. I was left to wonder what supports could be made available for siblings.

Madeline

Madeline's transitions were challenging, but because of her age and position in the family (born after Henry), her ability to interact and moderate communication between speaking and signing family members seemed less stressful. One of Madeline's communication challenges involved her own developing speech. She seemed to be aware that family friends and extended family members often had difficulty understanding her communication attempts in spoken English. She used ASL to accommodate for and supplement her developing speech skills, when her mother wasn't available to interpret for her, or in addition to her mother's efforts. Madeline changed her choice of communication modality when people asked her to repeat her statements, by adding signs or repeating her statement using ASL only.

Using signs and speech separately or to supplement one another did not appear to be a confusing task.

Madeline was often the focus of Henry's attention after school while Daniel was watching television or doing homework and Sara prepared dinner. Henry seemed to take great sport in chasing Madeline in a circle around the living room/dining room area. Their loop from room to room was repetitive, starting typically with Henry snatching a toy from Madeline's hands. Henry dangled the toy in front of her, bobbing his head from side to side and wagging his tongue, implying, *Nah, nah! I have your toy*! (FN:31:4:18). He allowed Madeline to recover the object, and the chase began.

Madeline screamed, *No! No! Mine!* skirting the chairs and table legs in the dining room, rounding the corner through the kitchen. I could tell when they entered the kitchen because Sara always sounded a warning, *No running in the kitchen! Hot stuff in here! Danger! Danger!* I could also tell by the stilted sound of Sara's commands that she was signing and talking at the same time. The pair always headed back into the living room where sometimes Madeline sought protection from an adult if one was present or Daniel, flopped on his belly in front of the television. Most evenings by the time Mark arrived home for dinner, Henry and Madeline were sweating and had worked up quite an appetite.

While Madeline frequently appeared consumed with structuring her life around the power struggles of a "spicy" 2-year-old, she was also attentive to and observant of her new home environment. In some respects, Madeline made sure that she was included in the regular bustle of family activity by assuming the role of the delegate or moderator of family interactions.

Paul Preston's dissertation, later published as a book (1994), explored the experiences of hearing children who grew up with deaf parents. Granted, having an auditory orientation and growing up with deaf parents is a different circumstance than having a deaf sibling. However, Preston saw sibling relationships as characteristically more likely to be "reflective of self," and distinctive to the process of identity development, serving to set the sibling relationship dynamic apart from parent-child interactions. Consequently, some of Preston's findings shed light on Madeline's developing perceptions of self within the intimacies of her family and her relationship with Henry.

Preston (1994) interviewed 123 informants who had more than one sibling. He devoted one portion of his investigation to learning about the developing perspectives of deafness among deaf and hearing siblings. He noted that "birth order, temperament, and gender all had an effect on [sibling] communication skills and uses" (p. 96). My observations of the siblings in the Camillo family agreed with Preston's findings, particularly within the topic of "designated interpreter."

Preston (1994) found that 63 of his 123 informants "described one sibling in their family as the principal interpreter" (p. 97). While more than half of Preston's 63 informants (37) described the eldest child as the designated interpreter in families with Deaf parents, "the remaining 26 families identified the eldest daughter," Madeline's position among her siblings, as the person most likely to assume the primary interpreting role in the family (p. 97).

The Triplets

Until the triplets began to respond to Henry and others by imitating signs or babbling in a gestural way, Henry most frequently vocalized without signing to the babies, regardless of others' encouragement to use sign language. The way that Henry interacted with the babies in the early months appeared to be a replica of the interactions he observed between the babies and other hearing family members. Like everyone else in the family, Henry would lean in close to each baby's face, widen his eyes, exaggerate his facial expressions, and say, "Ba-ba-ba-ba-ba!"

Frequently, I overheard Sara and Mark explain to Henry that he should sign with the babies. "They want to see you sign!" (FN:61:1:26). It seemed that Henry learned and produced interactive behavior by watching, not through instruction or direct requests.

A wellness checkup for the triplets at the end of April evidenced the duality of the babies' developing worldviews. While not much information is available concerning how infants reflect internally upon their own behaviors, there is considerable evidence that they learn by watching and modeling the behaviors of individuals in their immediate environment. The babies were almost 9 months old, and Sara took them to see a team of doctors for a routine check of their growth and development (FN:135:1:6).

Sara told me that they arrived early for the appointment. Mary, Luke, and John were all in good spirits. The weather had been unseasonably warm and they enjoyed traveling in the truck when they didn't have to be bundled and unbundled in heavy winter clothing. The babies were also developing greater mobility, which seemed to reduce their day-to-day frustration. At this point, John and Luke were able to sit up on their own, and Mary could sit with supervision if she was "propped."

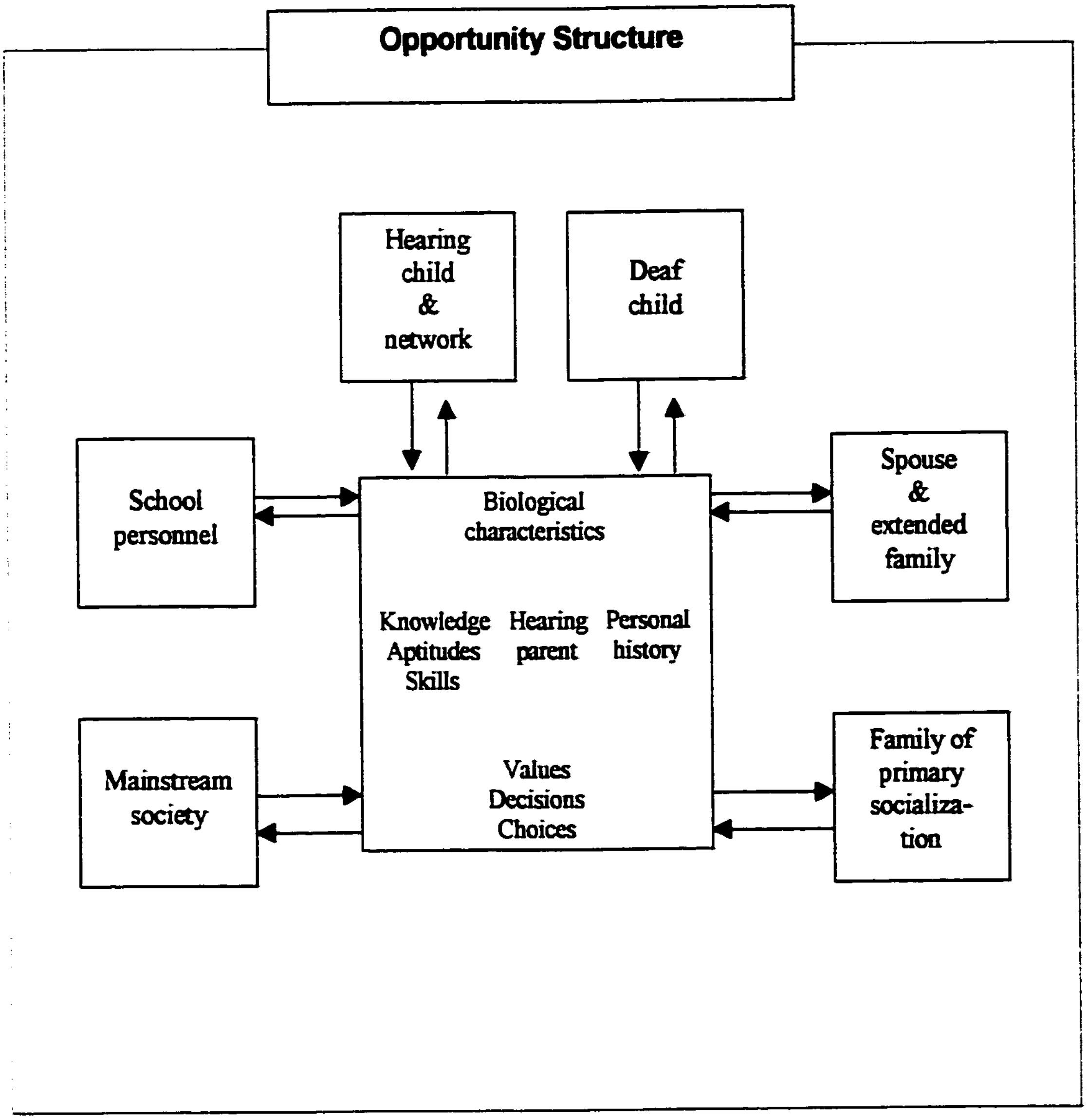
Sara undressed the babies and arranged them sitting up in a circle on the floor of the examination room. Two doctors and a nurse circled the children and performed some play-based tests to check their responsiveness to sound and light. The doctors noted that several times Luke reached out and touched the doctor's arm, made eye contact, and smiled--they noted his behavior as unusual. Next came the vision check--the babies easily followed flashlight beams around the room. Finally, the doctors began to bang and tap on tabletops and toys. Their expectations for the babies were for them to look to the source of the sound. Instead, when the doctors banged on different objects in the room, the babies' gaze shifted to make eye contact with the doctor making the noise. The doctors were surprised by their behavior, and Sara explained to me that it took her a few minutes to "cue in" to why the babies' responses were unusual. She explained to the doctors that their family used sign language in the home because her 4-year-old is deaf. She demonstrated that frequently deaf people communicating in sign language gain attention by tapping on tabletops and waving their hands. Evidently Mary, Luke, and John had learned this behavior by watching and modeling others in the home. In the end, the doctors changed their notations that indicated "unusual" behavior and instead commented that the babies are "more visually responsive" than most hearing babies their age (FN:135:1:27).

The body of literature concerning the contributions and needs of siblings, and interactions among children in deaf/hearing families is sparse. One is left to question what the future holds for Henry and his siblings. Because of gender, will baby-Mary some day assume the "back-up" interpreting role in the Camillo household? What decisions will they make concerning the place for American Sign Language and spoken English in their family interactions? In the next section that addresses interactions among extended family members, the reader will see how Henry's siblings provided a tangible linguistic and cultural bridge between immediate and extended family members.

Section 3: The View of Extended Family Members

It is important to preface the findings presented in this section with a brief description of the views of deafness held by extended family members who chose to participate in this investigation (see Appendix B for a list of extended family member expert informants). These views emerged using Figure 5.4: Model of the Hearing Extended Family Member of a Deaf Child. The details of this model concerning extended family worldviews are particularly important when presenting the meaning of the stories they told concerning how they make sense of deafness and their developing, interactive relationship with Henry. Notice that within the model, there are less interactional spheres than the other three models (hearing parents, hearing siblings, deaf child), and opportunities to meet and maintain relationships with deaf persons other than Henry are rare. Henry's extended family members live at a geographic distance from his primary family of socialization. While many of his grandparents, aunts, and uncles kept in close, regular contact with Mark and Sara via telephone conversations, a small percentage of the extended family were able to interact directly with Henry on a regular basis. Due to Henry's identification as a deaf person, certain individuals in the extended family had more opportunities for

Figure 5.4. Model of the hearing extended family member of a deaf child.



Note. From "Deafness, Communication, Social Identity: Ethnography in a Preschool for Deaf Children," by C. J. Erting, 1994. Copyright 1994 by Linstok Press. Adapted with permission of the author.

interaction than others, due to their personal characteristics (i.e., age, marital status, etc.) and other aspects of personal history (e.g., taking sign language classes before Henry was born, experiences with Deaf people outside the family).

In order to provide further personal background about Henry's extended family members, this section begins with the brief introduction of individuals who volunteered to participate in this investigation, as well as a description of the environmental contexts where data were gathered. The second part of this section describes how Henry Camillo's extended family members made sense of his deafness as they gathered information from multiple sources. This second component describes the four views of deafness that resulted from analysis, depicting how Henry's aunts, uncles, cousins and grandparents are influenced by their views of deafness as they interact among one another, Henry and his immediate family members, and participants in general society.

In comparison to the long-term engagement that I experienced as a field worker in the Camillo home, data analysis of the family reunions more closely resembled examining a "snapshot" of how extended family members made sense of deafness. Therefore, the form of my data, the types of analyses I conducted, and the resulting portrayal of extended family perspective is qualitatively different from other findings presented previously in this dissertation. Data concerning the perspective of adult extended family members consist primarily of ethnographic interviews. The two separate family reunions were scheduled back-to-back. We visited the Camillo extended family for one week (6/28/97 to 7/4/97) and the Medinas the second week (7/8/97 to 7/15/97).

The Camillo Family Reunion (June 28 to July 4, 1997)

Most of Mark's family of origin (the Camillos) live in a northern United States city that I call Jamestown. The vacation officially began as Mark and Sara loaded their truck full of children and enough food supplies to last for a week. The children were particularly excited because I followed the truck in my own vehicle. Before we left for the trip, Henry provided me with a play-by-play description in ASL of how I would do my best to keep up with his Mother who was driving. He teased that their truck was stronger and faster than my car (FN:175:12:5).

During the first few minutes of the 6-hour drive, Daniel, Henry, and Madeline waved to me from their seats in the truck and then gradually settled into their private travel conversations. Sara had to pull over one time along the way because one of the babies got sick. Henry was particularly concerned about my safety as I walked from my car to their truck on the side of the road. He questioned me as I peered into the truck, "WHY OUT CAR?" meaning, "What are you doing out of your car?" I explained that I got out of my car to see why we'd stopped. Henry responded, "MARY THROW-UP" and pointed insistently in the direction of my car.

During the week of the Camillo extended family reunions, we stayed with Mark's brother Harry Sr., his wife Maura, and their four children: Harry Jr. (13 years old); Joshua (11 years old); Britta (7 years old); and Melissa (5 years old) (see Appendix L for a Camillo family tree diagram). When we arrived in Jamestown, we unpacked our suitcases in Harry and Maura's Victorian-style home and Sara gave me a quick tour. The house was old and large with a screened-in front porch and a long, grassy backyard. It appeared that the house had undergone several additions, extensions, and partitions over the years as Harry's family grew and spread out.

I stayed in a playroom that had been converted into a guest room. In addition to the single cot with the pink and yellow quilt, the room contained piles of art supplies and toys, a roll-top desk, and an old school desk with benches, designed as a work or art area for the children. The room was located in the back corner of the house and had two windows, one overlooking the backyard and the other, the sidewalk that ran along the side of the house. I was able to gather most of the interviews with Mark's family from this playroom location. I also recorded video footage of the children riding bikes and playing baseball from a perch I discovered on the back-porch roof, extending beneath my temporary bedroom window.

Mark, Sara, and the Camillo children stayed in a bedroom, partitioned with sheets, located on the top floor of the house. One half of the room was arranged with three cribs for the babies while the other side of the room had beds and sleeping bags made up for Mark, Sara, and the three older children. In their room, the window shades were drawn and two air conditioners ran non-stop in an effort to control the summer heat that baked the side of the house.

Activities for the children were numerous at the Camillo gathering. One night "the boys" went to a professional baseball game, and on another night, we celebrated the shared birthdays of two of Mark's siblings with a cake and ice cream party in the backyard. The entire family also attended cousin Karl's Little League game, a fire works display, and the 4th of July family picnic.

On the days when "formal" activities were not planned, Daniel, Henry, and Madeline busied themselves playing whiffle ball in the backyard or riding vehicles up and down the sidewalk on the other side of the yard. Other social activities included having dinner at Aunt Margaret and Uncle Christopher's house (cousin Karl's parents), visiting Aunt Bobbie and Uncle Michael at their restaurant (cousin Roberta's parents), playing with the all-terrain vehicle in cousin Bart's backyard (Aunt Elaine and Uncle Joe's son), meeting Uncle Steve for story hour at the local library, and stealing sweets from Grandma and Grandpa Camillo's cookie jar (Steve and Geneva Camillo).

The Medina Reunion (July 8 to July 15, 1997)

Henry and his family and I flew on separate flights to Sara's sister's home in a southern part of the United States to a place I call Marble Beach. We arrived two days after Aunt Nannette and Grandma Medina (Peggy), and one day after Francis drove into town with his two girls, Marie and Christine (see Appendix M for the Medina family tree). We stayed with Bobbie and her husband Jerry. The couple were newlyweds and had just purchased their three-bedroom "fixer-upper" home.

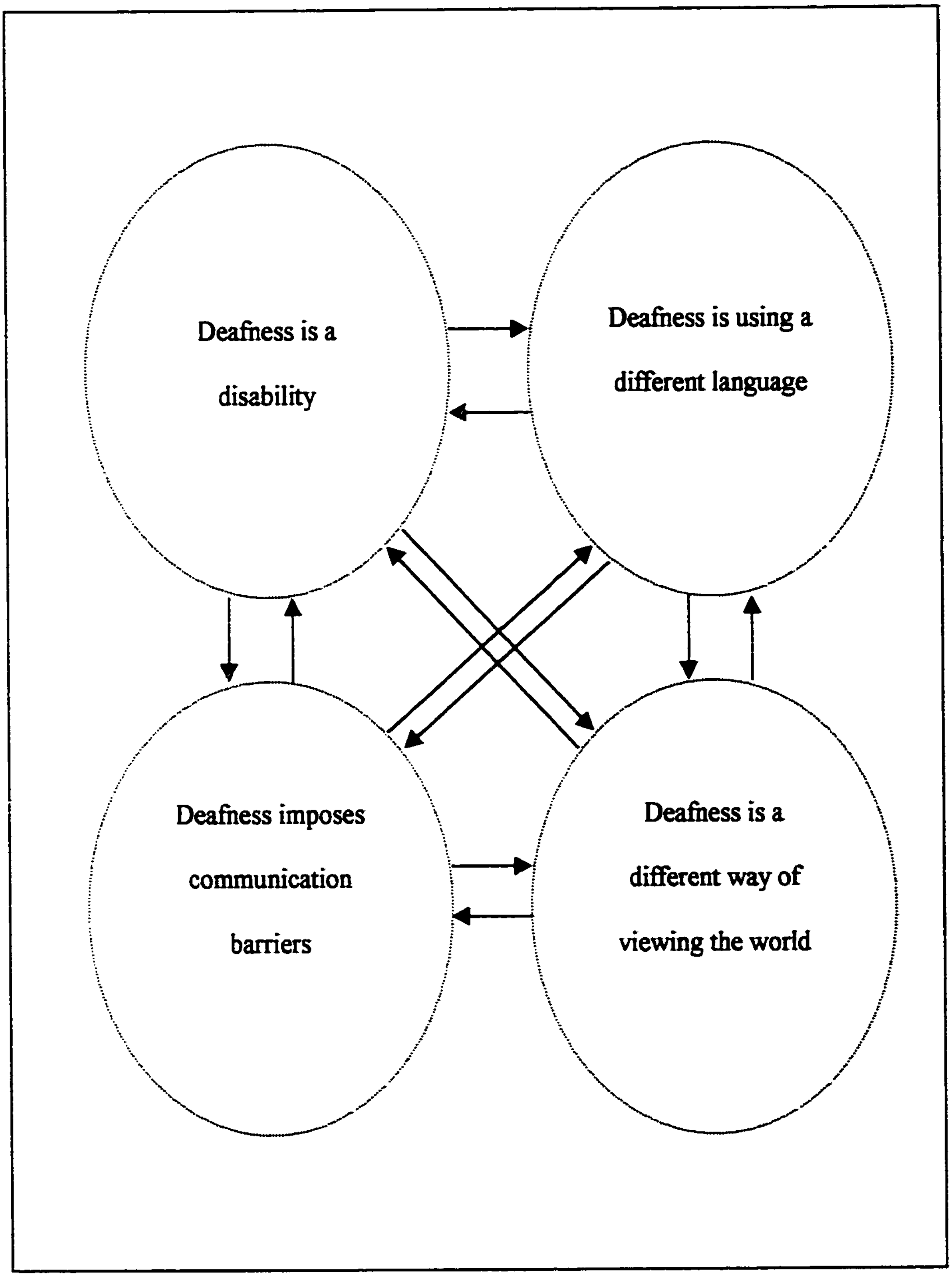
The first evening at Bobbie and Jerry's they proudly showed us their "before-and-after" snapshots, detailing the renovations they had recently completed. After a week of "on-the-go" activities while visiting the Camillo extended family, Mark and Sara breathed a sigh of relief when they arrived at Bobbie and Jerry's. Their intent for the week was to stay home and relax. They proclaimed, "We're not going anywhere until we have to get on the plane next week!" Several days later, they changed their mind and decided to rent cars to visit Sara's brother Ernest Jr., living with his wife and family in a town near Marble Beach. The main attraction at Bobbie and Jerry's house was their pool, located in their fenced-in backyard. Other than day trips to the ocean and Ernest's house, most of the days at Marble Beach were filled with parties by the pool, more birthday celebrations (Daniel turned 7 and the triplets turned 1), and long visits between Sara, her siblings, and their children.

Extended Family Understandings of Deafness: Four Worldviews

The following worldviews of deafness emerged primarily from the analysis of ethnographic interviews conducted with extended family members. Many of the questions asked during ethnographic interviews were open-ended and inductive. However, some of the interview questions were developed before the field visits to the homes of extended family, with the intent of looking at the process of how extended family members make sense of deafness.

It is important to understand three critical aspects of the worldviews presented (see Figure 5.5). First, making sense of deafness via one of the four worldviews is not a mutually exclusive experience for extended family members. I am taking the position that the beliefs and understandings of each family member are permeable entities, capable of alteration through the process of interaction. It is possible for Henry, his parents, and his siblings to move about within any of these worldviews at any one time, depending upon the particular experiences and information they are provided during interactions. In other words, anywhere there is human interaction within a sphere that involves symbolic exchanges related to deafness, a particular view of deafness will be constructed. Second, while I am grouping different extended family

Figure 5.5. Extended family member's worldviews.



members within the four worldviews that emerged, each family member does not belong exclusively to that worldview, nor are they considered "stuck" with a particular worldview. Aspects of each worldview, and each model of individual social actors may create the tendency for one person to stay within a particular worldview longer than another. However, the boundaries that separate these worldviews from one another are fluid, changing, and porous. Lastly, I am not taking the position that these worldviews represent a continuum of understanding; rather, they model distinct belief systems that can be experienced in isolation or simultaneously. One worldview is no better than another. In other words, each worldview simply represents the results of interactions within different spheres related to deafness. Movement from one worldview to another depends on increased or decreased opportunities for interaction with individuals who possess various perspectives of the Deaf experience.

Deafness is a Disability

Individuals within this model make sense of deafness as they access traditional, medical, and educational sources of information. Hearing people in mainstream society are most likely to be found with deafness is a disability beliefs. Accessing information about the deaf experience within this opportunity structure takes minimal effort for hearing people as "deafness is a disability" interactions are frequent and common in the media (i.e., television broadcasting, popular movies, and newspapers). It is understandable that certain members of Henry's extended family would be found within this model because their life experience lends minimal contact and interaction with Henry, as well as individuals who are culturally Deaf.

Grandmother and Grandfather Camillo. Joe and Geneva Camillo had 11 children and Henry was one of 22 grandchildren. Another one of their grandchildren (Bobbie and Michael's daughter, Roberta) was diagnosed with Downs Syndrome when she was a year old. Joe and Geneva are in their mid-60s, and live comfortably in a townhouse in Jamestown, where 8 of their 11 children have also established homes nearby. Joe is a quiet man with a warm smile and Geneva is the spokesperson for the couple and the family. Their parenting and grandparenting style is "hands off" or disengaged in nature. When asked their opinion during our interview, Geneva was quick to state, "Oh, advice I give only when it's asked for, no matter what!" (INT:8:19:29). They did not consider providing unsolicited advice to their children about child-rearing and parenting as one of their roles as grandparents.

Geneva and Joe had several prior experiences with individuals who are deaf or hard of hearing, who used only spoken English to communicate, and hearing people who learned to sign from books and videos, independent of interactions with deaf people who sign. Henry was the first person they had ever met who used sign language as his primary modality. I asked them the question, "Do you know any other people who are deaf besides Henry?" Their response required me to qualify my answer concerning how I define the term <u>deaf</u>. Geneva asked and then elaborated, "People who are deaf or people who sign? I know some people who are deaf and I know one lady who signs, but she doesn't know me from the man in the moon." She explained that she also has had interactions with others who can hear but use sign language to supplement their speech.

> I know Father David. I was at a [church] meeting one time and he gave a speech. He moved away from the speaker's place so he could sign to this deaf lady who was there, so she wouldn't be [left] out. (INT:8:15:36)

Geneva went on to tell me about other family members who lost their hearing later in life. "My mother's cousin was deaf. She couldn't sign. She played the piano beautifully, but she never heard a note." Geneva turned to Joe and asked, "[Do] you remember Helen?" Joe responded, "Yeah, she was a neat gal." Geneva continued to explain how her great cousin Helen was late deafened and tried to use a hearing aid. "She got a hearing aid when she was, I guess maybe in her 50s. She carried it in her purse. It bothered her [because] she heard too much" (INT:8:15:45). Joe added a description of other late-deafened adults that were within his opportunity structure:

> Maybe for the last 50 years of my mother's life, she was deaf in one ear. You could talk to her through the one [ear], but if you were on this side of her, she couldn't hear a word. It wasn't where you had to sign for her. (INT:8:16:4)

Geneva added, "Same with my dad. He was hard of hearing and my sister; she wears two hearing aids. But she doesn't sign either because she lost her hearing gradually" (INT:8:16:21).

The majority of Joe and Geneva's interactions with individuals who are deaf were with people who initially had their hearing, but lost it later in life. Their experiences told them that deafness is a disabling condition that is rehabilitated using amplification devices. In light of their interactions with Henry, Joe and Geneva lived at a distance from Henry and saw him at family gatherings once or twice a year. Although Henry is their grandson, they'd had few interactions with deaf people who used sign language.

Joe and Geneva shared their perception of communication experiences with Henry. Geneva explained,

> In his [immediate] family, he does very well. But with us--we don't know enough sign language to really communicate. All I can do is hug him and kiss

> him and tell him I love him. (INT:8:12:2)

Because they did not have the ability to use sign language to communicate with Henry, Joe and Geneva stated that, "deafness requires patience and can be frustrating" (INT:8:17:26). When asked what it was like to have a deaf family member, Joe and Geneva did not discriminate between their deaf and hearing grandchildren. They believed that addressing the differences among the children would show favoritism.

> Geneva: Great! I don't know that there is any difference!
>
> Joe: Personally, I don't think that we can differentiate between any of them. We love one as much as the other and I hope we don't show any partiality for any reason, whether it be deafness or dumbness or whatever. (INT:8:17:26)

In their efforts to be impartial, Geneva admitted, "One thing is that sometimes I forget that he is deaf." Joe agreed, "[nodding] That's easy." Geneva elaborated on their predicament, "I try to talk to him with his back to me and, of course, he doesn't hear me." While Joe and Geneva didn't like to discriminate between how they interacted with Henry and the other grandchildren, they did view him as an "exceptional" child. Geneva described how their interactions with Henry were grounded in how they interacted with their granddaughter Roberta, who has Down's Syndrome.

> One thing, you can't treat any exceptional child too much different than the regular child. You have to keep them more or less the same [Joe nods in agreement]. We learned that with Roberta. They get to know it if they get treated special and they expect it and I don't think it would be right. So, you have to treat them more or less normal. (INT:8:20:9)

Joe explained that they developed their philosophy of interacting with Henry by watching how Roberta's parents (Bobbi and Michael) responded to her. Joe revealed that the reason they did not address their grandchildren's differences was because they didn't want Roberta and Henry to know that they were different from the other grandchildren. Geneva agreed, "Yes, she doesn't know any different. She knows she looks different because if she sees someone with Downs on TV, she says, "Oh they look like me." She recognizes that. At the same time, Joe admitted, "[It's] frustrating for us, you know, that we can't communicate with him [Henry] like you do or like a lot of our other kids do." Geneva agreed and explained that the resources available to them to learn sign language were not adequate, "Bobbi and them--they communicate very well, and I have cards. We don't go through them the way we should. We have books, but still [shaking her head]" (INT:8:12:10).

As they expressed their frustration about communication, Joe and Geneva acknowledged that their lack of sign language influenced Henry's degree of access to communication in their home.

Geneva: One thing I don't want is to ignore [Henry].

Joe: Oh no! We don't do that.

Geneva: You can't do that.

Joe: He looked sad the other day when he was at our place. He was sitting back all by himself and all the other kids were playing and he looked like he was bored.

Geneva: Really? Oh no!

Joe: Maybe he was just tired. I don't know.

Geneva: But as soon as he gets out of the car, he jumps into your arms and that makes you feel good. (INT:8:12:30)

Aunt Bobbi and Uncle Michael. Bobbi is Mark Camillo's older sister. She married Michael, and together they owned and managed a popular up-scale restaurant on the outskirts of Jamestown. They are the parents of 13-year-old Roberta, who has

Down's Syndrome. In her short life, Roberta was also diagnosed and treated for childhood leukemia. At the time of this interview (July 2, 1997), Roberta was weeks away from being declared formally as "in remission"--a cancer survivor. Bobbi and Michael have had both positive and negative experiences while advocating for Roberta within both medical and educational systems, to ensure that their daughter receives quality health and educational services. Bobbi and Michael's interactions with individuals who are deaf were limited to childhood friends (Michael remembered a deaf child in the neighborhood who used spoken English to communicate), individuals they encountered during interactions with mainstream society (media events such as guest stars on the "Johnny Carson Show," and the movie "Mr. Holland's Opus"), and a few of Roberta's classmates--deaf children who were educated in full inclusion educational settings. Consequently, Bobbi and Michael's understandings of deafness were built on information they gathered from a medical perspective, and viewed Henry as a child with a disability.

Bobbi told me her story of Roberta's birth and diagnosis. She described this process as a traumatic one. During her interview, Bobbi shared sentiments of empathy concerning what Mark and Sara experienced when Henry was born and identified as deaf. Bobbi felt that Roberta's birth and diagnosis helped to prepare Mark and Sara for Henry's arrival, as well as his differences.

> We really broke the family in, when Roberta was born. I knew right away Roberta had Down's Syndrome. Her pediatrician fiddle-faddled around with it [the diagnosis] and he told me two days after she was born. As soon as I saw her, I knew in my heart right away. He said, "I think maybe she has Down's, but maybe not. There are some characteristics there, but some aren't there, but I don't think we have anything to worry about. We'll just see how she develops. (INT:12:3:22)

Bobbi shared another experience that compared her experiences with Roberta to Mark and Sara's feelings with Henry--a lengthy delay before they knew "what to do" with the diagnosis.

> And he [the doctor] did this [delayed diagnosis] for a whole, entire year. Some family members came back to me later and said, "Well, we knew something was wrong, but we didn't want to say anything." Then Michael was like, "Well, don't say anything because if the doctor doesn't know, how do you know?" So, you that's how we broke our family in. That broke the ice for the entire family, because some of them knew and wouldn't say anything. Some of them had no clue and it was just hard. So, when Henry came along, it was like the ice is already broken. No problem. We can handle it. (INT:12:4:2)

Bobbi empathized with her brother Mark's situation to the point that she became emotional when she recalled Henry's birth during the interview:

> I was at work and that was like, whew! It was just hard to keep working. They didn't really know a whole lot that was going on at the time. I'm going to cry [Bobbi covers her face]. (INT:12:4:6)

I interjected, "Well they said that they thought he had some kind of internal problems." Bobbi continued, "Yes, they thought he had a cleft roof and you know, the initial impact [information about Henry's physical condition] was a lot stronger than the outcome, thank God." I asked, "Do you remember what you were thinking?" Bobbi explained,

> Oh, I just started praying right away, "Just keep him. And if there's something wrong, let everybody deal with it and help him." And that's your initial shock when a child with a disability is born. You know, that's not what I expected. (INT:12:4:28)

Bobbi's experiences as a mother of a child with a disability had a strong influence on the way she views the world. As mentioned previously, she had a strong inclusionist perspective, believing that people with disabilities require an education that emphasizes being "integrated" into society. For Bobbi, being "normal" meant fitting in and behaving like most people in mainstream society, including using a spoken language as a primary form of communication.

Bobbi and Michael developed views of sign language that exemplified the perceptions of mainstream society. Bobbi saw sign language as a tool that she could use with Roberta or others if she was in a noisy environment or in a situation where it was inappropriate or not possible to use spoken English. She explained,

> [Sign language] comes in handy if [Roberta] is in a crowd or, like one time she was in a play and she wasn't really participating. She was shying away, and I signed to her, "LISTEN" or "SIT" and "STAND." [Bobbi signs the three directions]. So, it came in handy. And when she was in the hospital that one time and she was deathly ill when she couldn't talk. She couldn't communicate with the doctors. Her tongue was swollen to three times its size. She had sores all through her mouth and down her throat and she was signing to us. And that was the moment where Michael agreed that sign language was good for her. (INT:12:4:8)

Bobbi and Michael were remedial signers, meaning they did not understand the intricacies of using American Sign Language (ASL) to interact, nor did they have ready access to Henry's thoughts and perceptions of the world. Consequently, when asked what it was like to communicate with Henry, Bobbi and Michael provided stories of interactive experiences that typified miscommunication, and lacked a thorough understanding of the intent of Henry's expressive communication. Bobbi explained,

> I sort of play off him, you know? Like I thought he was telling me [that] I was crazy, but it all clicked when you said he was really saying, "I don't understand." Sometimes I think he looks at me like, "What the heck are you trying to do?" There was one time at the house, though, where he sneezed and I just made this face [puzzled expression]. I guess he caught my face and I said, "Well how do you say 'God bless you'?" And he looked at me and signed, "BLESS-YOU." (INT:12:7:1)

Bobbi also underestimated Henry's ability to be a competent communication partner. In the next story, Bobbi explained how Henry interacted with her, asking if she was going home after she waved good-bye.

> Whenever I was here [Harry and Maura's house] the other night, I said I was going [and waved] "BYE-BYE." Henry went [Bobbi signs], "HOME? HOUSE?" He went just that little bit further to show me the signs HOME and HOUSE. It was...a 4 year old. I think that's pretty neat. (FN:12:7:22)

Bobbi was impressed with Henry's ability to participate in this simplistic exchange of information, and gave him credit for behaving like a "typical" 4-year-old. During our interview, I explained to Bobbi the conundrum that exists concerning the many hearing parents of deaf children who choose to sign with their child but never develop fluency in the language. I asked Bobbi, "Why do you think hearing parents don't sign to their kids?" Bobbi responded,

> Well, I think maybe sometimes they're embarrassed. I really do. And it's not that they don't want to get involved. I just think that that's just not the way it's supposed to be. And [they think] "If I don't do it, then maybe it [the deafness, or need to sign to the child] will go away." You know, maybe the child will become more normal, more what I was expecting. (FN:12:10:31)

Henry's Uncle Michael, Bobbi's husband, viewed sign language as a crude, gestural form of communication. Michael made sense of deafness based on his experiences with the special education system that addressed the needs of his child who could hear and television programs that were popular in mainstream society. His interactions with Henry were minimal, and he was not interested in learning to use sign language. Michael told me a story during our interview that demonstrated how he learned misinformation about the deaf experience from a late-night television program. He explained,

> I'm not totally for sign language you know? Agree with the sign language? [My opinion] all came from an interview on the Johnny Carson show. There was an actor--I forget his name now but he played on "Simon and Simon." One of his children is deaf. He said that with the sign language--I don't want to say [it's] the easy way out--those aren't the right words. But [sign language] doesn't give the challenge to the person that's deaf to learn or to speak verbally. They can't hear but sometimes they can speak.
>
> He [the actor] brought his child on there. He does know the sign language but it was after that he went to this other school where they really tried to teach him how to speak. He [the deaf child] did a very good job on TV. So, ever since that show, I had a thought that maybe that was the right method [the oral method] and this sign language was not challenging the deaf person. (FN:15:2:34)

Michael's understandings of sign language and the people who use it to communicate were also influenced by his interactions with a childhood acquaintance. During his interview, he told me a brief story regarding his interactions with a deaf child who lived in his neighborhood.

> I grew up with a person that--well I didn't grow up with him, but he was a friend of the family. His name was John. I can't think of his last name right now. Anyway, he was from the neighborhood. He had like a plastic ear--similar to Henry. Anyway, so he didn't do any of the sign language. His was more verbal.
>
> He did quite well watching and listening and concentrating on lips. Once I was around him for a period of time, more than a half hour or so, I could really understand what he was saying. Yeah, he could really communicate without the sign. (FN:15:7:10)

Bobbi and Michael, viewing deafness as a disability, possessed the misperception that Mark and Sara have a choice concerning how they will communicate with Henry. In contrast, they saw interactions among Henry and his immediate family members through the same lens that they used to view their own interactions with their hearing daughter Roberta. They believed that if hearing individuals in the deaf child's environment assume responsibility or work hard enough to include the child in the day-to-day interactions of the home, communication barriers would disappear, and the child would successfully "be included." Bobbi stated that Mark and Sara insisted on Henry's involvement, but unfortunately, as Mark and Sara have learned, diligently mandating interaction in a spoken language is not effective in Henry's case. The crucial element that Bobbi and Michael overlook in their understanding of including Henry and using sign language, is that Henry does not have auditory access to spoken interactions--he is deaf. Despite the activity and conversation that unfolded around him, if the environment contained primarily hearing individuals or people who did not use a visual language fluently, Henry was an outsider. Simply placing Henry in an environment where the actors are willing and able to interact did not ensure that he would have the access he needed to grow and develop equal status among participants.

Deafness is a Problem that Imposes Communication Barriers

This view considered deafness as a problem that produced barriers to effective communication. Typical problems expressed by individuals in this model were "not being able to get your point across" or failure to have one's message reciprocated by a deaf person. Members within this model talked about complications and frustrations related to communication, such as not remembering how to sign information correctly or being concerned that there was something wrong with the signed message they were conveying. Individuals in this worldview insisted that "there is nothing wrong with Henry." He is not disabled but merely communicates differently than the rest of the family. Individuals who viewed deafness as a problem with communication assumed responsibility for the communication barriers that existed, typically because they were unable to master sign language fluency. Most of all, individuals who saw deafness as a communication barrier were convinced that despite obvious communication breakdowns, Henry cryptically understood their intended message that was conveyed through their facial expressions or affection.

Grandmother and Grandfather Medina. Despite geographic distance, Ernest and Peggy Medina traveled frequently to visit their daughter Sara and her family. Henry was born when Mark and Sara lived across the street from her parents and both Peggy and Ernest continued to seek out regular interactions with members of the immediate Camillo family after they were transferred out of state. Peggy Medina stayed in the Camillo home to help Sara adjust to the babies for at least three months during my extended fieldwork in the Camillo home. Neither Peggy nor Ernest mastered sign language, and they saw deafness as a problem that inhibited their communication with Henry. Peggy and Ernest shared their thoughts about Henry and deafness during their interview in October 1997:

> Peggy: As for him being deaf, well, we've accepted it. It was very difficult. He had a difficult birth, and Sara had a difficult birth with him. So, we're lucky to have him and I think he's done wonderful! He signs so good and I think he's so smart, and so beautiful!
>
> Ernest: He tends to be very smart, not brain-impaired. That's for sure.
>
> Peggy: No, no. Not at all.

Ernest and Peggy elaborated on their concerns:

> Ernest: Which adds to the complications and frustrations of how to deal with it [Henry's deafness].
>
> Peggy: I think that most of Ernest's worry is that we can't correspond--or we can't talk to [Henry] the way we want to. Like, I can talk to Daniel or Luke or someone. I tried, you know [to learn sign language. It's funny how I forgot everything--all my signing. When I came in June, it was

> very difficult for me to bring it all back. And, I kind of held back a bit because I was afraid I was doing it wrong, so rather than to do it wrong, I wouldn't sign at all. And that was wrong of me because Henry and I weren't getting along. Although, like Dad [Ernest] says, I think he [Henry] understands me real good, even with me not signing very well to him.
>
> Ernest: [nods "Yes" in agreement]. Oh, he understands the message.
>
> Peggy: Yeah, he gets the message by our actions and when we do our hands [gestures]. You know, sign language is mostly action. (INT:2:4:9)

Perhaps Peggy and Ernest saw deafness as a problem in part, because they were protective of Sara and clearly saw her challenges as a mother of six children. Their view of Sara's life may have facilitated their view of Henry's deafness as a problem. Ernest and Peggy voiced their concerns:

> Ernest: My concern is for the mother, Sara--that she doesn't try to stretch herself too far and blow up with high stress. She may not admit it or may not realize it because she's right in the middle of it.
>
> Peggy: She does too much...
>
> Ernest: You can't be "on" on a 24-hour basis. Constantly--you can't be the perfect mother--perfect wife--whatever, and keep up with everything without something giving out. And that's my concern, see. She's very strong-willed in well-managing her program, but there's too much running around. That's my concern as a father--the mechanical things. Going here and there, and the potential of something being problem-some. I think the triplets are doing fine. I don't see any medical problems with them at all. But, it's still a demand now with three more in the family, see?
>
> Peggy: Thank God there's nothing wrong with Henry now, expect for the fact that he's deaf. (INT:2:6:17)

Aunt Elaine. Elaine is Mark Camillo's younger sister. She was married and had one son, who I call Bart. Elaine was a soft-spoken and thoughtful person. She tried to communicate with Henry and could do so using one and two signs strung together to produce simple meanings. Elaine had some interactive experiences with deaf adults who frequented Bobbi and Joe's restaurant, where Elaine was a waitress (INT:13:4:39). Elaine told her story:

> I never took formal sign language classes but my sisters have taught us, Steve and I, ever since we were little. Margaret's the one who always took sign language classes when Steve and I were like in elementary school, and we were interested in it. Of course, Steve picked up on it better than I have, but I know the basics. At least I can talk to a 4-year-old anyway. (INT:13:1:30)

Elaine understood that communication barriers existed between her, Henry, and other family members who did not sign fluently. Last year she hosted a birthday party for her son, Bart, and hired a signing clown so that Henry would have opportunities for interaction at the party. Elaine told me how she came to hire the signing clown for Bart's party:

> I met her at the restaurant the day before Bart's party. I was going to get a clown, and then I figured, "No, I'll hold off, because he's going to have a lot going on at his party." She [the clown] overheard me talking to a musician who knows Mark [Henry's father] real well. Mark was talking about where Henry goes to school and she came over to the table. So we started talking and [I found out that she performs as a] clown professionally and she showed up at the party. She wanted to meet [Henry]. She's hearing. Most of the kids didn't know that, though. She was that good, you know? She was almost like a mime. Bart seemed to enjoy it, too. All the attention was on Henry, but Bart didn't care. He didn't notice any difference and [Henry] really enjoyed that moment. She was mainly there for him. It was perfect. (INT:13:5:1)

During her interview, Elaine emphasized the need to overcome communication barriers. The topic came up when I asked Elaine what she would recommend to parents who just found out their child is deaf:

> I would tell them the first step is actually just to go to school. There's a lot of schools around here for that. Even if they can't afford it, there's a lot of free classes for signing and all that. That's the best thing. It's just [important] to get started on [signing] so they can communicate. All the frustrations will be taken care of because they're learning [to sign]. Just so long as they can communicate. They're going to get rid of their frustration. Like Mark and Sara--right away they grasped [sign language]. Sara started schooling and she

> wasn't as frustrated, whereas other parents aren't even going to notice that they aren't [able] to communicate with their children. (INT:13:9:1)

Aunt Megan. Megan is another of Mark's younger sisters who lived in a city near Jamestown. She began taking sign language classes when Henry was identified as deaf. Megan never met a deaf person before Henry but remembered seeing people sign to one another for the first time on a bus in Washington, DC (INT:14:3:16). Megan took sign language classes to overcome the communication barrier that existed between her and Henry:

> I'm attending sign language classes and I want to be extremely good. It was just clear to me [when Henry was identified] that I'm the one that has to do something about it. You know, I want to communicate with him. I have problems with it [learning to sign], but at least I can communicate on a word-to-word basis with him. Hopefully by the time he's in high school, I'm gonna be real good at it. So I'm not deluding myself to the fact that it's gonna take some time. (INT:14:2:24)

I asked Megan if communicating with Henry was different from communicating with other children in the family who were hearing. Megan's beliefs about communicating with Henry were similar to those of Bobbi and Michael's. She misunderstood that if a person "worked hard enough" at communicating, reciprocity and understanding would happen "naturally." In other words, Megan believed that Henry could understand the majority of communication events around him, even if his communication partner was not using sign language.

> If you relax with it [communication], I think it's the same. Because you can develop your own language with him. He is so intelligent that if you're relaxed and treat him like any of the other children, you find that he's communicating just the same as you're communicating with everyone else. So I have no problem with it now. But it took me a while to get to that point. It really did. Where I thought, "Hey, he knows what I'm doing! He knows what I'm saying!" He's so intelligent! (INT:14:6:9)

Deafness is Using Another Language

Extended family members within this model viewed deafness as a condition that required using a language other than, or in addition to, spoken English. Family members within this model talked about barriers to communication but placed a greater emphasis on the solution to communication barriers. They viewed the solution as the use of American Sign Language.

Aunt Nannette. Nannette was one of Sara Camillo's younger sisters. She was single and lived in a suburban neighborhood near Ernest and Peggy Medina. Nannette was a "Head Start" teacher, working with young children with disabilities and their families. During her interview (July 1997), Nannette described what it was like for her to communicate with Henry when he was younger:

> Remember, I haven't seen Henry in a long time. The last time I was over there [at Henry's house] was when Madeline was born. Henry and Daniel would get up [in the morning while] I was sleeping down in the basement. They would want breakfast right away. They'd come downstairs to wake me up and I'd say, "Let me sleep for a little bit longer." "Okay no problem." So, they'd come down again like an hour later. Henry would always say, "NAY-NAY I WANT HOTDOG." (she signed and talked at the same time). (INT:16:5:30)

Nannette wanted to be a more fluent sign language user but confessed that she was not able to master the language because she didn't have regular, day-to-day interactions with Henry or other individuals who are deaf. Nannette commented on how easily Henry's siblings were acquiring ASL, "It's just like a second language! And it's so easy for them" (INT:16:5:9). Nannette understood that if she were able to acquire ASL like Henry's siblings, the communication barriers between she and Henry would lessen:

> I wish I would know it [sign language] better. Like today, Mark was asleep in the car driving to the beach, and Henry wanted to be sure he was going to

> swim [she demonstrates how Henry pulled on his swim trunks to ask Nannette if they would be swimming]. I could understand what he was saying, but I wish I could just whip it out [ASL] and do that [gesturing with her hands]. I don't remember it. I mean I remember the letters and I could sit and fingerspell everything. (Nannette shrugs to indicate that fingerspelling alone would be ineffective). (INT:16:4:2)

Uncle Harry and Aunt Maura. Harry is Mark's older brother. Harry and his wife Maura both worked in social service professions--Harry was a Marriage and Family Counselor and Maura was a Registered Nurse. Both Harry and Maura have had opportunities to work with deaf adults through their respective professional interactions. Harry once counseled a family regarding the topic of deafness and language/communication barriers (INT:9:7:24).

> Yeah, I had a family once that I worked with. The father was deaf. I asked, "Did everyone in the family communicate with him?" Henry shook his head "no" and said, "In fact, part of our focus was teaching, trying to teach the kids, his children how to sign. They did communicate, but with more of a crude way. (INT:9:7:12)

Maura described her experience with a deaf child other than Henry, who she met in the hospital setting:

> I remember a little girl who was deaf on the Pediatrics floor that I worked on and I remember that situation. I remember them just telling us--the father said, "If she wakes up crying, just call me" because nobody [Maura pauses to shake her head]. You know, I remember that I worked night shift and I thought to myself, "Wow, I wish he would just stay." You know, "Don't leave!" But it was the type of floor and the type of hospital that didn't really encourage parents staying. But I remember her waking up and calling him and he came in. (INT:9:9:3)

Maura and Harry had four children of their own, and frequently discussed what family life would be like if one or more of them used a different language to communicate. I asked Harry and Maura what they had learned about Henry's family life since he was born and identified as deaf. Harry shared with me that he had learned a lot about Mark and Sara's character and their level of commitment to their children (INT:9:4:29). The following excerpt from the interview with Harry and Maura demonstrated that Harry viewed using sign language as a "normal" way to communicate:

> There's a lot of things that I've learned. I've gained a greater understanding of Mark and Sara's character. Right from the start they were determined to raise him [Henry] as normal as they could and to be very much involved in what he needs. You know, I think that helped even for extended family to be committed. Our desire, even though we struggle to follow through, most of us still have a desire to learn sign language so we can communicate with him, because we want to treat him as normal as everyone else. (INT:9:4:12)

Maura and Harry agreed that the language barrier sometimes made them feel helpless, and that the relationship they shared with Henry is unlike what they shared with other nieces and nephews:

> Maura: I think I'm feeling it this time more than ever that I don't know Henry like I know Bart, like I know Karl [Henry's cousins].
>
> Harry: Yeah that's a good point. You feel like you know Daniel and Madeline.
>
> Maura: Like a real, real helpless feeling.
>
> Harry: Oh, yeah.
>
> Maura: You want to do something. You know, you want to be able to just do little things for him and it's difficult to do that, when you can't ask him anything.
>
> Harry: Yes. [nodding] Just things we take for granted, because we're in a hearing world. Daniel, Madeline, and everyone else follows because they hear and Henry doesn't follow. He has to be told what's going on. Mark and Sara do that almost automatically anymore. I don't think of it. (INT:9:5:13)

Aunt Bobbie and Uncle Jerry. Bobbie is Sara's younger sister. She lived with her husband Jerry in Marble Beach. Mark and Sara had arranged that should something happen to them, Bobbie and Jerry were considered the legal guardians for all six Camillo children. Bobbie had a formal background in school counseling and had a strong relationship with Sara. Sara and Bobbie's strong bond was enhanced by their mutually supportive and respectful relationship. Bobbie professed to "follow Sara's lead" in matters concerning her children's best interest. At the same time, Sara valued Bobbie's formal training within the education system, and often asked her advice about school-related issues.

Consequently, when Mark and Sara found out that Henry was deaf, Bobbie's recommendation to place him in a "special" school carried weight (INT:3:18:29). Mark and Sara considered her a source of expertise within the family and promptly sought special programs for Henry to attend. When Henry was identified as being deaf, Bobbie began taking sign language classes immediately. Bobbie told me about her initial experiences learning ASL in a formal setting:

> The first class was fun! The first teacher I had--she was real good. She's an interpreter and she was just wonderful, wonderful, wonderful. Her mother was hearing but somebody in her family, I think her grandmother, was deaf. So they grew up learning it [sign language]. Her mother worked as a teacher aide in the public classroom [for deaf children]. So, she would come in every now and then. I think maybe [there were] eleven people in there. It was wonderful. (INT:3:6:18)

I asked Bobbie if she'd taken other formal ASL classes after the first successful experience. Unfortunately, the poor quality of later sign language classes filled the learning process for her with frustrations and barriers to achieving fluency. Bobbie withdrew immediately from her second class because she wasn't comfortable with the large number of people enrolled in the class, and felt that the instructor's style limited her learning to the contents of the class text:

> [Despite these classes] I consider myself a beginner, still. I've only had one class. I signed up to take another one this last Fall--it was a combination class at a community center for beginners and intermediate. There were too many people in there for one teacher. I didn't care for it. She [the second instructor] limited us right away that first night to the words on the page. All of us knew a little bit more than that and we wanted to interact, even though we were still beginners. So, I just dropped it that night. (INT:3:6:29)

Uncle Francis. Of all the extended family members who viewed deafness as using a different language (ASL), Francis' perspective was the most pliable in terms of his ability to be introspective about the worldviews of others. The expression, "still waters run deep," was a good way to describe Francis' character. He is the single father of two young daughters (Marie and Christine) and was a military veteran who served on the front lines of the Persian Gulf War. Despite his sensitivity, Francis also had a playful and easy-going nature. His ability to shift lenses on a particular situation may be a character trait that developed as a consequence of his diverse and often challenging life experiences. Francis admitted that he was not a fluent signer but made repeated, consistent attempts to communicate with Henry. He explained that he communicated with Henry by showing him visual examples of what he was talking about (i.e., pointing at objects, gesturing, and role playing) and recognized that Henry used a different language than the other children in the family:

> [Communicating with Henry] I feel is not that bad--it's pretty easy as long as everybody else is around. I guess if we were one-on-one, it would be a problem 'cause I don't know any of that [lifts his hands to indicate he's talking about sign language]. I show him examples. If I wanted to show him something, I'd just have to look at [signs LOOK towards the window] where I wanted him to look. (INT:17:1:18)

Francis was moving toward trying to view the world the way Henry saw it but was attaching his reflections to a hearing perspective. During our interview, Francis asked questions about how Henry learned about his environment when he didn't have access to sound. The following conversation I had with Francis was a good example of how he tried to make sense of the experience of being deaf and the use of a visual, rather than an auditory language to acquire literacy in written English (INT:17:3:14).

> The one thing that really amazes me that I always think about is what they [deaf people] really can't do--as far as hear. You know, I'm always wondering what it's like to not be able to hear anything--constantly. Sometimes it'd be great [laughs and looks toward the living room where the children are making a lot of noise]. Certain things like, what does it sound like when he goes under water? Or does it sound like when I go under water? Or, can Henry hear in his own ear--in his own body like the swallowing noises that we make. Because if I plug my ears, I can hear myself swallow, or something like that. I just wonder if he hears that kind of stuff. (INT:17:3:6)

Francis moved on to puzzle about the topic of fingerspelling and how it related to developing literacy:

> Like I asked you the other day, how does he know when you spelled out [fingerspelled] BUNNY. How does he know that [fingerspelling] spells bunny? You were telling me he just recognizes the hand signals. That's wild. There's a lot of different things that I don't know about that I'll learn hopefully. (INT:17:4:13)

Francis acknowledged that Henry made sense of the world in visual ways, but he struggled with comprehending Henry's visual-only view. His understanding of Henry's perspective seemed to oscillate. In the following interview excerpt, Francis demonstrated his uncertainty by stating that Henry was perfect but then mentioned there was something wrong with him because he could not hear, indicating that perhaps Henry wasn't perfect after all. Francis may even feel the tension of being "stuck" in his understanding of deafness.

> Francis: It's just that Henry's special. He's a Godsend. I mean we <u>all</u> are, but to me he's special.
>
> Laura: Why is that?

Francis: I don't know--he's so perfect! He's got a lot of things wrong with him but he's such a perfect little person. He's all there!

Laura: Yeah.

Francis: He is! He may not be able to hear but he's there! I can't imagine--I can't believe he's learned so much! And how just communication-wise, he can communicate by [gestures with his hands] starting from zero--starting from scratch! He could never hear from the beginning. How's he learning how to do everything [gesturing with his hands again]? (INT:17:9:20)

At the end of our interview, because he is a parent himself, I asked Francis, "If someone came up to you and said, 'I just found out my child or my nephew or niece is deaf.' What would you tell them? What should they do?" (INT:17:6:15). Francis responded, "Just learn to stand in their shoes and learn as much as you can." I asked, "Stand in whose shoes?" Francis explained:

> Stand in the deaf person's shoes. Because if you understand where they're coming from then you'll know that there's a lot of knowledge to be found. I mean you have to look at Sara. She's learned so much just being with Henry on a day-to-day-basis! (INT:17:6:15)

Deafness is Viewing the World a Different Way

Uncle Steve. Steve is Mark's youngest brother. Many extended family members professed that they would like to sign as well as Steve and admitted that he's "really taken off with it" (INT:7:6:20). Ironically, Steve never took a formal sign language class. His interest in sign language began in elementary school. His older sister Margaret took a sign language class in high school and practiced at home by teaching and interacting with her younger siblings. Steve explained his early understandings of sign language and people who are deaf:

> So, I had that little bit of the basics, like family signs and other basic signs. When Henry was born, I looked around for classes and I got books. I didn't find any classes, so I just tried to learn from the books. He just remember

> thinking, "He's not going to talk. I just knew he was deaf and when they said that he was missing one ear. I just knew that that meant he won't hear and we have to learn how to communicate with him. I don't remember it being something I had to figure out. (INT:7:6:25)

While other people in the family saw Steve as a proficient signer, he still wanted more interaction with deaf people.

> I still don't get enough interactions with Deaf adults to have a good understanding of Deaf people. I have a good understanding of Henry. So I'll probably have a good understanding of deaf people as Henry grows up. I'd like to associate more with deaf people for – if nothing else, to get my signing up. That's why I'm glad I made friends with that teacher back in college. He's a good friend. (INT:7:27:25)

Steve described the challenging experience of navigating in Deaf interactive spheres, and building relationships with Deaf people:

> It is so frustrating. There's a performance group that signs to music at the university where I take classes. I helped out by handing out brochures at the performance. During intermission, I sat up in the back of the auditorium and watched some of the deaf people in the audience. I was watching some of them have a conversation--I wasn't really eavesdropping because they were having broad conversation among different topics. But anyway, I couldn't understand any of it. Here I am working so hard and taking these classes and I only caught maybe one or two signs. If I knew what they'd started out talking about I might have had a better understanding. [To me it seemed like] their hands were all over the place. (INT:7:28:8)

Steve admitted that he sometimes still felt intimidated about interacting with Deaf people, but continued to seek out interactions. Steve reiterated that he wanted more involvement:

> Yeah--I want more exposure. There aren't that many deaf people around where I live. At least I haven't found a Deaf community in the small town of Jamestown. (INT:7:27:28)

I asked Steve how communicating with Henry was the same or different from communicating with his other nieces and nephews in the family. Steve clearly stated that Henry communicated differently than the other children and mused about how Henry seemed to use both English and ASL signs in his interactions.

> [communicating with Henry is] more of a challenge because it's not a natural way for me to communicate. I have to really think about what I'm [signing]. Sometimes I'm amazed that I'm actually able to sign what I'm thinking and not make a mistake. I mean I have to think ahead of what I want to sign. [Anticipating what I will sign is] a lot easier to do when I'm anticipating being with him, than when I'm there because I can think of what I want to talk to him about and how I'm going to put that into sign. (INT:10:6:36)

I asked Steve what he meant by anticipating his signs and he explained:

> An example, one time when I was down there [at Henry's house] this summer, I was able to walk on the paths and I saw a butterfly. I thought, I'm going to tell Henry about this, so I thought visually. I thought about how in the sun the butterfly was just sitting there and what color it was and then how it was just sitting there and as I approached, it fluttered away. [signed: THOUGHT BUTTERFLY COLOR BUTTERFLY PRO-1 APPROACH BUTTERLY FLYING AWAY] So, I was able to put it in visual terms, but if I'm in a conversation, then I just revert back to English signs, especially if I'm signing while I'm speaking. (INT:10:7:4)

Laura: Right. Do you remember who taught you how to do that?

Steve: Ah, mostly it was from my reading. [Reading about ASL grammar] really helped me to understand more of it, to get a better understanding of the language's grammar and structure.

Steve explained that he was trying to reach a particular level of fluency in ASL that allowed him to leave an "English-oriented" approach to signing behind. He explained:

> That's what I'm trying to get to and that's the frustration. If I were more over here [English oriented], then I would be blissfully ignorant, and it would be easy. I would know the sign for each English word. But now I know that that's not ASL. I know I'm not there [ASL] yet, but I'm trying to get there. (INT:10:8:5)

Steve compared learning ASL to the task of learning a foreign language. He saw deafness as a different way of viewing the world, resulting from accessing information in different (visual) ways and using a different language to share and exchange information. I asked Steve to describe some important lessons he has learned from Henry and other individuals who are deaf. He told me some stories to explain how he understands differing deaf experiences:

> You can't generalize. Individuals who are deaf are individuals and they are all different. One woman here [in Jamestown] runs a kind of a class at the church; she's deaf. I've read about some people who consider themselves to be Deaf with a capital "D" or deaf with a lower "d." The deaf lady from church is deaf with a lower "d." She became deaf late [in life] and she's oral. She looks to the graduate student who attends the class for how to sign this or that. It's kind of strange to have a deaf person look to a hearing person, but she's deaf. I can't sign to her the way I sign to Henry. She doesn't catch it. She doesn't understand what I'm saying. (INT:10:14:1)

Steve continued to describe interactions he has had with a friend who considers herself culturally Deaf, with a capital "D":

> I can sign to another deaf friend of mine the way I sign to Henry, which is the best I can possibly sign because she is Deaf with a capital "D"--she uses ASL. That's one thing I've learned I guess is that you just have to get some understanding of their experience and knowledge. I know deaf people do that all the time with people they meet. It seems like with hearing people they get a gauge of their level of signing and adjust their sign accordingly. They either sign slower or sign closer to English. They meet us in the middle. That's the one big thing I've learned about individuals who are deaf. (INT:10:14:19)

Section 4: Henry's View

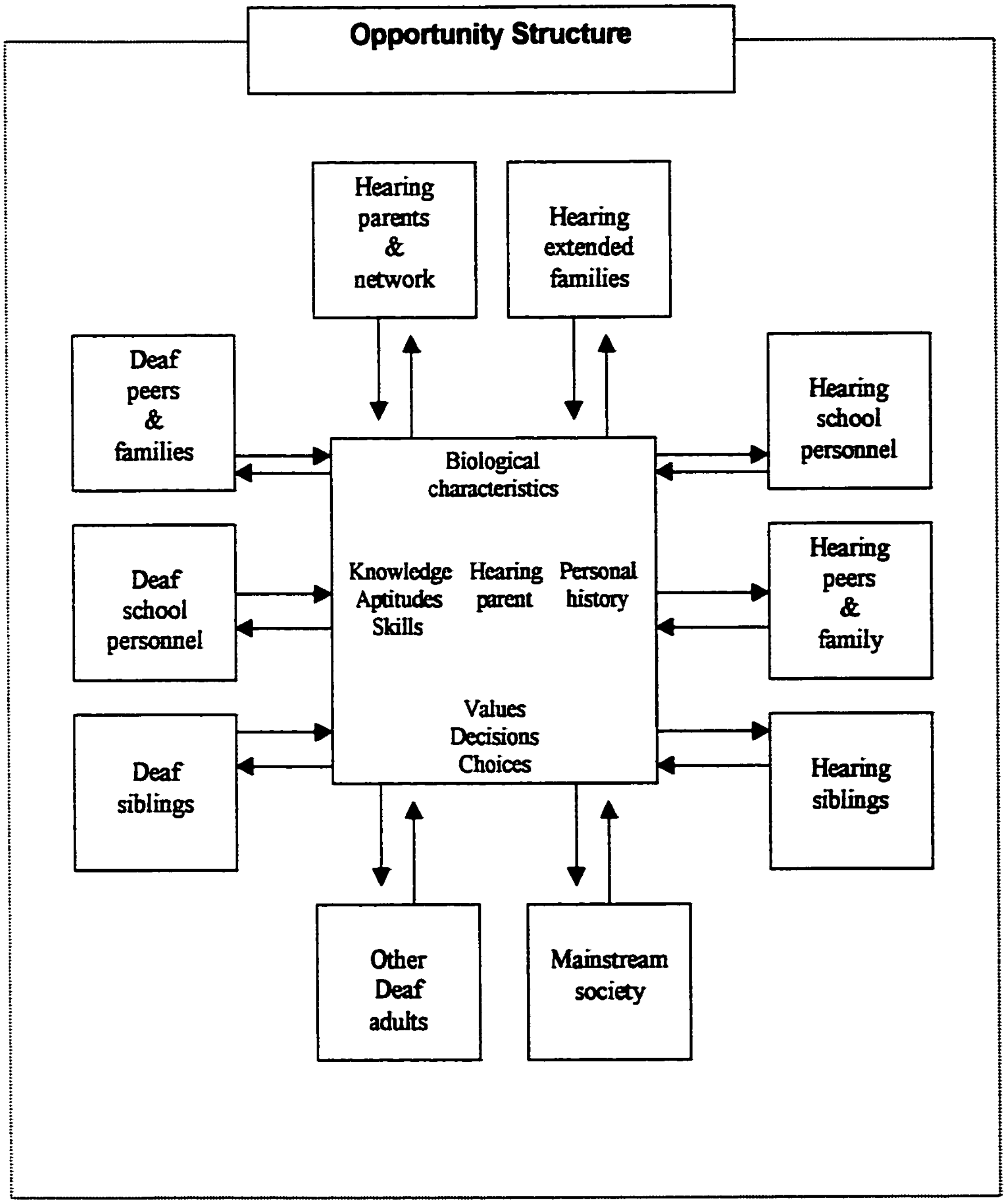
The findings presented in this section developed from the contextual analysis of fieldnotes, as well as the microanalysis of selected video clips that showed Henry interacting during visits at the homes of extended family members (June 28 to July 15, 1997). The stories and descriptions of interaction described in this section represent "typical" interactions that occurred among Henry, his siblings, and his cousins. While I did not have direct access to Henry's thoughts and feelings, in this section I presented the interactions as they apply to Figure 5.6, entitled "Model of the Deaf Child of Hearing Parents," adapted from Erting (1982).

Erting emphasizes that her models of individual social actors represent theoretical differences in how individuals construct their worldview in three important ways: "structurally, personally, and interactionally" (Erting, 1982, p. 22). It is important to recognize that because Henry is part of a hearing family system, there are differences in these three aspects of the model which pervade the development of his worldview in profound ways. Structurally, unlike a deaf child from a deaf family system, Henry's does not have Deaf adults within his primary family of socialization. Like his parents and siblings, as the model indicates, Henry has regular opportunities to interact with Deaf people at school or during school-related activities. However, the model in Figure 5.6 demonstrates his predicament and the complications of his development as a person who views the world in visual-only ways but is immersed in an environment that is set up for individuals who manage their environment in both visual and auditory ways.

Consequently, this section describes Henry's interactional spheres within that context. First, I will tell a story that describes Henry's typical interactions with his siblings. In the second part of this section, I describe four interactive contexts that are typical for Henry when he is with groups of hearing family members: (1) no access to interaction (video clip #1), (2) delayed access to interaction (video clip #1), (3) contingent access to interaction (video clip #2), and (4) comprehensive access to interaction (video clip #3).

It is important to point out that some of Henry's behaviors were evidence of his variable access to communication and interactive activities at home. For example, Henry always knew where his shoes were, and they typically were on his feet first

Figure 5.6. Model of the deaf child of hearing parents (Erting, 1982, p. 21)



Note. From "Deafness, Communication, Social Identity: Ethnography in a Preschool for Deaf Children," by C. J. Erting, 1994, p. 21. Copyright 1994 by Linstok Press. Reprinted with permission of the author.

thing in the morning until it was time for bed at night. Sara explained that Henry wore his shoes habitually to be sure he "didn't miss anything." In other words, there were times when Mark and Sara discussed an outing using spoken English. Perhaps they were in separate rooms saying to one another, *I'm almost ready to go, have you changed the babies?* and *I'm getting their bottles ready for the road!* In this situation, family members who were not directly involved in the preparations to leave the house (i.e., Daniel and Madeline--hearing siblings) still had passive access or the ability to "over hear" communication and conversations about the errand or trip. For Henry, family outings may have sometimes had the appearance of the group making a hasty exit for the door. He kept his shoes on to adapt in an environment consisting of primarily hearing people using a spoken language. Because Henry did not have passive access to communication in his home environment, he learned to watch for shifts in patterns of behavior (i.e., packing the diaper bag, changing the babies' diapers), kept his shoes on, and expected to be informed of the decision to leave the house shortly before departure.

Henry's visual worldview and the behavioral adaptations he made in his home environment were evident in many parts of the following story. For example, when Henry was not standing at the front window with Daniel watching the snow fall, he was sitting on the stair landing in the living room (see Figure 4.1 located in Chapter IV to identify Henry's spot on the stairs). The stair landing was a popular location for Henry to locate himself when he anticipated a special family outing or activity. Henry sat on the stairs because it was the one location on the entire main floor of his home where he had almost 100% visual access to family interactions. If the family was expecting company, Henry could see the guests walk up the steps to the front door. If it was almost time for dinner, Henry could see the food being prepared and watch for his father's arrival at the same time. On Thanksgiving Day, Henry waited at the bottom of the stairs for his father to wake up from a mid-day nap which would signal it was time to carve the turkey. And finally, when Henry sat on the stairs on this particular snow day, he could simultaneously watch for his mother to come down the stairs as he monitored the interactions among his siblings, "the maid," and the snow falling outside.

Events on a Snow Day

An overnight snowfall canceled school one morning in early January for Daniel and Henry. I heated up frozen pancakes from the refrigerator at their request. On this snow day, Sara went upstairs to catch up on her sleep after she realized school was cancelled (in January, the babies were not sleeping through the night yet, and a snow day for Sara meant a small window of opportunity to catch up on her rest). She reminded the boys before she went upstairs not to open the front door. Henry had been opening the front door all morning, letting in the cold air from the outside. From Henry's perspective, peering through the storm door was the best spot to watch the falling snow and see the snow plows in action.

Obeying Sara's request, Daniel and Henry remained at the front windows from early to mid-morning. As they watched the snowfall, the brothers signed to each other endlessly about what sleds they would use, and about the snowmen they would build later in the day. Daniel used his voice in a quiet whisper when he signed to Henry.

For other parts of the morning, Daniel busied himself building an elaborate castle with discovery blocks and watching comics on television. Henry entertained himself from his perch on the stair landing by watching me, even when I didn't think he was paying attention. For example, when I moved from floor to floor in the house, Henry repeatedly stopped and asked me where I was going, *WHY WALK-WALK? WHY BASEMENT*? (FN:72:1:22). On this particular morning, I explained twice why I was going downstairs (*I'm checking the clothes in the dryer*) and five times why I moved my car (*The snow plows are coming and I need to move my car off the street*). Henry was diligent at making sure he understood what was happening next, nor was he bashful about asking me to repeat my responses.

As the morning progressed, Sara called for Daniel to come upstairs several times to help her with errands around the house. Sometimes she called Daniel upstairs to get Madeline out of her crib or to bring the portable telephone. Henry waited and watched everyone move about the house because he didn't want to miss a moment of going outside to play in the snow. Henry was the first child dressed that morning. Sara explained that when he thinks the family is headed somewhere, he is sure to keep his shoes or boots on--he wants to be ready to leave on time with the rest of the family. Every time Sara called Daniel upstairs that morning, Henry followed. He got out his sledding clothes and put them on before anyone else. At one point, Henry couldn't find his socks and became frantic. He knows it is Mark's job to lay out his clothing in the morning and commented to Sara "Daddy forgot my socks!" (FN:72:2:17).

When Sara came downstairs later in the morning dressed in her long johns, the children considered it her signal that it was almost time to go outside and play in the snow. Henry asked her, "Where are the snow plows?" I assumed he was concerned that the plow hadn't come into the cul-de-sac yet, and he didn't want to miss it. I remembered viewing my parents as all knowing in my early childhood and wondered if he thought Sara had some sort of a snow plow time schedule.

Even as Daniel and Madeline visibly dressed to go outside, Henry repeatedly asked Sara, *PLAY SNOW SOON, RIGHT?* meaning, *We're going out to play soon, right?* (FN:FN:72:1:31). Fortunately for Henry, Sara was aware that day that the weather might quickly change to sleet or freezing rain. She decided to take the children outside sooner than later. Henry was so excited that as he added more layers of clothing, he stopped to physically shake his mother to ask one more time if they were really going out to play in the snow. Sara told him, *STOP SHAKING MOMMY*! He immediately kissed her apologetically and she responded, *I KNOW [you are] EXCITED BUT PLEASE DON'T SHAKE MOMMY's BODY*! (FN:72:2:13).

When the time to play in the snow finally arrived, the babies and I watched the older children and Sara romp in front of the house. Each child had a different colored plastic sled and they slid down the slight hill near the house. I marveled at the resemblance between Sara and her father today. She was moving sluggishly in the snow with boots and a baseball cap to cover her hair. Everyone was wearing gloves instead of mittens so they could use sign language to communicate. The foursome built a snowman and Sara sent Daniel in to ask for raisins and carrots.

Later when they came inside, Sara made hot cocoa and we sat around the dining room table and discussed their sledding adventures. I asked Henry if he saw any *KIDS* outside on the sleds. Madeline joined our conversation, signing and speaking she said, *KIDS YES-YES [pointing outside] SNOW! Yeah! We saw kids outside in the snow!* Henry saw her attempting to imitate the sign KIDS and laughed out loud. He mimicked Madeline's incorrect handshape or "baby sign" to make his point and said, *YOU CUTE.* He and Madeline giggled over their hot cocoa about her baby sign (FN:72:3:2).

Later Henry helped me feed the babies and Madeline stepped in to teach him her expertise (Madeline had spent many days at home with Sara and the babies when Henry and Daniel were at school). When we were feeding the babies, Henry tried to prop the bottle for Luke on the edge of the bouncy seat and didn't know how. I saw the situation unfold as Henry shrugged in Luke's direction and set the bottle down next to the baby on the floor. Before I could cross the room and show Henry how to prop the bottle, Luke was already wailing in frustration. Madeline quickly came to his rescue, explaining to Henry in ASL, *NO NO MORE EAT MORE!* meaning *No! The baby wants to eat more*! (FN:72:3:8).

After Luke finished his bottle, Henry spent about 10 minutes chatting with the baby, articulating signs on the baby's body. I was surprised to see Henry using the baby's body space to articulate signs because I wasn't aware that Henry had ever seen a Deaf adult model that type of early interactive motherese. Henry told Luke about the snow outside and how he waited and waited to go sledding. The babies became more responsive as they grew and Luke watched Henry attentively--cooing and waving his hands in response to Henry's signs.

While siblings generally took their home communication in two languages and several modalities as a fact, Henry's interactions with cousins had a different quality.

Their responses to using visual communication strategies were naïve, but genuine. Older relatives typically assumed a "care-taking" or "big-brother" role with Henry. Many of the older children had the advantage of recollecting previous interactions--the idea of deafness and Henry as a person were not new to them. In contrast, cousins who were Henry's same age or younger reacted with curiosity, confusion, frustration, and in some cases anger. The response of Henry's youngest cousins was clearly one of culture shock.

The next section details the results of videotape microanalysis. I looked at selected social interactions among Henry, his siblings, and cousins. My findings build upon Evans' (1994) continuum of communication, ranging from inclusion to exclusion. Evans' posits that deaf children from large hearing families have numerous opportunities at home to interact in communicative contexts ranging from dyads to small-groups, to large-group family gatherings. She supports that the quality of access available to deaf children from large hearing families ranges from fully inclusive to exclusive. The results of my analysis found the size of interactive groups to be pertinent, but also the quality of interactions and the role of actors were critical to Henry's communicative success.

Henry and his Cousins: Selected Interactions

A no-access to interaction situation depicted a social scene where Henry did not have access to communicative messages and information that were being exchanged in his environment. Individuals participating in the social scene around Henry might have viewed him as being attended to in the field of interaction when actually, he was not included. In some instances, family members made overt attempts to include Henry in the field of activity by signing to or interpreting for him. However, for one reason or another, in a no-access situation, Henry was not focused on the same interactive situations as other family members. In a no-access situation, Henry did not attempt to obtain information from family members or to engage himself in the interaction going on around him. In other words, a no-access situation typically appeared as though Henry was isolated among a group of people, entertaining himself "in his own world," attending to entirely different objects and activities in the environment than other family members.

No-access situations generally led to delayed-access situations. In delayed-access situations, Henry entered the field of activity "at the tail end" of the social situation that had held the interest of other family members. He either used time upon entering the scene trying to determine what had happened or missed the meaning or importance of the interaction completely. In delayed-access situations, Henry sought clarification of the event, asking questions of family members who he considered to be competent communication informants.

Situations of contingent- or conditional-access typically occurred within the context of one-to-one and small group interactive scenes. In other words, Henry had greater access to interactions that occurred when he was with a small group of family members where he could independently monitor interactive exchanges, or when he was with one or more family member who was willing or able to interpret for him. This type of access was deemed contingent or conditional because Henry's degree of access to the scene was subject to the communicative competence and attentiveness of the person facilitating interaction. In other words, contingent-access situations can quickly become no-access, delayed-access, or comprehensive-access situations, based on the level of involvement and skill of the facilitator and individuals present in the interactive scene. The only measure of control or independence available to Henry in contingent-access situations was his degree of assertiveness within the social situation. Henry demonstrated his vigilance when obtaining comprehensive access in two ways: (1) by using his voice or body language to state his position, and make demands or requests; and (2) by asking questions through an interpreter, as well as redirecting and reminding the person or persons who serve as the moderator(s) of interaction.

Comprehensive access occurred when Henry was able to thoroughly interact among a group of individuals who may or may not be using American Sign Language (ASL) to communicate. In a comprehensive-access situation, Henry was able to contribute fully to the interactive situation and thoroughly understood the contributions of others. In some comprehensive-access situations, Henry taught others about his visual way of viewing the world during their exchange of information. Comprehensive-access included some lapses in communication, but these scenes were characterized primarily as interactive situations where Henry was able to participate fully in the field of interaction.

Scene 1: Finding a Frog Poolside at Marble Beach

The following poolside scene demonstrated a no-access situation for Henry that led to a delayed-access situation. The scene opened at Bobbie and Jerry's home during the family vacations immediately after the children (Henry, Daniel, Madeline, and their cousins Marie and Christine) were permitted to enter the pool for a morning swim (video segment #6). It is important to recognize that no one was signing in the first two minutes of this scene. Henry did not have access to the spoken conversations that transpired among the children until half way into the 4-minute segment.

During most of the 4-minute scene (10:14 to 10:18 AM), Francis, Mark, and I were focused on putting sunscreen lotion on the children and blowing up flotation toys for the pool. Henry, Daniel, Marie, and Christine were already playing in the shallow end of the pool (see Figure 5.7 that provides a picture of Bobbie and Jerry's backyard and pool). Daniel, Marie, and Christine were bobbing in the water as an interactive triad, passing two flotation devices, and a plastic ball between them.

Daniel:	[Growls at Christine] Ha! Ha! I made you drop! I made you drop!
Christine:	No you didn't!
Daniel:	Yes I did! I went like [growl] and you dropped it!
Christine:	No it didn't! I wanted to let go.
Marie:	Brrrr! [comments on the chilly water]. Daddy! You can be the lifeguard! [Francis doesn't respond]
Christine:	Daddy, you're the lifeguard, okay? [Francis doesn't respond]
Laura:	[I respond for Francis] You know what? Daddy's going to get the sunblock and we're going to put it on your body. Okay? [Christine and Marie turn to where Laura is talking outside the pool]. (VC:6:1:7)

Henry was standing on the steps in the shallow end, engaged in his most common play activity: maneuvering his toy vehicles on the edge of the pool. Occasionally he glanced over his shoulder to watch the older children bobbing in the water. When he noticed Marie and Christine turning their heads toward the picnic table, Henry glanced with them to see what is happening. He surveyed the situation (I am putting lotion on Madeline at the picnic table) and returned to pushing and lining up his vehicles.

Madeline and my conversation could be overheard as we sat at the picnic table next to the video camera, set up to capture interactions in the pool. I was saying to Madeline, "You can go in the water as soon as I finish putting on this lotion, okay?"

Daniel pushed the two flotation devices out of the pool and walked past Henry, up the stairs and alongside of the pool toward the deep end, where Francis was blowing up toys. Marie and Christine continued talking to Francis:

Marie: Daddy, can you please give me that thing?

Francis: Okay, but you've got to put suntan lotion on.

At this point, the ball that Marie was playing with in the water floated out of her hands and became inadvertently stuck under Henry's arm as he climbed out of the pool. Henry got out of the pool and walked away with the ball.

Marie: Give it here! Come here! Come here! Henry! Henry! [talking to his back] Come here! Henry! Henry! Henry! Henry! (VC:6:1:10)

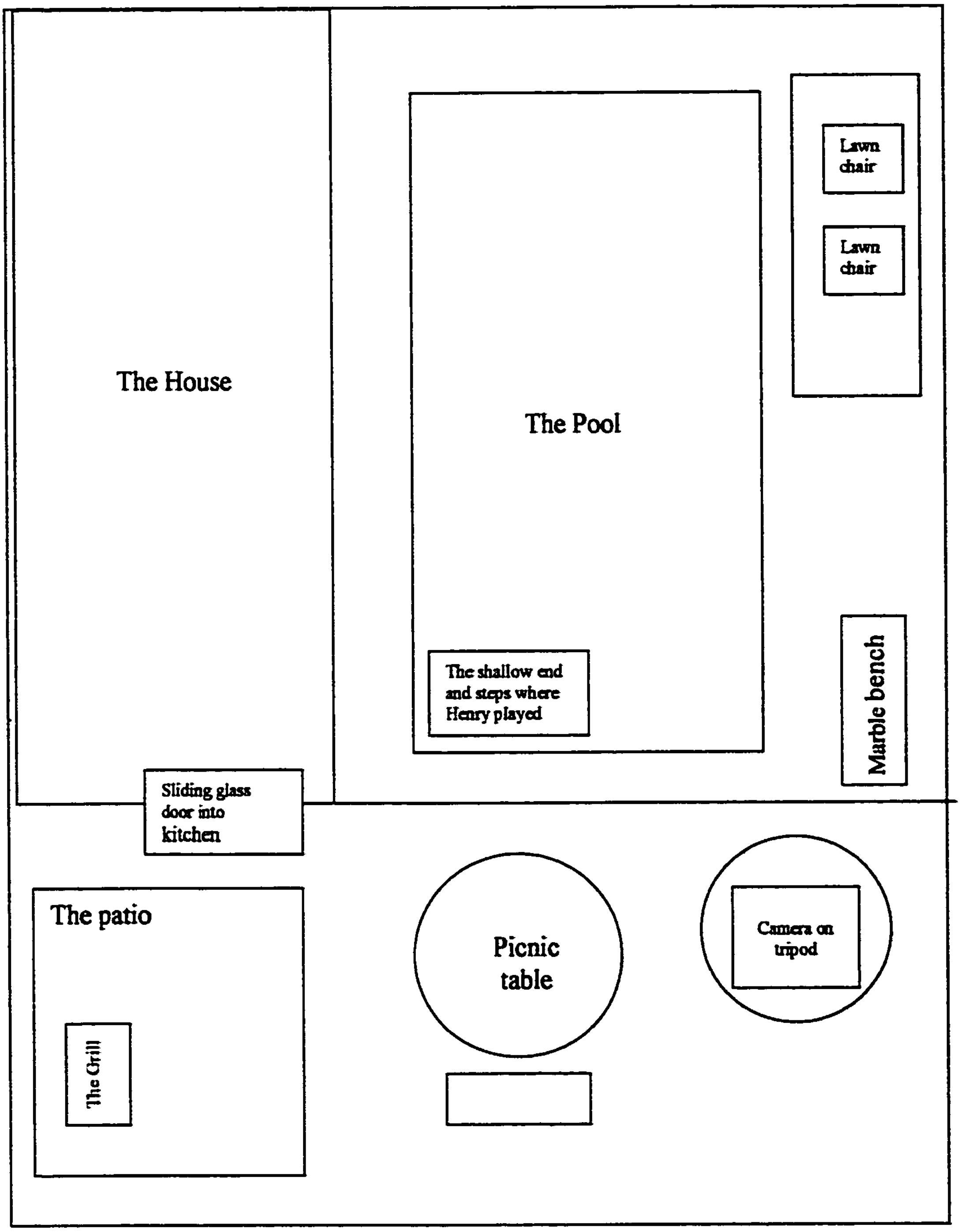
Henry's back was turned and he didn't know that Marie wanted the ball back. His perception of the situation was that the ball floated to him by chance and he decided to remove it from the pool because no one was playing with it. Henry decides at the water's edge that he should push all of the floating toys into the water and threw the ball and another floating toy back into the pool. Meanwhile, Daniel had made his way into the deep end of the pool and found a frog floating near the filter flap.

Daniel: Ewe! A frog!

Christine: Let me see it!

Laura: Is it in the water?

Figure 5.7. A diagram of Bobbie & Jerry's backyard and swimming pool.



Marie was still trying to get Henry's attention and when she heard me ask about the frog ("Is it in the water?") thought I was asking about the ball.

Marie:	I can't get it [the ball] because he [Henry] threw it over there [in the deep end]!

Christine joined Daniel at the deep end of the pool. Henry continued to throw floating toys into the pool, oblivious to the other children's conversations about the frog, and Marie's protests about the ball.

Christine:	It's a toad, Daddy!
Francis:	Leave it alone!
Mark:	Is it alive?
Daniel:	I'm trying to get it [out of the water] so it could be alive! (VC:6:1:18)

Henry returned to the steps at the shallow end and, after throwing all the floatable toys into the pool, entered the water and picked up his vehicles to begin playing with them again. Marie forgot about the ball floating out of her reach and became interested in Daniel's frog discovery.

Marie:	Where's the toad?
Daniel:	It's down here! I'm trying to get the dumb thing!

Marie got out of the shallow end of the pool and walked to the deep end to see the frog. On her way out of the water, she accidentally bumped Henry at the steps. Henry got out of the water and shook the water off his feet. He was still not aware that the children were talking about a discovery at the other end of the pool.

Mark:	Here Daniel [approaches Daniel with sun block lotion].
Daniel:	[protesting about getting out of the pool to apply sunscreen] Dad, there's a toad in the pool!

Mark: [shaking his head playfully in disagreement]

Daniel: Yes there is! (VC:6:1:26)

Henry finished shaking the water off his feet and began to make his way around the edge of the pool. He was again focused on bumping flotation devices into the pool. On his way to the deep end where Mark and the children were gathered, he nonchalantly kicked one more floating ring into the water. Henry walked past the group gathered at the edge of the pool and started to pick up other toys to throw in the water. Mark, Daniel, Christine, and Marie huddled closer around the toad.

Christine: [says to Mark] Look! It's a toad!

At this point, the no-access situation becomes a delayed-access event. Henry recognized that the group of children was looking at something on the edge of the pool. He pointed and spoke to his father, "Da-Da-Da," meaning "What are they looking at Dad?" Mark responded to Henry's question by signing, "LOOK FROG" and then asked Henry to come closer so he could put on sunscreen lotion. Mark signed, "LITTLE-BIT [and pointed to the lotion in his hand]" meaning, "Let's put a little bit of this on you." Henry didn't respond to Mark's request and Mark repeated the original answer to Henry's question, "FROG [points to the frog at the side of the pool]," meaning, "There's a frog at the side of the pool." Henry's cousin and brother continued to talk about the frog.

Christine: It's a baby frog! I've never seen one before!

Marie: What is that thing right there?

Henry moved between Christine and Marie, standing on the edge of the pool. He bent over and looks in the filtration flap at the water's edge. As Henry tried to see the frog, Daniel scooped something into his hand, which might have been the frog, and threw it into the grass at the pool's edge. Henry turned to look into the grass and started to walk to the grass to find the frog. Mark stopped Henry as he tried to put lotion on Henry's back. The other children were finished looking at the frog, and Henry's delayed access to the event caused him to miss it entirely. The scene dissolved as Christine and Marie jumped in the pool with Daniel. I walked around the edge of the pool to get more lotion from Mark for Madeline. Henry's eyes were still glued to the grass as he strained his body away from Mark's grasp to get a better look. Mark vocalized and signed,

Mark: Henry, Henry.
STOP PLEASE WAIT.

Laura: Can I have some more lotion?

Daniel continued to discuss the frog siting with his father.

Daniel: Daddy! I saw it! Daddy, I saw something Daddy! I saw something and then I saw it was a frog! (VC:6:1:31)

Henry turned and tapped Mark's arm while he put lotion into my hands. As Henry tapped his father's arm, he continued to look in the grass for the frog. Mark returned his attention to putting sunscreen on Henry and tapped him to draw his attention from the grass. Henry's eyes remain glued to the grassy area and he raised his outstretched palm for Mark to put lotion in his hand.

Mark: [responding to Daniel] Are you serious?

Christine: That's the first time I've seen a baby frog!

Daniel: That's my second! I seen one in Texas!

Marie: [responding from the shallow end of the pool] You have never been in Texas before!

Daniel: [talking to Marie] Uh huh!

Mark continued to put lotion on Henry's front and back torso and then lifted his face to him to apply lotion, breaking Henry's line of vision with the grass. Francis was finished blowing up toys for the pool and asked Christine:

Francis: Do you have lotion to use?

Christine: Why can't we use Uncle Mark's?

Francis: [no response]

Christine: Why can't we use Uncle Mark's?

Francis: I think Nay-Nay [Aunt Nannette] has some for you to use.

Christine: I want to use Uncle Mark's Daddy!

Marie: I want to use it too!

Mark: [responding to the girls' requests for his sunscreen lotion] A special blend of herbs and spices!

Christine: [gets out of the pool to retrieve lotion from Mark) I'm next!

Marie: I don't need any!

Daniel: (to Marie) I'll race you to it!

Marie: I'll still get to be next 'cuz I asked first.

Daniel and Marie got out of the pool in the shallow end and raced to where Mark and Henry were standing near the deep end. Mark finished putting sunscreen on Henry and signed,

Mark: FROG IN GRASS. DANIEL THROW.

Daniel and Christine arrived at the edge of the pool and tried to take the sunscreen from Henry's hands. Mark reprimanded them, signing and talking:

Mark: Well tell him, don't grab it!
TELL! DON'T GRAB!

The scene ended as another creature at the water's edge distracted Christine:

Christine: Ewe gross spider!

Marie: Spider!

Christine: Ewe gross! (VC:6:1:34)

Scene 2: Playing with Cars at Cousin Roger's House

One of the days at Marble Beach was spent visiting Sara's brother Ernest Jr., his wife Heather and their four children (video segment #7). Ernest Jr. is Henry's Godfather--a role presented to Ernest because Henry's birth and identification as a deaf person affected him notably. While Henry had seen pictures of Ernest and his family, this was the first face-to-face meeting between Godfather Ernest and Godson Henry. In an effort to win Henry's favor and show his affection, Ernest gave Henry a large number of toys, including a large cylinder filled with toy cars and trucks.

Scene 2 began shortly after Henry received his gifts from Ernest. Communication in this scene illustrated Henry's contingent access to interaction in several ways. The clip opened with brief interaction among adults and children. Sara acted as Henry's interpreter and voiced his responses for extended family members. Henry's access to interaction during the beginning of the scene was contingent on Sara's ability to sign and voice interpret effectively, as well as how long she decided to remain in her interpreting role. After Henry opened his gifts, Sara left the room to visit with her siblings while Daniel and Henry played with their cousin Roger for the first time. At this point, Henry's ability to access interaction was again conditional. Henry's access to effective interaction was dependent on his ability to make his needs and wants understood without using ASL and the degree of communicative competence held by his playmates. Henry understood that he was required to communicate independently with his brother and cousin.

The scene opened as Henry opened his canister of toys. Sara responded to Henry's gift by signing and saying:

Sara: For you only! Wow! Kiss Uncle Ernest!
WOW. KISS ERNEST [name sign E at the heart]. (VC:7:1:34)

Henry kissed Ernest and returned his attention to the toy in his hand. Sara had taught Henry how to spell the first names of extended family members earlier in the week. Making an effort to bridge the communication gap between Ernest and Henry, Sara said:

Sara: Henry, spell his [Ernest's] name.
FINGERSPELL NAME PRO-1 [points at Ernest].

Henry: I-DON'T-KNOW.

Sara: Remember? Tell him!
REMEMBER? E- TELL E-. (VC:7:1:37)

Henry's cousin Marie watched Sara and Henry's interaction intently. Marie tried to imitate the signs and fingerspelling they are using to interact. Unknowingly, Marie was making sense of deafness by mirroring interactions in a social setting. Marie was learning that Henry communicated in different ways and required visual rather than auditory interactions.

Henry seemed shy and looked down at one of his new toys. Sara voice interpreted for Henry,

Sara: He says, "I don't know [how to spell Ernest's name]!"

Sara tapped on the new toy in Henry's line of vision to get his attention. Marie continued to watch, learning how to get a deaf person's attention. Sara asked Henry,

Sara: You like that?
LIKE THAT?

The next segment of the video clip began as Henry, Daniel, and their 3-year-old cousin Roger played with Henry's new cars and trucks on the "traffic carpet" on the floor of Roger's bedroom. Henry was trying to get the lid off the cylinder filled with toy cars. Sara continued to mediate interaction among the children by engaging Henry in conversation. Henry's access to interaction was still contingent on Sara's ability to use spoken English and ASL to interpret for both Henry and hearing extended family members who did not understand sign language. For example, Grandmother Medina (Peggy) was watching as the boys play with cars, and chattered about different items in Roger's bedroom that reminded her of when her own children were young. Sara mediated or interpreted part of the interaction that was occurring in the room for Henry. However, Henry was only paying attention to the action that was centered on his new cars.

Sara: What do you have? Whose is that?
WHO THAT?

Henry: DRIVE DRIVE PRO-1 [points at the cylinder and shows Sara the toys inside the cylinder]!
There are cars inside this cylinder!

Peggy: He wasn't expecting it. It's a surprise from Uncle Ernest and

Sara: SURPRISE WHO? [Sara rephrases Peggy's comment in the form of a question for Henry].

Peggy: from Arthur [Henry's cousin] and his Daddy [Ernest Jr.

Sara: [Sara asks again] And who's it for?

FOR WHO? [and Peggy responds]

Peggy: For Henry! (VC:7:1:40)

Daniel was sitting on the bottom bunk of the bed listening and watching. Cousin Roger was setting up his share of the cars on the bottom bunk next to Daniel. Sara continued to facilitate interaction, speaking and signing simultaneously to set up the parameters of the play session for Daniel, Henry, and Roger. From a mother's perspective, Sara understood that it was important to clearly define what toys belonged to whom in order to stave off arguments and miscommunication after she left the room. Sara explained to Henry,

Sara: This [car] is for Henry!
THIS FOR HENRY PRO-1 [points to cousin Arthur who is standing off camera]!

It's a surprise from Uncle Ernest and Arthur and Aunt Heather [Sara moved out of camera range and her signs are unintelligible].

Henry: [Nods] YES YES YES YES YES, meaning, "Yes! I understand the cars are from Arthur."

Sara: Okay! He's fine with that. (VC:7:1:41)

Henry vocalized to get his mother's attention. Grandmother Medina was learning about deaf and hearing interactions by watching Sara and Henry. She repeated or filled in "gaps" in their visual and auditory interactions by talking aloud to herself as she followed their conversation:

Peggy: Okay, he knows that, he says.

Henry pointed into the cylinder containing cars and signed to Sara,

Henry: NO MORE CARS [meaning, "There are no more cars in here"].

Sara walked over to the bottom bunk to sit between Daniel and Roger and turned her back to Henry briefly to clear a space to sit on the bed. Henry continued to vocalize her name in order to gain her attention. When Sara settled into her spot on the bed, she took the cylinder from Henry, waved her hand to get his attention and signed/said,

Sara: Here, pour it out [there's more at the bottom you can't see].
POUR

Sara poured the contents of the cylinder, at least 10 more matchbox vehicles, into the middle of the traffic rug. Grandmother Medina squealed in excitement, and Sara interpreted her response.

Peggy: Look Henry! Wow Henry! Yeah Henry! Yeah!

Sara: Wow!
WOW!

Henry smiled, surveyed the pleased expressions of his Grandmother and mother, and then knelt on the floor to start playing with the cars.

Peggy: He's so happy! (VC:7:1:42)

Daniel moved to the floor with Henry. The pile of cars was between them. Sara signed silently to Henry and Daniel, reminding them to share.

Sara: LOOK FOR BOTH-OF-YOU.

Grandmother Medina started to talk about items in Roger's bedroom and Sara chose not to interpret their conversation:

Peggy: Look Sara, do you recognize that? [points to the dresser in the room]

Sara: What?

Peggy: Those pennies? That bowl [pointing at Roger's dresser]?

Daniel looked on top of the dresser.

Peggy: That [container] was in Ernest's room! It was Ernie's! I brought it here for Roger!

Daniel asked Sara a question but she did not have the opportunity to respond.

Daniel: Mommy, do you know what? Can you put that stuff together? [he points to other new toys that are on the bed]

Sara: Yes. I'm going to put this stuff together.

Peggy: [Grandmother Medina asks me a question from behind the camera] See this bowl here, Laura?

Laura: Um hm?

Peggy: It was Ernest's!

Laura: Wow, neat!

Peggy: And we filled it up with pennies and dimes again!

Laura: Wow!

Peggy: We brought it here for Roger!

Laura: Isn't that neat? (VC:7:1:43)

Sara and Peggy left the room and the boys continued to play with the cars on the rug without looking up. The responsibility for Henry's access fell more heavily on his shoulders, or upon Daniel or myself to act as interpreters or mediators at this point. It was interesting to note that as Daniel and Henry began to interact, Daniel initiated interactions using ASL and Henry responded using his voice. Both boys seemed to understand that adult mediators had left the room, and accessible interaction was their responsibility. Henry got up from the traffic rug to peer into the cylinder for more cars. Daniel handed Henry a blue tractor-trailer truck and asked using ASL only,

Daniel: HENRY PLAY THAT? meaning, "Does Henry want to play with that truck?"

Henry responded to Daniel by speaking and shaking his head, "NO!" Again, Daniel responded using sign language only, "WHAT (PRO-1 across his hand)?" Henry signed, "NO." Daniel grabbed for the cars Henry was holding in his arms and Henry turned his body away and refused to give the cars he was holding to Daniel. Henry signed, "MINE" (VC:7:1:44). Roger understood by observing Daniel and Henry's interactions that it was time to stake his share of the toys and establish the pecking order for who got the "best" cars. What Roger does not fully understand is that Henry does not hear his requests. Roger's exaggerated body language and facial expressions seemed to indicate that he understood on some level that his attempts to communicate with Henry had to be visual. However, his anxiety markedly increased as he attempted to negotiate with Henry and did not receive a response to his requests. It appeared that Henry was aware of what Roger wanted, and purposefully did not allow Roger the opportunity for visual interactions. Henry's degree of access and success in this interactive situation was contingent upon Roger not fully understanding the "rules" of interacting with a deaf person.

> Roger: I was playing with that! [Henry puts the car back down by coincidence and Roger grabs it and holds it to his chest--copying Henry's behavior]. I was playing with that. Hey! Those are mine! Give it back! Mine!

Henry picked up a car and showed it to Daniel. He seemed aware that Roger was irritated but continued to ignore his attempts to interact. Roger and Henry established a competitive environment with their body language (i.e., grabbing the cars and holding them, facial expressions, etc.). Daniel's head was cocked to the side as he listened and watched Roger and Henry squabble. He chose not to participate in their interaction, but was keeping a watchful older-brother look out. Daniel ignored

Henry's car offer and Henry put the car down right in front of Daniel. Roger persisted,

Roger: It's mine! Give it back!

Grandmother Medina came up behind me at the doorway and commented about the upcoming storm. Roger heard her comment and turned to look at us, apparently unaware that I had been standing in the doorway. Roger smiled for the camera, wiggled his eyebrows, and returned to his power struggle with Henry. Roger tried to take a car out of Henry's hands and Henry held fast to the vehicle:

Roger: Mine! They're mine!

Roger tried again to take the cars and this time Henry pushed him away vocalizing, "No!" Roger tried a third time and Henry turned his body and shielded the cars, glancing up at me as if to say, "Aren't you going to do something about this?" When Henry realized I was not going to intervene, he shook his head, an emphatic "NO" for Roger. Roger's temper was getting the best of him. He threw a car into the pile in the middle of the rug and screamed, "Share! I <u>said</u> share!" (VC:7:2:3).

From behind the camera, I asked Roger, "Do you want to learn how to sign 'SHARE'?" and he ignored my question. Instead, he picked up another vehicle that had the ability to open and shut and "clacked" it in front of Henry's face. Henry smiles victoriously. By now Daniel was monitoring the interaction overtly, ready to step in if necessary and break up a fisticuff. Roger attempted one more time to strike a preschool deal:

Roger: You can play with this one and I can have that back.

Henry: [vocalizes] No!

Roger looked to Daniel for his reaction and threw down the "clacky" car in disgust, shaking his head from side to side. Daniel looked to me, and back to the play situation. Roger got up and walked out of the room. I assumed that he was leaving to collect himself when actually he left to tell his father (Ernest) that Henry was refusing to share. In the interim, Daniel and I had a brief spoken conversation about the traffic mat, and how it was similar to the mat they had in their basement at home (VC:7:2:9). Moments later, Roger returned with support; Ernest and Sara were now standing behind me at the doorway of Roger's bedroom. Roger jumped across the traffic mat to where Henry had his cars "running." Ernest stayed briefly, long enough to give the boys a cursory reminder, "Be careful!" Roger made one last effort to retrieve his car from Henry's arms and was thwarted every step of the way. Roger's verbal requests were emphatic but each time he reached for Henry's car, Henry avoided his reach and did not respond to Roger's attempts at visual communication:

> Roger: Can I have my car? That's my car! Give me that car! <u>I said</u>, 'Give me my car!" (VC:7:2:13)

At the end of the clip, Henry got up and walked away from the traffic mat and Roger followed him from the room, shaking his index finger and saying, "<u>I said</u>, 'Give me my car!' Give me my car!" Henry continued to walk out of the room and did not respond to Roger, seemingly oblivious to his requests.

<u>Scene 3: Sara Leads the Game, "Pretend You're an Animal"</u>

One afternoon near the end of the visit to Bobbie and Jerry's house, the skies were filled with severe late-afternoon storms. The children had been cooped up in the house too long and in order to harness their energy and keep them occupied, Sara began to lead them in a series of group games (video segment #10). Henry's cousins

Christine and Marie participated in these activities, along with Daniel, Henry, and Madeline. There were even parts of the third game when adult on-lookers praised baby John for participating.

The first game Sara called, "Mommy Says," an adaptation of the traditional "Simon Says" listening skills game played by hearing children. The rules of "Mommy Says" involved Sara signing and calling out commands to the group of children (i.e., Mommy says, take 2 baby steps; Mommy says, spin 3 times, Take one giant step, etc.). The trick to "Mommy Says" was that the only commands that children were permitted to follow were the commands that began with the phrase "Mommy says." Despite the fact that this game was originally designed to include listening strategies, Henry participated and followed Sara's directions along with the other children who were participating. The task of listening or watching for "Mommy says" seemed to be equally difficult for all the children. Sara needed to review the directions several times throughout the course of the game (VC:10:1:10).

The second game involved short relay races across the room while performing a special skill (i.e., carrying an egg on a spoon, walking sideways, crawling like a crab, etc.) (VC:10:2:32). During the third game that Sara called "Act Like an Animal," Henry moved from having contingent access to participation in the games via Sara's moderating techniques, to an example of a <u>comprehensive access situation</u> where he was able to fully participate and even contribute to the group members' interactions. Sara started the game by explicitly explaining (signing and speaking simultaneously) the directions to the children:

> Sara: Mommy is going to say the name of an animal, and you have to pretend you're that animal."

MOMMY SAY NAME ANIMAL. HENRY [points to all the other children sitting on the couch] PRACTICE ACT THAT ANIMAL O-K? (VC:10:5:19)

Then Sara checked their understanding by asking them to respond to a sample animal:

Sara: If Mommy says bird, then you have to pretend you're a bird.
MOMMY SAY BIRD THEN PRACTICE ACT BIRD

How does a bird go?
WHAT-DO BIRD? (VC:10:5:20)

All the children were sitting either on the couch or on the floor in front of the couch. Christine got up off the couch and demonstrated what a bird looks like by flapping her wings (arms) across the room. Sara asked Henry and Madeline to show her what a bird does:

Sara: Show me. Show me
SHOW ME. SHOW ME.

Madeline and Henry followed Sara's directions, flapping their arms (wings) all around the living room. After these trial runs, Sara officially began the game:

Sara: Okay, you understand. Okay, Mommy is thinking about a fish. Show Mommy a fish! (VC:10:5:21)

Daniel, Christine, Marie, and Madeline immediately launched into their own "fish" portrayals. They bent at the waist and moved their arms in a human swimming motion that resembled the breaststroke. Henry paused for a moment, obviously thinking about how a fish behaves. Rather than copy the behavior of his siblings and cousins, his mouth was the first body part that we saw in motion. Henry showed us his interpretation of a fish by sucking in his cheeks, pursing his lips and wiggling his raised eyebrows. Then he raised his hands to his waist and suddenly sprung "fins" as he swam through the imaginary water in the living room. Sara was excited to see his response:

> Sara: Good! Good!

As Henry-the-fish "swam" back to the couch, he moved his hands from his waist to the sides of his face, creating a "gill" effect with his cupped hands. Again, Sara responded enthusiastically:

> Sara: Oh that's right! That's right!

Sara's remarks drew Madeline's attention. She turned to look at Henry and copied his version of a fish. Sara continued,

> Sara: Okay, Mommy's thinking of a dog. Show Mommy a dog. (VC:10:5:26)

Daniel and Christine immediately moved to their hands and knees and began to bark. Henry joined them and the rest of the children, including John the baby. All were crawling on the floor making barking noises. Even Bobbie's dog Murphy abandoned his bone and joined the children with his tail wagging as if to say "Hey! I can do this one!"

The third animal Sara suggested was an elephant (VC:10:5:29). Henry puffed out his chest and began to move his body in a "lumbering" motion, swaying side to side and moving his head up and down. As he made his way across the living room floor, he stopped occasionally to put his hands at the side of his head and "flap" his oversized ears. Meanwhile, Daniel was making a high-pitched sound, imitating the sound of an elephant roaring through its trunk. Cousin Marie, who had been carefully watching Henry's previous animals, placed her forearm to her face and pretended that her arm was the elephant's trunk. Sara continued with the fourth animal, "Mommy's thinking about a duck." Immediately the hearing children began to "quack," and this time Henry chose to imitate their actions. Henry used his voice, "Ahhhhh--Ahhhhh" to imitate a quacking sound.

"Mommy's thinking about a cow!" (VC:10:5:32). Because of our prior conversations about Henry recognizing and producing the sounds for animal sounds, I was particularly interested in how Henry would describe a cow "saying moo." Christine and Daniel began to vocally moo immediately and again, Henry paused to think. Henry bent over as though he were going to crawl on the floor, and placed one of his hands on his stomach, fingers dangling down to represent the cow's udders. During the clip, I asked Sara, "That's a cow?" and Sara responded, "Aren't those his udders?"

The game continued through horses, snakes, rabbits, lions, and bears. Eventually all the children grew tired of the game and one animal became difficult to distinguish from the next. The children were enjoying crawling on the floor and making loud noises--details for them became secondary to burning off energy. The event ended after Sara's requested, "Mommy's thinking of a cat" (VC:10:6:7). Henry immediately put his hands to his face so that his fingers were splayed to resemble a cat's whiskers. As the other children purred and meowed, Henry-the-cat's body twisted and roamed slinkily around the living room. On the way back to the couch and as the game ended, Henry the cat stopped for a lengthy period to lick his paws and clean his face.

This video segment description is a good example of a comprehensive-access situation for Henry because he was fully engaged in the activity and was able to make contributions to the group without changing or adapting his particular visual orientation. It was particularly interesting to see how the other children responded to Henry's ideas during this game and how all the children modeled and learned from each other's behavior. In other words, learning and interacting among the children during this activity was reciprocal and mutually enjoyable.

Discussion

This section discusses the findings (e.g., the social actors, their stories, and interaction contexts that resulted dynamic tensions) presented in Chapter V that exemplify how Henry and his family members made sense of deafness, and how that sense-making was demonstrated in their actions. Table 5.1 serves as an organizational tool that presents these findings explicitly.

The stories in Table 5.1 share two over-arching themes:

1. Cultural tensions were experienced by members of the Camillo family both within their immediate family and in the interactional sphere outside their home. Findings indicate that cultural tensions among deaf and hearing family members were magnified, rather than reduced, by interactions with members of the special education system; and
2. The family was provided a "smorgasbord" of options concerning their child's communication options and educational placements (C. Erting, personal communication, April 16, 1999). This smorgasbord lacked a framework that could logically guide the family's actions through the process of making sense of deafness and the educational choices available.

Table 5.1. A Summary of Chapter V Findings.

The Story	Related Social Actors	Context(s) of Interactions
1. Creating a "fair" communication environment	Mark and Sara Camillo	Henry's parents with extended family members, and other parents
2. "TRAIN HEAR ENVISION BLUE"	Mark, Sara, Henry, and Madeline Camillo	Madeline, Henry and Sara at the dining room table
3. "How do we sign KETCHUP?"	Henry, Justin, Peter, Sara and Mark, Laura	Dinner table interactions with two (deaf) visitors
4. The Camillo Dilemma	Graduate students studying about families with deaf children and Sara Camillo	A videotaped question while Sara was on bed rest
5. Henry Darts Away From Conversations	Sara, Mark, and Henry	Henry's conversations with his parents at home
6. "WHY TALK TALK?"	Sara, Mark, Henry, and Laura	Henry's question to Sara when observing family members and visitors communication
7. Henry's Bus Stop	Parents: Sara and Patty	A parent-to-parent discussion about Parkwood at the bus stop
8. The Parent-Teacher Meeting at Parkwood	Sara and Mark Camillo; other parents of preschool children at Parkwood; Henry's teachers and classroom aide; and the Parkwood's acting principal, Anthony Salins	A parent-teacher meeting to address behavior problems in the preschool
9. "How can we teach Henry to make sense of sound?"	Sara, Justin, Mark, and Laura	A discussion prompted by materials sent home by the speech pathologist and audiologist at Parkwood
10. The Maid in the Basement	Daniel, Henry, Madeline, and Laura	The older Camillo children make sense of her moving into their home
11. A Present for the Triplets	Daniel, Henry, and Sara	Daniel and Henry argue over a package

Table 5.1. A Summary of Chapter V Findings (continued).

The Story	Related Social Actors	Context(s) of Interactions
12. After School Interactions	Henry and Madeline	Play between Henry and Madeline at home
13. The Wellness Checkup	Medical doctors, Sara, Luke, Mary, and John	During a wellness checkup for the triplets
14. Deafness is a Disability	Joe/Geneva Camillo; Aunt Bobbi/Uncle Michael	Extended family members respond to interview questions
15. Deafness Imposes Communication Barriers	Peggy/Ernest, Sr. Medina; Aunt Elaine; Aunt Megan	Extended family members respond to interview questions
16. Deafness is Using Another Language	Aunt Nannette; Uncle Harry/Aunt Maura; Aunt Bobbie/Uncle Jerry; Uncle Francis	Extended family members respond to interview questions
17. Deafness is Viewing the World in a Different Way	Uncle Steve Camillo	Extended family members respond to interview questions
18. Events on a Snow Day	Sara, Daniel, Henry, Madeline, Luke, John, and Mary	Laura observes Henry's primarily visual orientation in the home setting.
19. Finding a Frog at Marble Beach	Mark, Uncle Francis, cousins Christine and Marie, Daniel, Henry, Madeline, and Laura	Videotaped interactions among Henry, his siblings and cousins
21. Playing with Cars at Cousin Roger's House	Sara, Peggy Medina, Daniel, Henry, cousin Roger, Uncle Ernest, Jr., and Laura	Videotaped interactions among Henry, his siblings and cousins
22. Pretend You're an Animal!	Sara, Cousins Marie and Christine, Daniel, Henry, Madeline and the babies	Videotaped interactions among Henry, his siblings and cousins

CHAPTER VI

DISCUSSION AND RECOMMENDATIONS

The process of participating in and observing the day-to-day lives of Henry Camillo and his family members, analyzing the words and statements that they offered during interviews, and systematically documenting their social interactions among extended family, led to the end of a project that, for me, requires some conclusion. However, the reality of family life is that as I write these final words and provide recommendations, somewhere the Camillos and other families like them continue to live, learn, and navigate through a system of education that provides a great deal of both information and misinformation. The challenge facing families is how to choose information pertinent to their child's needs and then integrate that information into their daily lives.

Since this research project began, Henry has moved to a different part of the country, and changed schools twice. His triplet siblings are now 2-year-olds, Madeline begins preschool in the Fall, and Daniel is well on his way to the fourth grade. Using Sara Camillo's words, "Time doesn't stop for anyone." Quite literally, the Camillos continue to make their way along a "deaf education road" that provides no promises about Henry's future as an independent and literate member of our society. Keep in mind that as the reader completes this dissertation, Henry Camillo is somewhere blowing out six birthday candles placed carefully on homemade vanilla cupcakes. He and his family members are invested in this research and hope that this document will make sense of their story, perhaps to the benefit of other deaf children and their families. We are left to answer and then act upon the question, "What do the findings contained within this dissertation mean within the context of providing better early education experiences and services for young deaf children and their families?" This chapter attempted to respond to this question by presenting a brief summary of the dissertation's design as well as findings and implications of the project. The second section presented recommendations provided by Henry's parents, Mark and Sara Camillo. Third, the methodological strengths and limitations of this investigation were considered, followed by my recommendations for future research. This dissertation ends with a final glimpse at Henry's worldview, permitting the reader to consider the implications of his perspective.

Summary

This dissertation tells the story of a deaf child, Henry Camillo, and his hearing family's social, linguistic, and cultural experiences among their own relatives, immediate and extended. Ethnographic research methods were used to examine the interactions that took place in the Camillo home over a 10-month period, paying particular attention to the intersection of the family's two languages (e.g., American Sign Language and English), as well as their differing behaviors and understandings related to deafness. The central problem that led this investigation was that deaf children from hearing families frequently grow and develop in home environments that lack common forms of language use and communication among family members, leading to the presentation of cultural tensions that further complicate family interaction and often hamper identity development in the deaf child (Erting, 1982/

1994; Meadow, 1967). The central problem for deaf children and their families gathers complexity as one realizes that the educational system, that is presumably designed to provide support, frequently recommends only medical solutions in an effort to repair or remediate the child's deafness, thus disregarding solutions to a problem that is also grounded in socio-cultural differences. Therefore the purpose of this investigation was to examine the various worldviews held by the deaf child and his hearing family members, in an attempt to understand how family members socially constructed their knowledge and understandings of deafness among themselves and with others.

The theoretical perspective of this work is based on a socio-cultural view of deafness. Erting's model of the family members as social actors were used to provide a theoretical framework for the Camillos' experiences (Erting, 1982/1994). In other words, the theoretical position for this investigation is that cultural behavior and knowledge are learned through the process of interaction within various reciprocal and social environments. Individuals can not learn about themselves as social beings in isolation. A person's identity development or particular view of "reality" is developed through various opportunities for interaction with others, as well as the components of the worldviews of others. Therefore, cultural knowledge and identity development occurring within a family that has deaf and hearing members produce unique kindred circumstances and related issues that need to be addressed when considering the educational needs of the deaf child and his or her family.

The main participants of this investigation were Henry Camillo, a 4 year old deaf child, and his seven immediate family members who were all hearing. Mark and

Sara are his parents and his five siblings are Daniel (6 years old); Madeline (2 years old); and the triplets, Mary, Luke, and John (1 year old). Henry's mother Sara agreed to interview for the pilot investigation that preceded this dissertation and then invited me to move into their home for a long-term, day-to-day view of their family's lived experiences. Extended family members from both maternal and paternal sides of the family also volunteered to be interviewed and videotaped as part of this investigation.

Data were collected primarily within the Camillo's home, which served as the main hub of activity and interaction for the family. Participant observation events were documented in the form of condensed and expanded fieldnotes on a daily basis over the 10-month period that I lived with the family. Nineteen ethnographic interviews were recorded on audio and videotape with Mark and Sara, as well as fourteen extended family members (Henry's grandparents, aunt, and uncles). Interactions among Henry, his siblings, and cousins were captured during the last two weeks of data collection as I accompanied the Camillos on vacation to visit extended family members.

One of the primary discoveries of this dissertation was that different family members (i.e., the deaf child, parents, siblings, aunts, uncles, etc.) hold divergent understandings of deafness. The research design combined three types of analysis that worked in tandem to identify the various perspectives of family members (Agar, 1986; Ely et al, 1991; Erickson, 1992). The use of three differing forms of analysis allowed me to "shine spot lights" in different corners of the Camillos' life. First, the methods recommended by Ely and her associates organized fieldnotes and interview transcripts by themes that were pertinent to the family's experience. Second, Agar's methods helped to illuminate cultural tensions and social dilemmas that ensued among family members. Finally, Erickson's microanalysis of specific social interactions enabled me to capture the various and diverse perspectives of different participants, as well as build connections between (triangulate) the three different types of data (e.g., fieldnotes, interview transcripts, and videotaped interactions). The next section identifies selected methodological strengths and weaknesses of the research design.

Methodological and Validity Considerations

Several aspects of this research design are uncommon in the field of Deaf Education, creating a "double-edged sword effect" when considering the investigation's strengths and limitations. In other words, some may view aspects of this research as positive while others see it as a shortcoming, depending on one's research position regarding qualitative and quantitative works.

Strengths and Limitations of the Study

Long-Term Data Collection Efforts

This investigation involved the in-depth and detailed examination of one deaf child and his family's experiences. I had the unusual and privileged opportunity to live with the Camillo family for a 10-month period. My extended participant observation allowed me to study the family until the data became recurrent. The recurrence of data is desired and occurs when patterns of language use and behavior demonstrated by the informants are documented in the database over time. Recurrent data assists the researcher in the tasks of substantiating new discoveries, making sense of discrepancies in the words and behaviors of informants, as well as accurately and completely describing the lived experiences of the research participants.

Researcher Bias

Some might argue that because I conducted my fieldwork as both a participant and observer within Henry's home that my findings are more subjective than scientific in nature. I accounted for my own researcher bias in several ways. First, rather than attempt to eliminate researcher bias, I made conscious efforts to acknowledge and document my biases overtly in order to use them productively in the research process (Maxwell, 1996). The stories that are told in this dissertation pertaining to my relationship and life experiences with my Deaf uncle are the products of my efforts to acknowledge researcher bias. Secondly, I was able to conduct thorough member checks with Mark and Sara Camillo as I gathered and analyzed information. I considered Mark and Sara as equal partners in this research process. Their perspectives and contributions bear a strong influence on the type of material presented in this dissertation, as well as future publications. Lastly, as my findings emerged, I worked consistently with my Peer Debriefer and other members of the LLCD research team to obtain feedback about the research process as well as the product--this dissertation.

Researcher Reactivity

My longevity in the field also helped to account for researcher reactivity among informants. Researcher reactivity can be defined as how the informants' behavior is influenced by the presence of the researcher (Maxwell, 1996). Some of the stories I have told as part of this dissertation are good examples of how family members reacted to my presence when I first moved in the home. For example, initially the children were standoffish. In addition, Sara and my daily plan of activities were more formal and regimented in the beginning of data collection. My role within the household as well as my understanding of the family members' typical and atypical behaviors developed over time. By the time I interviewed extended family members, it was common for individuals to remark, "You fit in so well, I sometimes forget you're a researcher!"

Generalization of Results

The purpose of this research was to determine the perspectives of informants or develop a better understanding of how they define their individual "realities." Therefore, it is inappropriate to make statements concerning the generalizability of these findings concerning other families. However, while some may characterize the Camillo family as having unusual characteristics (perhaps the size of their family or the diversity of their members is considered unusual), it is reasonable to state that some of their experiences within the family and among others in the special education system are comparable to other families with deaf and hearing members. The next section details some of Mark and Sara's challenges and concerns that are frequently experienced by other deaf children and their hearing family members.

Mark and Sara Camillo's Questions and Recommendations for Practitioners from Parents

Mark and Sara Camillo's views of deafness are grounded primarily in their roles and responsibilities as parents to Henry and his five young siblings. Their goals are to provide food, love, and shelter for their children while meeting their diverse and changing needs. Throughout my fieldwork and particularly during the final retrospective interview (February 14 & 15, 1998), Sara and Mark Camillo discussed the implications of this research for Henry and their family. They also reflected upon questions that have been ongoing and in some ways undecipherable since Henry was identified as deaf. The following questions and recommendations are arranged by two themes: Recommendations and Questions for Educational Practitioners, and Words of Encouragement and Questions for Other Parents and Family Members. Mark and Sara's paraphrased statements from fieldnotes (text in italics) and quotes from the final interview transcript are used to contextualize the recommendations from their perspective.

- The assessment process was, and still is, confusing and unnerving for parents and family members. They view testing as effective when they act as team members in the assessment process. Parents appreciate knowing what is happening when their child is being assessed along each step of the process.
- Parents appreciate when testing and follow-up interventions are conducted at their convenience. "At their convenience" means scheduling testing sessions around the family's regular schedule (i.e., around the child's napping and eating schedule) rather than during regular school office hours.
- When teachers, doctors, or psychologists test the child, parents need to be informed about the purpose of the assessment, the sequence of the testing process, and what the results mean in terms of progress.

Learning Sign Language

- Learning sign language was a challenging and fascinating experience for the Camillos. Is there a way that learning sign language can be introduced so that it is not a frightening process filled with grief and confusion?

- The quality and type of sign language classes are a confusing and frustrating component of learning to sign. The task of learning to sign might be less confusing if parents and family members had fewer "systems" and "methods" to choose from and focused particularly on the form and function of American Sign Language alone. Mark and Sara also mentioned that they are not sure how to evaluate our skills among one another as they were learning--they need regular access to native ASL users who can provide immediate answers to their questions about signing. The Camillos suggested a strategy of videotaping family members and shortly after, watching the videotape with a native signer who can provide recommendations, knowledge, and support.
- Family members are confused about the various of "levels" of sign language classes that are offered (i.e., beginning, intermediate, and advanced sign language classes). Mark and Sara expressed a desire to learn the difference between various levels of ASL fluency. They would like to be provided with specific strategies for achieving fluency in ASL.
- Fingerspelling was a constant challenge for Henry Camillo's family members. The fingerspelling component of ASL was a difficult concept for them to understand and use on a regular basis. The Camillos considered fingerspelling to be the most difficult and intimidating part of learning to sign fluently. They want to learn strategies for becoming better fingerspellers and develop a better understanding of how Henry makes sense of fingerspelling as he develops literacy in ASL and English."

- Mark and Sara disagree about the best way to learn sign language but agree that they have a "thirst" to become fluent ASL users. Mark prefers a structured learning environment and wants to take more classes. Sara wants more interactive experiences with Deaf adults. They want more opportunities to learn sign language through a variety of classes and interactive experiences combined.

Recommendations from Parent to Parent

"Fair" Doesn't Always Mean "Equal"

Mark and Sara Camillo have a rule among their family members that *everyone is treated the same*. What they mean is that despite the recommendations of child-rearing experts, the best strategy for managing deaf and hearing children in the same family is to treat them the same, meaning treat them with the same amount of respect and attention. The discoveries of this investigation demonstrate that while communication, interaction and the resulting worldviews of each child differ, it is possible to meet a variety of different needs within the same environment if differences are respected and reflected upon.

Work as a Team Member with School Personnel.

Part of working as a team member is recognizing first, who is on the team and what you're trying to accomplish together. The next step is identifying who will lead the collaboration efforts. Mark and Sara Camillo identified this research project as the type of collaborative, team-based relationship they would like to share with educators and administrators. They felt that the experience was very positive and addressed the needs of their children <u>first</u>. Mark and Sara describe our research relationship as true teamwork because there was room for "give-and-take in the relationship." Both sides made compromises and contributions.

Discussion

The diverse perspectives of Henry and his family members were one of several surprises I experienced as my analysis unfolded. First, I did not expect to discover a family environment where individuals live within the same physical space, breathe the same air and eat the same food on a day-to-day basis, but frequently view the same situation from contrasting positions within their shared environment. Secondly, I did not anticipate the complexity of family life that comprises Henry with his family members. I was often startled as I witnessed family members sharing deep emotions, the incredible challenges of parenthood and marriage, the numerous questions that are left unanswered on a daily basis, and the sheer exhaustion that results from raising six young children. However, the most resounding discovery of this dissertation for me was the invisible gorilla that appeared from time to time in their living room. I never saw the creature while I lived in the Camillo home. When it initially appeared during analysis, I wasn't quite sure what to make of it. What follows is a discussion of how I made sense of the gorilla and how I believe it influences the family environment of deaf children from hearing families.

Claudia Black, author of It Will Never Happen to Me, writes about pink elephants in the living room in her discussions about dysfunctional families who live with alcoholism. Black defines a pink elephant as the condition of alcoholism within the family system where all family members can see the disease, but do not to speak of it for fear of "breaking the no-talk rule." The underlying assumption behind pink elephants and the no-talk rule is that if someone actually sits up in their easy chair and says, "By golly, there's a pink elephant in our living room!" that the conditions and behaviors associated with alcoholism will have to be addressed and resolved. In other words, the no-talk rule is a covert understanding among family members who see that one or more of them is an alcoholic but agree through their mutual silence not to talk about the condition. As long as the condition is left unaddressed by family members, alcoholism is perpetuated in the family, blocking healthy communication and disrupting family relationships.

I am borrowing Black's metaphor, in part, using an invisible gorilla as the symbol that represents the concepts of culture and cultural tension in hearing families with deaf children. The "no talk rule" also applies to what happens to deaf children and their families but not because of a covert agreement. The invisible gorilla stays invisible in hearing families with deaf children because no one ever tells them to look for it in their home. In many ways, living with the invisible gorilla is a much more frightening and anxiety-ridden experience than the situation of the pink elephant. In contrast, family members experience the feelings of fear and trepidation that are associated with being in close proximity with a gorilla, but they do not know what is causing their anxiety.

We need only to consider some of the cross-cultural experiences, perspectives, and stories told by Henry Camillo and his family members and the gorilla will materialize. For example, when Sara shared her "dilemma" with my group of students from her hospital bed, she described a cultural tension between her and Henry. She understood there were communication "rules" to follow with Henry that were not necessary with her other children (i.e., maintain eye contact with Henry while communicating). Sara also told the students repeatedly, "I need more," and "I don't know how to manage communication, but I don't want to be rude to my son."

Six months later (January 1997), the gorilla was present at the dining room table while Sara continued to puzzle over what could be preventing Henry from making sense of sound. In "The Reading Story," she led an emotional discussion with the family's reading mentor, Justin, about different communication methods and tools she needed to overcome what she perceived as a delay in Henry's development. "I feel like we've lost time because we thought he was so smart-smart-smart and that we were ahead. Now I feel like we're behind!" (INT:4:10:14). Sara's questions were left unanswered, in part, because she was asking questions related to experiencing cultural differences while receiving answers that addressed the issue of language and communication. Her feelings were very real and need to be addressed, but the solution to resolving her feelings does not lie in finding a new tool or communication methodology. Sara's problem lies in the most basic difference between her and Henry, which is that she accesses information primarily in an auditory way and Henry accesses information in a visual way.

Lastly, yet another common perception of hearing family members is that the Deaf community will eventually "steal" the deaf child from his or her hearing parents. During my years as a classroom teacher, I overheard countless hearing parents speak with fear in their voices about their child's unique relationship with members of the Deaf community. They seem to understand Deaf Cultural values as a threat to their family bonds and relationships. Actually, there are no factual accounts of Deaf people physically stealing or coercing young deaf people away from their hearing family members. Again, cultural tensions and differences, appearing as the invisible gorilla, are what threaten the union of deaf children with hearing family members.

The question that remains to be asked is, How do hearing families understand a view of deafness and their child's experience with the world when it is not presented to them as part of their early education experiences? How do they identify the source of their anxiety if no one helps them to make their understanding explicit? This dissertation and the work of others (Erting, 1982/1994) have demonstrated that there are few, if any, naturally occurring social circumstances where hearing family members can integrate Deaf cultural knowledge as part of their own unique worldview. In response to the invisible gorilla phenomenon, educators are left to answer two critical questions: (1) when do we tell hearing family members about cross-cultural tensions, and (2) how do we teach them effective strategies for working through cultural tensions towards cross-cultural competence? I hope that Mark and Sara's recommendations for educational practitioners coupled with the following recommendations for future research will serve as acceptable grounds for discovery.

Recommendations for Future Research

In light of the information presented in this dissertation, I am making the following recommendations for future research:

1. Ethnographic and longitudinal research methods should be used more frequently to investigate the homes where deaf children live and grow.
2. To ensure the success of future research agendas related to deaf children and

their families, greater efforts should be made to establish team-based and collaborative research partnerships among members of the Deaf community, parents, and teachers.

3. Additional efforts are needed to investigate the perspectives of fathers, siblings, and extended family members, in addition to the worldview of mothers. Efforts to address the needs of all family members will result in early education efforts that address the unique views of oft-overlooked and important family members.

4. Early education programs for deaf children and their families should include a component that addresses deaf and hearing cultural differences in the family. Consequently, there is a great need for future research to closely examine the process of how deaf and hearing family members learn to recognize and relieve cultural tensions.

5. The empirical investigation of sibling interaction and development in families with deaf and hearing membership is rich with promise. There is a need for investigations that address linguistic and socio-cultural development as it is influenced by birth order, diverse gender among siblings, and family size.

A Final Look at the World Through Henry's Eyes

At the time of this investigation, Henry was 4 years old--too young to participate in an interview, but old enough to demonstrate through his actions and language use that he does view the world in different ways than his immediate and extended family members. In closing, I would like to take an author's privilege and present a hypothetical statement that might feasibly come from Henry, if he were in a position to provide a description of his present-day life, and propositions for his future:

My name is Henry Camillo and I'm 4 years old. I am smart and full of energy and I love playing outside. I come from a large, active family and I love my Mom, Dad, brothers and sisters more than any people in the world. I play with trucks and go sledding with my big brother Daniel--he looks out for me and I do the same for him. Daniel and I are the older brothers and we get special privileges like a larger weekly allowance, boy scouts, and after school soccer. I pick on my sister Madeline because I like to see her reaction when I tease her. When she cries she makes a funny face and it's hard not to laugh at that. Also, Madeline and the babies make me laugh because they sign like babies. I count on Daniel, Madeline and my Mom and Dad to let me know what's going on around the house when people are in other rooms just talking or when they forget to sign. I ask them a lot, "What are you talking about?" and they usually tell me. I know I can go to them to help me figure out what people are saying if we have company at the house and they don't know sign language, or when we go to visit my cousins and aunts and uncles.

I love my family but I'm different than them. I'm the only one that's deaf. I know for sure that I'm the only deaf person in the family because Dad and I have talked about it and he told me I was right--Dad's hearing, Mom's hearing, Daniel's hearing, Madeline's hearing, John's hearing, Luke's hearing, Mary's hearing, and Henry's deaf--I'm the only one. I don't know how it worked out that I'm the only one who's deaf, but I go to school with other kids that are deaf like me so I know I'm not the only one in the world who's deaf. I know my one ear is broken and Mom tells me that the doctor is going to give me a new ear. Sometimes I wonder if I'll be hearing like the rest of the family after the surgery or maybe when I grow up? I try to learn to hear better when I'm in speech class at school, or when someone asks me if I hear the babies crying or an airplane overhead. Sometimes I have to wear my hearing aids but I really don't like them because they hurt my ears.

I've figured out that when I'm with hearing people, if I stay ready and pay attention, I can figure out what's coming up next just by watching them. Sometimes I don't do so well figuring out what happens next if the regular routine changes around the house - when the routine changes I get nervous. Like sometimes Mom and Dad go out on a date with each other and they tell me when they are leaving and who is coming to baby-sit, but I forget some of the details and have to ask them a couple times before I remember what happens next. That's what I do to keep up with what's going on in the house--I watch people and ask them questions before they leave the room so I know where they're going and then I have a better idea of what's going to happen next.

I like my babysitters because they know sign language and we get to stay up late when Mom and Dad go out. But when there are babysitters at the house I stay up as late as I can. Before I feel comfortable enough to go to sleep at night I like to see that Mom and Dad are home with us. If I close my eyes and go to sleep, I have no way of knowing if they're home or not. The same thing happens if we're on vacation or away from the house. Just last summer when we flew to visit Aunt Bobbie I fell asleep on the airplane. When I woke up it felt like we had been on a plane a long time and I asked Mom, "Did you sleep already?"

I ride a big bus to school and it takes me a long time to get there. Mom takes me to the bus stop after she drops Daniel off at his school in the neighborhood. I have to travel far because I go to a school for deaf kids like me. I like going to school with other deaf people because I always know what's going on and they teach me how to fit in and feel comfortable when people don't know how to communicate with me. When I learn new signs at school, I remember to tell Mom about them when I come home from school. Mom likes to learn new signs and gets excited when I teach them to her. She says, "My Henry is so smart-smart-smart because he teaches Mommy new signs!" Moms can be kind of silly sometimes, and my Mom is the silliest of them all.

So, that's what it's like to be a deaf person in a hearing family. Sometimes I can figure out what's going on and sometimes I can't. Sometimes I get frustrated and tell them so. I tell them that their behavior is unacceptable and that they need to remember that I understand the world through my eyes alone, not my ears and my eyes together. It's just hard sometimes because I love my family, but sometimes it's just easier to be with deaf people or people who sign really well. When I'm with deaf people I don't have to try so hard to watch what's going on and to figure things out. I don't have to look at their lips moving and wonder what they're talking about. The thing I like best is just knowing what's going on around me. I'm a kid, you know. I have a lot to learn and a lot of life to live. I just wish I could spend less time trying to figure out what's happening next, and more time living, learning, and having fun with the people I love the most--my family.

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Appendix A

Abstract

The Development of Language and Literacy Skills among Deaf and Hard of Hearing Students in ASL-English Classrooms

The purpose of this proposed research is to describe the interaction, language acquisition, teaching, and learning strategies of preschool children and their teachers in the classrooms where ASL and English are the languages of instruction. By taking an ethnographic perspective, gathering and analyzing empirical data on the nature of everyday interactions in the classrooms and families, this study will seek to uncover the complex relationships among physical and demographic characteristics of students, languages of home and school, social identity, and academic achievement levels in the areas of reading and writing. By working collaboratively with teacher-researchers and following a participatory research model, the study will provide direct feedback between school personnel and researchers for the duration of the project.

The research will be conducted at Kendall Demonstration Elementary School (KDES) in Washington, DC. The sample of students includes deaf and hard of hearing students with culturally diverse backgrounds at the parent-infant and the pre-school level. In the first year the study will focus on three of the six classes that have been designated by KDES as "ASL research classrooms" starting in September 1993. In 1994-95, four classrooms will be studied.

This research is based on the view that language learning takes place within a sociocultural context and is a complex linguistic, cognitive, and social process. The project is designed to take account of this complexity and to situate the investigation of the learning of language and English literacy within the everyday lives of the students in school. To meet the goal, the design of the research is ethnographic, qualitative, and holistic. Data will be collected through participant-observation, structured and informal interviews, and sign language assessment measures for students and teachers, videotaping of classroom and home interaction, and portfolio assessment. Researchers will visit each classroom regularly. Analysis will proceed in tandem with data collection, each process informing the other to build theoretical categories and elucidate patterns. Data from multiple sources will be used to fine-tune emerging hypotheses and resolve contradictions. The final results of this study should advance our understanding of the relationship between ASL and English when they are used by deaf and hearing teachers as school languages, as well as the relationship between the acquisition of ASL and emerging literacy skills in the deaf and hard of hearing preschoolers in these classes.

Appendix B

List of Expert Informants

Father's family		**Mother's family**	
Camillo Adults/Ages	**Camillo Children/Ages**	**Medina Adults/Ages**	**Medina Children/Ages**
*Harry (42) - Mark's brother *Maura (36) We are staying with this family	Harry Jr. (13) Joshua (11) Becka (7) Melissa (5)	Ernest (38) - Sara's brother Heather (34)	Maria (17) Arthur (12) Samantha (10) Roger (3)
*Steve (27) - Mark's brother	single, no children	*Francis (33) - Sara's brother	Marie (5) Christine (7)
Lila (31) - Mark's sister Ted (21)	James (10) George (3) Christine (8 months)	Bobbie (30) - Sara's sister Jerry (28) We are staying with this couple	no children
*Bobbi (43) - Mark's sister *Michael (43)	Roberta (12)	*Nannette (25)	single, no children
Margaret (38) - Mark's sister Christopher (40)	Karl (7)	Grandfather Ernest Sr. Medina Grandmother Peggy Medina	
Elaine (32) - Mark's sister Joe (35)	Bart (6)		
*Meg (44) - Mark's sister	single, no children		
*Mark (Henry's father) (34) *Sara Jane (Henry's mother) (36)	Daniel (6) Henry (4) Madeline (2) Mary (10 months) Luke (10 months) John (10 months)		
Steve & Geneva Camillo (paternal Grandparents)			

Appendix C

Families who participated in the Pilot Investigation: A List of Pseudonyms

The Bartholomew/Norris Family ▪ John Bartholomew; John is the youngest (5 years old) deaf ▪ Sheryl Bartholomew (mother, hearing) ▪ Bill Norris (John's oldest step-brother, hearing) ▪ Alice Norris (John's older step-sister, hearing) ▪ Frank Norris (John's youngest step-brother, hearing) ▪ Scott (family matching person, hearing) ▪ David Norris (the three oldest siblings' father, and Sheryl's first husband, hearing) ▪ Martha (David's mother, John's Paternal Grandmother, hearing)	***The Arnold Family*** ▪ Don Arnold (father, deaf) ▪ Jennifer Arnold (mother, deaf) ▪ Claire Arnold (older daughter, deaf) ▪ Charlotte Arnold (youngest daughter, deaf)
The Camillo Family ▪ Sara Camillo (mother, hearing) ▪ Mark Camillo (father, hearing) ▪ Daniel Camillo (oldest son, hearing) ▪ Henry Camillo (second son, deaf) ▪ Madeline Camillo (first daughter, hearing) ▪ Camillo (Sara's "pet" name for Mark) ▪ Mary Camillo (girl triplet, hearing) ▪ Luke Camillo (boy triplet, hearing) ▪ John Camillo (boy triplet, hearing) ▪ Geneva Camillo (paternal Grandmother, hearing) ▪ Joe Camillo (paternal Grandfather, hearing) ▪ Peggy Medina (maternal Grandmother, hearing) ▪ Ernest Medina Sr. (paternal Grandfather, hearing) ▪ Steve Camillo (Mark's brother; Henry's paternal uncle, hearing) ▪ Bobbie (recently married; Sara's younger sister; Henry's maternal aunt, hearing) ▪ Ernest Medina Jr. (Sara's older brother; Henry's Godfather, hearing) ▪ Francis Medina (Sara's younger brother; Henry's maternal uncle, hearing) ▪ Marie Medina (Francis' daughter; Henry's 5-year-old cousin, hearing) ▪ Christine Medina (Francis' daughter; Henry's 7-year-old cousin, hearing) ▪ Nannette Medina (Sara's youngest sister; Henry's maternal aunt, hearing)	***The Small/Young Family*** Karl Small (foster son, deaf) Bernice Young (foster mother, hearing) Dakinia Small (Karl's birth sister, hearing) Claudia Smith (Social Worker) Linda Sheffield (Karl's classroom teacher, hearing) Tim Bernard (Karl's classroom teacher, hearing) Yolanda (Karl's older foster sister, hearing) Hillary (Karl's older foster sister, hearing) Bernice's partner – James (hearing)

Appendix D

Interview Protocols

- Protocol 1: Beginning of the Pilot Interview (6/4/96)
- Protocol 2: Grandparent Interview (10/23/96 & 7/1/97)
- Protocol 3: Maternal Aunt/Uncle Interview (12/27/96)
- Protocol 4: Audiologist Interview (5/26/97)
- Protocol 5: Henry's First Parent-Infant Educator Interview(5/26/97)
- Protocol 6: Extended Family Members Interviews (June – July, 1997)
- Protocol 7: Final Interview (2/13/98 & 2/14/98)

Protocol 1: Beginning of Pilot Interview (June 4, 1996)

1. What type of questions do you expect me to ask? In other words, what areas concerning your family would you like to share (that you think would be important for other parents to know)?

2. What is it like to be _______'s Mom?

3. What is it like to be the parent of a deaf child, in contrast to what it may be like to be the parent of a hearing child?

4. What have your experiences been with medical professionals?

5. Tell me something about your experiences with Deaf Education and Early Intervention Programs?

6. Describe for me the structure of your family....how would you describe your family? Can you draw me a picture of what it looks like?

7. Share with me some anecdotal family stories....

8. How did you meet your husband?

9. What is the story of your family's creation? What did you imagine it would look like, or consist of? How does your family differ now from that pre-existing vision?

10. What major changes (positive or negative) have your family experienced since it was first established?

11. What has been the reaction of family members to the birth of your child?

Protocol 2: Grandparent Interview (October 23, 1996)

1. What type of questions do you expect me to ask?
2. What is important for me to know about your family? Tell me about your family.
3. How did you meet?
4. When did your family start?
5. Can you draw me a picture of your family? Tell me about it.
6. Do you have any good family stories about Sara and Mark, and their children?
7. What major changes have you experienced as a family?
8. What is it like to be a grandparent?
9. What is it like to be Henry's grandparent?

EXTRA:

- What does the term "fairness" mean in your home?

Protocol 3: Maternal Aunt/Uncle Interview (12/27/96)

1. What type of questions do you expect me to ask? In other words, what areas concerning your family would you like to share (that you think would be important for other extended family members to know)?

2. What is it like to be Henry's guardian? What type of responsibilities do you accept as the children's guardian? What type of expectations and/or do you have for each of the children? What would happen in case of Sara and Mark's death?

3. How did you learn to sign? How would you rate your sign language skills? Tell me about this. What have been your impressions of Deaf adults that you have met separately or through Sara and Mark's family?

4. What has been helpful for you concerning building a relationship with Henry? What has not been helpful?

5. Tell me what you reflected about in your journal when Henry was born? How have your entries changed? What things have you written that surprise you?

6. Tell me about Sara and Mark's experiences with Deaf Education and Early Intervention Programs/Professionals?

7. Describe for me the structure of your family. How would you describe your family? Can you draw me a picture of what it looks like?

8. Share with me some anecdotal family stories.

9. How did you meet your husband?

10. Growing up with Sara, what did you imagine your family's would look like, or consist of? How does your family differ now from that pre-existing vision?

11. What major changes (positive or negative) have your family experienced since it was first established?

12. What was the reaction of family members (i.e., your reaction, your mom and dad's reaction, your siblings, your extended family) to the Henry's birth (versus Madeline and the triplets' birth)? From your perspective, how were these births the same or different?

13. Do you remember what you were thinking when this picture was taken?

14. What else can you tell me that I haven't asked? What else can you tell me that will help me to learn more about the life experience of this family?

Protocol 4: Audiologist Interview (May 26, 1997)

(Oral Program where Henry and the Camillos started)

1. What sparked your interest in your profession?
2. What is the philosophy of your program concerning working with deaf children and their families? What is the history of the program?
3. Where do most of your teachers and family advisors come from? What is their background in teaching and working with families?
4. What is your own professional philosophy concerning deaf children and their families?
5. What "works" when teaching children who are deaf and advising their families?
6. What type of information did your program and you personally provide for the Camillo family when they were enrolled in your program?
7. What did you tell the family about their son, his deafness, the field of deaf education, individuals who are deaf, etc.?
8. What were your impressions of the family during their time in your program? Do you remember your first impression of Henry? Sara? Mark? Daniel? What was your vision for them?
9. What is important for me to know about Henry and his family's experiences?
10. Is there anything else that you'd like to share with me that you think is important information about the family and/or your parent-infant program?

Protocol 5: Interview with Henry's First Parent-Infant Educator (5/26/97)

1. What sparked your interest in your profession?
2. During our telephone conversation last week, you told me about your involvement in preparing parent advisors statewide. You mentioned that "great signers don't make great parent advisors." I'm wondering if you could elaborate on that for me? In other words, what makes a great parent advisor for children who are deaf and their families?
3. What is the philosophy of your program concerning deaf children and their families? What is the history of your program?
4. What is your own professional philosophy concerning deaf children and their families?
5. What "works" when teaching children who are deaf and advising their families?
6. What type of information did your program and you personally provide for the Camillo family when they were enrolled in your program?
7. What did you tell the family about their son, his deafness, the field of deaf education, individuals who are deaf, etc.?
8. What were your impressions of the family during their time in your program? Do you remember your first impression of Henry? Sara? Mark? Daniel? What was your vision for them?
9. What is important for me to know about Henry and his family's experiences?
10. Is there anything else you'd like to share with me that you think is important information about the family and/or this program?

Regarding the Early Videotape of Sara and Henry

11. Do you remember what you were thinking when you recorded this video?

Protocol 6: Interviews with Extended Family Members (June--July 1997)

Introductory Statement: My name is Laura Blackburn. I am a doctoral student at Gallaudet University. I have been working with Mark and Sara's family collaboratively to understand how having a deaf child has influenced their immediate family and extended family members. I am here to interview you to learn about your experiences and perspectives. This research is a collaborative effort, so I share materials with Mark and Sara. In an effort to check the validity of my notes and interview transcripts, they read over my fieldnotes, and watch the videotaped interviews in order to make sure I've accurately documented their experiences and understandings. I want you to understand that the researchers at Gallaudet as well as Mark and Sara are the only individuals who will view your interview and the associated field notes.

Research Question #1

What does communication and interaction look like among Henry and extended family members?

Related interview questions:

1. Tell me about what it's like to communicate with Henry. What works? What doesn't work?
2. How is communicating with Henry the same or different from communicating with the other children in your family?

Research Question #2

What knowledge do extended family members possess regarding Henry and individuals that are deaf, and how have they acquired that knowledge?

Related interview questions:

1. Tell me the story about finding out that Henry was deaf.
2. What have you learned about Henry and individuals who are deaf? How did you seek out that information? Who provided it? Where did you learn it?
3. Do you know any other individuals who are deaf besides Henry?

Research Question #3

What experiences have extended family members had with Henry and other individuals who are deaf, and how do they make sense of those experiences?

Related interview questions:

1. What's it like to be Henry's extended family member? Tell me about some of the experiences or family stories you've created with him in the past, or since you met him at the reunion.
2. Based on what you've learned, if friends of yours were to discover their young child is deaf, what advice would you give them?
3. Have Mark and Sara ever asked your advice related to Henry?
4. Is there anything else I should know that I've failed to ask?

Additional questions for grandparents:

1. What is important for me to know about your family? Tell me about your family.
2. When you think about your family experiences, what have been the three most significant experiences you have shared? Tell me about them.
3. Do you have any good family stories about Sara and Mark, and their family?
4. What is it like to be Henry's grandparent?
5. Can you draw me a picture of your family? Tell me about it.

Protocol 7: Final Interview (2/13/98 and 2/14/98)
Potential Questions are ITALICIZED

1. The Early Years
- Beginning of Henry's first educational assessment

What were you thinking during this assessment?
What was your understanding of Henry's deafness at this point?

- Sara, Daniel, and Henry in the kitchen during a home visit (May 31, 1994)

Tell me about this segment.

- Sara, her sister Nannette, Grandma Medina and Henry in the living room discussing signs during the home visit (May 31, 1994) (What do you use for BUG? What's the sign for RED?)

What changes in Nannette and Grandmother's communication since this time?

- Sara diapering Henry and playing on Daniel's bunk bed (May 31, 1994)

What communication strategies do you notice in this clip?

Where did you learn these communication strategies?

2. Footage from the pilot
- Sara in the hospital, pregnant with the babies (June 27, 1996) (I don't have a sign name for Loraine--how do I sign that?)

What were your biggest concerns for Henry at this time concerning communication?

What about fingerspelling?

- Sara presenting the "Camillo Dilemma" (July 23, 1996 – in the hospital). The problem is maintaining eye contact with Henry "all the time." She is not able to watch the other children while talking to a deaf person. Henry is becoming frustrated when she interrupts their conversation and says "forget it mom." Sara says, "I don't want to be rude to my son, but I don't know what to do! What do Deaf mothers do?"

Was this question ever answered for you? If so, how did you find a "comfortable" answer? What do you think of the dilemma now? Does it still exist? What would you recommend to other parents who have this dilemma?

- Shared Reading clip--interaction among the family when Justin visits.

How does Mark lead shared reading?

3. Vacation trip to visit extended family (Mark's family--The Camillos)

- Henry signs with Camillo cousin
- Interaction when Uncle Steve arrives in the middle of dinner
- Teasing with cousin Bart in the kitchen
- Playing outside: Getting the tractor, waiting behind Henry, cousin Joshua teasing
- Interaction at the water fountain
- Aunt Elaine at the water fountain

I'm planning to show these clips (and the clips from the next section--section 4) back to back. Are these clips typical of their extended family interactions at that time? Would these clips still be typical of interactions now?

4. Vacation trip to visit extended family (Sara's family--The Medinas)

- In the pool with cousin Marie (she ignores him and refuses to respond to Henry's efforts to make eye contact (7/8/98)
- Henry dancing with cousins and siblings--Marie asks Henry, "Can you hear me?"
- Playing basketball with Uncle Francis and Dad
- Cousin Marie and Henry. Marie is still talking to Henry's back but is starting to understand attention-getting pragmatics (7/9/98).
- Taking the float from Marie
- Meeting Uncle Ernest's family
- Playing/fighting over toy cars and cousin Roger
- Hanging out on the couch with Mom and Uncle Ernest
- Moving like animals game

5. Category #1: Interpreting Among Extended Family Members

- Sara as interpreter (3 – 0:32:31)
- Daniel and Madeline interpret (4 – 0:07:02)

- Mark interprets for Grandmother Medina (6 – 0:23:47 to 0:24:29)
- Laura interprets (6 – 1:35:25)
- Sara interprets (7 – 0:02:07)

6. Category #2: Introducing and Discussing Signs Among Immediate & Extended Family

- Madeline uses sign and voice one at a time – not simultaneously (family members notice)
  (2 – 0:15:22)
- "IT MATTERS" (3 – 0:28:34)
- "BE CAREFUL" "DON'T FALL OUT" (4 – 0:18:49)
- Cousin Christine learns "NO" (5)
- "BROWNIE" (6 – 1:44:00)
- "HORSE" (9 – 1:33:52)

7. Category #3: Sibling Interaction

- Henry and baby (3 – 0:11:26)
- Henry and Madeline (3 – 0:23:08)
- Henry and babies--Daniel & Henry (3 – 0:08:30)
- Madeline, Henry, and Daniel (4 – 0:14:24 to 0:14:43)
- Henry looking at Madeline to check what's happening in hearing conversation
  (4 – 0:22:51)
- Baby Mary models Henry's communication (5 – 0:04:01)
- Madeline's eye shift (5 – 0:09:09)

8. Other Questions

- What challenges do you think you identified during the time that I lived with you? Share my list with them and see if they agree (re-structuring at the Parkwood School, limited communication between home and school, communication differences in the home, fairness among siblings, questions about language acquisition, questions about IFSP development, finding a new school for the deaf as you planned to move, adjusting to the triplets, considering cued speech, considering changing schools, planning for Henry's reconstructive surgery, etc.)

- How were these challenges solved or not? Do you have ideas about how to work towards a resolution? What would you recommend to other parents facing similar challenges?

- What does "being deaf" mean to you? Do you recall what you thought deaf meant before I moved in? How have your understandings of deafness and Henry changed over the past year?

- What strategies, experiences, or people were helpful to you in developing these understandings?

- What else did you learn this year?

- Talk to me about some of your ongoing frustrations pertaining to Henry, deafness, ASL, etc.

- If we could revisit last year, what would you change about the time I lived in your home?

- Would you recommend this type of research (ethnography) to other families? Why AND why not (because there has to be both a positive and negative side)?

- What message(s) do you want to share with other parents?

- What do you think you need to learn? What information has been left unexplored? What questions do you have?

- When you use the term signing, what does that mean to you? How do you think other family members define signing?

__Additional Questions for the February interview__

1. Was the communication environment on the family vacation typical of extended family interaction? Tell me more about that--describe "typical" for me.

2. I noticed a discrepancy concerning what you said about Henry's interaction with extended family (you need to act as the interpreter), and what you shared on the listserv (all Henry's family, including extended family members sign). Can you explain this discrepancy to me?

Appendix E

Sample Expanded Fieldnote Page

Monday, March 3, 1997
Fieldnotes.

I brought ASL videos home from the lab today. The speech teacher at school also sent home a videotape with Henry in it today. We watched the speech teacher doing auditory training exercises with Henry, and we were both shocked. Sara and I both puzzled, "Is he really hearing those 'environmental' (sheep, car horns, etc. – noises made vocally by the speech teacher) noises, or has he been conditioned to respond to the materials they are using?" Sara was a little upset about what speech teachers have been writing in reports about Henry. She said, "I don't want it put in his records that he can hear environmental sounds." Evidently the speech teacher explained that as he makes progress in recognizing environmental sounds that he will become eligible for receiving more "comprehensive" services. Sara believes this would technically mean less speech training under the guide that he could hear and recognize environmental sounds. She wondered if they were faking what we saw on the videotape.

I suggested that she obtain a copy of the reports that speech teachers are writing at school (related to evaluating Henry's ability to use his residual hearing), and write on her own comments regarding what she sees at home (no response to environmental sounds). I told her that she is permitted to see the report and make a copy for her files. We were discussing this in the kitchen and Mark came downstairs from putting the kids to sleep and listened to our conversation.

Sara also elaborated that Henry seems able to recognize environmental sounds in a "booth" (her words) setting but not at home. She asked me, "What does this happen?" I told her that they were teaching very specific skills that Henry may not be able to generalize – transfer or demonstrate in multiple environments but only where he learns the skill does he remember it. After I explained this to Sara, she mused that perhaps Justin would know the answer to this question. I was puzzled by her continued search for answers. I think she was thinking in terms of information from a seaf person though...and she knows Justin has had a lot of speech training and can give her "hands on" experiences from when he was growing up. Sara wants him to watch the tape. She also told me to ask Linda if I see her.

Appendix F

STATEMENT ON ETHICS

PRINCIPLES OF PROFESSIONAL RESPONSIBILITY
Adopted by the Council of the American Anthropological Association
May, 1971
(As amended through October 1990)

Note: *This statement enunciates general responsibilities for all anthropologists. Each of the units of the AAA may develop a more detailed statement of ethics specific to their particular professional responsibilities but in all cases consonant with the principles stated herewith.*

Preamble

Anthropologists' relations with their discipline, with the individuals and groups among whom they conduct research or to whom they provide services, with their employers and with their own host governments, are varied, complex, sensitive, and sometimes difficult to reconcile. In a field of such complex involvements, misunderstandings, conflicts and the need to make choices among apparently incompatible values are constantly generated. The most fundamental responsibility of anthropologists is to anticipate such difficulties and to resolve them in ways that are compatible with the principles stated here. If such resolution is impossible, anthropological work should not be undertaken or continued.

Anthropologists must respect, protect and promote the rights and the welfare of all of those affected by their work. The following general principles and guidelines are fundamental to ethical anthropological practice.

I. Responsibility to people whose lives and cultures anthropologists study

Anthropologists' first responsibility is to those whose lives and cultures they study. Should conflicts of interest arise, the interests of these people take precedence over other considerations. Anthropologists must do everything in their power to protect the dignity and privacy of the people with whom they work, conduct research or perform other professional activities. Their physical, social and emotional safety and welfare are the professional concerns of the anthropologists who have worked among them.

A. The rights, interests, safety, and sensitivities of those who entrust information to anthropologists must be safeguarded.

1. The right of those providing information to anthropologists either to remain anonymous or to receive recognition is to be respected and defended. It is the responsibility of anthropologists to make every effort to determine the preferences of those providing information and to comply with their wishes.

a) It should be made clear to anyone providing information that despite the anthropologist's best intentions and efforts anonymity may be compromised or recognition fail to materialize.

2. Anthropologists should not reveal the identity of groups or persons whose anonymity is protected through the use of pseudonyms.
3. The aims of all their professional activities should be clearly communicated by anthropologists to those among whom they work.
4. Anthropologists must not exploit individuals or groups for personal gain. They should give fair return for the help and services they receive. They must recognize their debt to the societies in which they work and their obligation to reciprocate in appropriate ways.
5. Anthropologists have an ongoing obligation to assess both the positive and negative consequences of their activities and the publications resulting from those activities. They should inform individuals and groups likely to be affected of any consequences relevant to them that they anticipate. In any case, however, their work must not violate these principles of professional responsibility. *If they anticipate the possibility that such violations might occur, they should take*

steps, including, if necessary, discontinuance of work, to avoid such outcomes.

6. Whether they are engaged in academic or nonacademic research, anthropologists must be candid about their professional identities. If the results of their activities are not to be made public, this should be made clear to all concerned from the outset.
7. Anthropologists must take into account and, where relevant, make explicit the extent to which their own personal and cultural values affect their professional activities. They must also recognize and deal candidly and judiciously with the effects that the often-conflicting demands and values of employers, sponsors, host governments and research publications may have upon their work.

II. Responsibility to the Public

Anthropologists have responsibility to be truthful to the publics that read, hear, or view the products of their work.

A. In expressing professional opinions publicly, anthropologists are not only responsible for the factual content of their statements but also must consider carefully the social and political implications of the information they disseminate. They must do everything in their power to insure that such information is well-understood, properly contextualized and responsibly utilized.

B. Anthropologists bear a positive responsibility to speak out publicly, bot individually and collectively, on issues about which they possess professional expertise. That is, they have a professional responsibility to contribute to the formation of informational grounds upon which public policy must be founded. Anthropologists should make clear the bases upon which their positions stand.

C. When engaging in public discourse anthropologists should be candid about their qualifications, and they should recognize and make clear the limits of anthropological expertise.

III. Responsibility to the discipline

Anthropologists bear responsibility for the good reputation of the discipline and its practitioners.

A. The integrity with which anthropologists conduct their affairs, and the rapport that they seek to maintain in the field and in other professional venues must be of an order that justifies trust and confidence. They must not behave in ways that jeopardize either their own or others' future research or professional employment. It is their responsibility to act in ways consistent with commitments to honesty, open inquiry, candor concerning sponsorship and research aims, and concern for the welfare and privacy of all concerned parties. Anthropologists must address such conflicts as do arise among the interests of those parties and attempt to resolve them equitably.

B. Anthropologists must not represent as their own work, either in speaking or writing, materials or ideas directly taken from other sources. Anthropologists must give full credit in speaking or writing to all of their professional colleagues, anthropologists or non-anthropologists, who have contributed to their work.

C. When anthropologists participate in actions relating to hiring, retention and advancement, they should (except in the case of affirmative actions taken to redress historical imbalances) insure that no exclusionary practices should be perpetuated against colleagues on the basis of sex, marital status, color, social class, political convictions, religion, ethnic background, national origin, sexual orientation, age, or any other criterion irrelevant to academic performance. Nor should an otherwise qualified individual be excluded on the basis of physical disability. Anthropologists should, furthermore, refrain from transmitting, and resist the use of, information irrelevant to professional performance in personnel actions.

D. The cross-disciplinary nature of the activities of many anthropologists requires that they be informed of, and respect, the requirements of the nonanthropological colleagues with whom they work.

IV. Responsibility to students and trainees

Anthropologists should be candid, fair, and nonexploitative in their dealings with trainees and students, and committed to their welfare and progress. They have continuing responsibility to recognize the changing nature of the discipline. In both its content and its methodology, and further, in novel applications of anthropological knowledge and approaches. They have a further responsibility to convey current understandings to students and trainees.

A. Anthropologists should accept students into their programs in ways precluding and redressing discrimination on the basis of sex, marital status, color, social class, political convictions, religion, ethnic background, national origin, sexual preference, age, or other criterion irrelevant to academic performance.

B. Anthropologists should strive to improve both their teaching techniques and the methods of evaluating their effectiveness as teachers.

C. Anthropologists should be receptive and genuinely responsive to students' interests, opinions, and needs.

D. Anthropologists should counsel students realistically regarding both academic and nonacademic career opportunities.

E. Anthropologists should be conscientious in supervising, encouraging, and supporting students in their studies, both anthropological and nonanthropological.

F. Anthropologists should inform students of what is expected of them, be fair in the evaluation of their performance, and prompt and reliable in communicating evaluations to them.

G. Anthropologists should impress upon students the ethical problems involved in anthropological work and discourage them from participating in ethically questionable projects.

H. Anthropologists should acknowledge orally and in print student assistance in research and preparation of their work; give appropriate credit for coauthorship or first authorship to students when their research is used in publications or lectures; encourage and assist in publication of worthy student papers; and compensate students justly for the use of their time, energy, and ideas in research, teaching, and other professional activities.

I. Anthropologists should energetically assist students in securing legitimate research support and the necessary permission to pursue research and other professional activities.

J. Anthropologists should vigorously assist students in securing professional placement upon the completion of their studies.

K. Anthropologists should beware of the serious conflicts of interest and exploitation which may result if they engage in sexual relations with students. They must avoid sexual liaisons with students for whom professional training they are in any way responsible.

V. Responsibility to employers, clients, and sponsors.

In all dealing with employers, clients, and sponsors anthropologists should be honest about their qualifications, capabilities, and aims. Prior to entering any professional commitment, anthropologists must review the purposes of sponsors, employers, or clients, taking into consideration their past activities and future goals. In working for governmental agencies or private businesses, anthropologists should be especially careful not to promise or imply acceptance of conditions contrary to professional ethics or competing commitments.

VI. Responsibilities to governments

Anthropologists should be honest and candid in all dealings with their own governments and with host governments. They should ascertain that they will not be required to compromise either their responsibilities or anthropological ethics as a condition of permission to engage in professional activities. Anthropologists are under no professional obligation to provide reports or debriefings of any kind to government officials or employees, unless they have individually and explicitly agreed to do so in the terms of employment.

Epilogue

Anthropological activity requires choices for which anthropologists individually and collectively bear ethical as well as scientific responsibility. This statement is designed to promote discussion and provide general guidelines for ethically responsible decisions. When anthropologists, by their actions, jeopardize peoples studied, professional colleagues, employers, employees, clients, students, or others, or if they otherwise betray their professional commitments, their colleagues may legitimately inquire into the propriety of such actions, and take such measures as lie with legitimate powers of the American Anthropological Association, as the membership of the Association deems appropriate.

STATEMENT ON
PROBLEMS OF ANTHROPOLOGICAL RESEARCH AND ETHICS
Adopted by the Council of the American Anthropological Association March 1967

The human condition, past and present, is the concern of anthropologists throughout the world. The study of mankind in varying social, cultural, and ecological situations is essential to our understanding of human nature, of culture, and of society.

Our present knowledge of the range of human behavior is admittedly incomplete. Expansion and refinement of this knowledge depend heavily on international understanding and cooperation in scientific and scholarly inquiry. To maintain the independence and integrity of anthropology as a science, it is necessary that scholars have full opportunity to study peoples and their culture, to publish, disseminate, and openly discuss the results of their research, and to continue their responsibility of protecting the personal privacy of those being studied and assisting in their research.

Constraint, deception, and secrecy have no place in science. Actions which compromise the intellectual integrity and autonomy of research scholars and institutions not only weaken those international understandings essential to our discipline, but in so doing they also threaten any contribution anthropology might make to our own society and to the general interests of human welfare.

The situations which jeopardize research differ from year to year, from country to country, and from discipline to discipline. We are concerned here with problems that affect all the fields of anthropology and which, in varying ways, are shared by the social and behavioral sciences.

I. Freedom of Research

1. The Fellows of the American Anthropological Association reaffirm their resolution of 1948 on freedom of publication and protection of the interests of the persons and groups studied:

Be it resolved:

(1) that the American Anthropological Association strongly urge all sponsoring institutions to guarantee their research scientists complete freedom to interpret and publish their findings without censorship or interference; provided that

(2) the interests of the persons and communities or other social groups studied are protected; and that

(3) in the event that the sponsoring institution does not wish to publish the results nor be identified with the publication, it permit publication of the results, without use of its name as sponsoring agency, through other channels.

-*American Anthropologist* 51:370 (1949)

To extend and strengthen this resolution, the Fellows of the American Anthropological Association endorse the following:

2. Except in the event of a declaration of war by the Congress, academic institutions should not undertake activities or accept contracts in anthropology that are not related to their normal functions of teaching, research, and public service. They should not lend themselves to clandestine activities. We deplore unnecessary restrictive classifications of research reports prepared under contract for the Government, and excessive security regulations imposed on participating academic personnel.

3. The best interests of scientific research are not served by the imposition of external restrictions. the review procedures instituted for foreign area research contracts by the Foreign Affairs Research Council of the Department of State (following a Presidential directive of July, 1965) offer a dangerous potential for censorship of research. Additional demands by some United States agencies for clearance, and for excessively detailed itineraries and field plans from responsible scholars whose research has been approved by their professional peers or academic institutions, are contrary to assurances given by Mr. Thomas L. Hughes, Director of the Bureau of Intelligence and Research, Department of State, to the President of the American Anthropological Association on November 8, 1965, and are incompatible with effective anthropological research.

3. Anthropologists employed or supported by the Government should be given the greatest possible opportunities to participate in planning research projects, to carry them out, and to publish their findings.

II. Support and Sponsorship

1. The most useful and effective government support of anthropology in recent years has come through such agencies as the National Science Foundation, the National Institutes of Health, and the Smithsonian Institution. We welcome support for basic research and training through these and similar institutions.

2. The Fellows take this occasion to express their gratitude to those members of Congress, especially Senator Harris and Representative Fascell, who have so clearly demonstrated their interest in the social sciences, not only through enlarging governmental support for them, but also in establishing channels for social scientists to communicate their opinions to the Government regarding policies that affect the future of the social sciences and their utilization by Government.

3. When queried by individuals representing either host countries or groups being studied, anthropologists should willingly supply evidence of their professional qualifications and associations, their sponsorship and source of funds, and the nature and objectives of the research being undertaken.

4. Anthropologists engaged in research in foreign areas should be especially concerned with the possible effects of their sponsorship and sources of financial support. Although the Department of Defense and other mission-oriented branches of the Government support some basic research in the social sciences, their sponsorship may nevertheless create an extra hazard in the conduct of fieldwork and jeopardize future access to research opportunities in the areas studied.

5. Anthropologists who are considering financial support from independent research organizations should ascertain the full nature of the proposed investigations, including sponsorship and arrangements for publication. it is the responsibility of anthropologists to maintain the highest professional standards and to decline to participate in or to accept support from organizations that permit misrepresentations or technical competence, excessive costs, or concealed sponsorship of activities. Such considerations are especially significant where grants or fellowships are offered by foundations or other organizations which do not publish balance sheets showing their sources of funds.

6. The international reputation of anthropology has been damaged by the activities of unqualified individuals who have falsely claimed to be anthropologists, or who have pretended to be engaged in anthropological research while in fact pursuing other ends. There also is good reason to believe that some anthropologists have used their professional standing and the names of their academic institutions as cloaks for the collection of intelligence information and for intelligence operations. Academic institutions and individual members of the academic community, including students, should scrupulously avoid both involvement in clandestine intelligence activities and the use of the name of anthropology, or the title of anthropologist, as a cover for intelligence activities.

IV. Anthropologists in United States Government Service

1. It is desirable that social science advice be made more readily available to the Executive Office of the President.

2. Where the services of anthropologists are needed in agencies of the Government, it is most desirable that professional anthropologists be involved at the project planning stage and in the actual recruitment of necessary personnel. Only in this manner is it possible to provide skilled and effective technical advice.

3. Anthropologists contemplating or accepting employment in governmental agencies in other than policy-making positions should recognize that they will be committed to agency missions and policies. They should seek in advance the clearest possible definition of their expected roles as well as the possibilities for maintaining professional contacts, for continuing to contribute to the profession through publication, and for maintaining professional standards in protecting the privacy of individuals and groups they may study.

RESOLUTION ON FREEDOM OF PUBLICATION
Adopted by the Council of the American Anthropological Association December 1948

Whereas a very great amount of purely scientific research in social science is financed by institutions which may have the legal right to publish, suppress, alter, or otherwise dispose of the research results in a manner that may be contrary to the will of the scientist and amount to suppression or curtailment of academic freedom; but

Whereas it is also true that indiscretion in publication may harm informants or groups from which information is obtained and may be damaging to the sponsoring institutions;
Be it resolved: (1) that the American Anthropological Association strongly urge all sponsoring institutions to guarantee their research scientists complete freedom to interpret and publish their findings without censorship or interference; provided that
(2) the interests of the persons and communities or other social groups studied are protected; and that
(3) in the event that the sponsoring institution does not wish to publish the results nor be identified with the publication, it permit publication of the results, without use of its name as sponsoring agency, through other channels.

Appendix G

Sample Coded Fieldnote

December 1, 1996

Field notes: #51

Mom and I arrived around 10:30 in the morning; Mark and Sara were catching a nap upstairs. Daniel, Henry, and ~~Natalie,~~ Madeline who were watching TV, greeted us. The table in the living room alcove was extended and decorated for the mid-day feast. On table that the family ordinarily uses for breakfast and the evening meal, Sara had an array of desserts (pumpkin pie, candy, apple pies); the mood was very festive. My brother David arrived around 11:30. Sara came downstairs, Mark took the older children out to ride bikes, and Mom, David, and I spent time with the triplets while Sara worked on dinner in the kitchen.

I was happy that Sara had invited my mother and brother to Thanksgiving dinner, because I wanted to take an opportunity to reflect on my thoughts and attitudes concerning families with deaf and hearing members. I am already aware that there are many aspects of the Camillo family that reminds me of my own. I wanted my mother and brother to experience the household from a naive perspective, in order to see if their observations of differences and similarities matched the perceptions I had already accumulated. I thought of this approach to collecting data on Thanksgiving Day, by remembering the stories that [redacted] tells about his mother. He sees his mother as a very smart person, but she is someone who is not an expert in deaf education, etc. Therefore, she is able to notice differences and similarities in the environment, but is not "muddled" by all the "expert" knowledge of the field. While my mother and brother lived in the same home with my Uncle, they have not chosen deaf education as their life's work.

parallels w/ my family of origin 50:1:13

My mother's observations at the end of the dinner and overnight stay were interesting. When she saw Daniel and Henry at play throughout the day, she said several times, "Doesn't that remind you of John and Bill? (my father and uncle)." During one of our conversations at the breakfast table, I had remarked to Sara at how I often imagined that Daniel and Henry have a similar relationship to that of my father and uncle. I also experience a remarkable sense of comfort in this home -- it feels natural to be here. My mother's reaction to the family suggests that the reason I feel comfortable here, is that this home mirrors the home I grew up in. Typically, my mother reacts strongly and negatively to individuals from different cultures and different backgrounds. She is the first to say, "Those people are crazy." or "How can they lead such a nutso lifestyle?"

parallels w/ my family 50:1:24

Mom & David really enjoyed themselves 50:1:27

Test of cultural boundaries 50:1:30

Appendix H

Sample Page from the Database

Date # hard pgs FN#	Other Information	Time Codes	Codes
07/13/97 3 pages FN#186		186:1:3	This morning when Mark got up with the first baby (John – 8:00 AM, not bad!). Daniel and Henry were already awake.
		186:1:9	Daniel compliments Madeline's knowledge of colors and ABCs at breakfast. Meanwhile, Henry is eating and watching TV. The sound is off on the TV.
		186:1:10	Henry has been very good about being quiet in the morning. He told Madeline to be quiet this morning because people were still sleeping.
		186:1:13	Last night, Sara re-directs Henry. Bobbie is signing to him and he's ignoring some of her attempts.
		186:1:19	Henry asks Sara is that is a commercial.
		186:1:20	Bobbie says, "Let's ask him what the commercial was about." Bobbie also wanted to practice the sign for COMMERCIAL.
		186:1:21	Bobbie asks Sara to sign it and then asks, "Why do you do it that way?" Sara responds, "Do it like you're passing it out."
		186:1:22	Henry didn't know what the commercial meant. Sara really misses the decoder on the TV.
		186:1:23	I reflect that the fieldwork is drawing to a close – birthday decorations are hanging off the walls and we are almost out of food. It is a bittersweet feeling.
		186:2:1	It is interesting to think that when the setting is complete, or no longer useful to the informants, the actors move on to create new memories and dramas in their life. As Goffman points out, it's almost like a stage show where the props from the show are cleaned up when the drama is over.
		186:2:5	This morning Daniel spilled cereal at breakfast and exclaimed to Mark, "It spilled itself!" Mark thought that was a funny thing to say, and Henry asked him why he was laughing.

Appendix I

Video Clip Schedule for the Final Interview

Clip #1: Changing table interaction between Henry and his mother (Sara) (May 1994)

The clip begins with Sara changing Henry on the changing table. Sara's mother (Grandmother Medina) is watching and sometimes commenting on their interactions. Henry's first early educator, as part of her regular home visits, filmed this video clip.

Notice the paper that is hanging over the changing table. This is a list of signs and their description for articulation. Sara and her husband hung signs like this all over the house when Henry was a baby.

Players:	Sara (hearing mother)
	Henry (deaf child)
	Sara's mother (Grandmother Medina, hearing)
	Henry's early educator (hearing)

☞Upper and lowercase print indicate spoken utterances and English
☞ALL CAPS indicates gestures and ASL GLOSS
☞*Italicized print indicates where two or more people are signing or speaking at the same time*

Sara: Smells bad!
SMELL GOOD/BAD DIAPER
(self-correction of sign)

Sara: You have a dirty diaper!
DIRTY DIAPER

Sara: Listen! <Pulls string of musical toy>
POINTS TO EAR

Sara: Listen!
POINTS TO EAR

Sara: Music!
MUSIC

Henry: mm-mm-mm-mm-mm <holds and toy while he babbles>

Sara: Okay!

Sara: um-um-um-um-um <models Henry's vocalizations>

Sara: um-um-um-um-um

Henry: ay-ay-ay-ay-ay <looks to his Grandmother off camera>

Sara: I hear you!
I HEAR YOU (PRO-1)
("I" and "HEAR" are Sign Supported Speech productions)

<Henry continues to vocalize and look at his Grandmother>

Sara: I hear you!
I HEAR YOU (PRO-1)
("I" and "HEAR" are Sign Supported Speech productions)
(Sara repeats the same utterance)

Grandmother: Hi Sweetie!
(off camera)
What is it darlin'?

<Sara brushes a wet-one on Henry's face to gain his attention>

Sara: Wee-ewe! Wee-ewe!

<Henry looks at Sara and makes mouth movements>

Sara: Ewe! It smells bad! Smells bad! Smells bad!
SMELL GOOD SMELL/GOOD BAD GOOD BAD
(self correction) (the sign for SMELL becomes the sign GOOD as it moves away from it's proper position of articulation [the nose], towards her mouth)

Sara: Ha! <sound of surprise as she looks in diaper>

<Henry rubs his head – what he still does to comfort himself>

Sara: Ha! <same sound of surprise>

Grandmother: He thinks it's funny.

Sara: Dirty! Dirty! Dirty!
DIRTY DIRTY DIRTY

Henry: mm-mm-mm-mm-mm <vocalizes to interact with his mother>

Sara: Oh really? Mom – Mom – Mom
<pops her mouth several times and sticks out her tongue "raspberry">

Sara: Look at me.

Henry: Ah-Ah-Ah-Ah

<Sara sticks out her tongue three more times>
Sara: OPEN MOUTH/CLOSE MOUTH – OPEN MOUTH/CLOSE MOUTH

<Henry models Sara>
Henry: OPEN MOUTH/CLOSE MOUTH – OPEN MOUTH/CLOSE MOUTH

Sara: Peppy Le Pew!

<Camera Shift>

Sara: I know – it feels good!
SILLY LIKE GOOD
(wide-eyed expression)

Sara: Feels good – wait – Feels good!
GOOD FEEL – LIKE GOOD

<Sara rubs his belly and plays with Henry vocally>
Sara: Rah-Nah-Nah

<telephone rings>

Grandmother: That was the realtor Sara. She'll call you back in 5 minutes.

Sara: Who?

Grandmother: The realtor from (name of the State)

Sara: Okay.

Come here – come here – let me have your hand

Grandmother: One of them (meaning one of the realtors)

Sara: Oh sure – rub that powder from down – Ah!

No! No! No! No! No! <shakes her head NO>

No, no! Ewe! It's dirty! Here – let's clean...
NO (misarticulated) DIRTY CLEAN

Let's clean your hand! Ah!
CLEAN YOUR FOOT

<Sara cleans Henry's hand and face. Henry coughs in protest when she wipes his face.>

Sara: COUGH-COUGH-COUGH-COUGH <modeling Henry>

COUGH-COUGH-COUGH-COUGH

COUGH-COUGH-COUGH-COUGH-COUGH <eye brow wiggle>

<Henry looks behind him in search of the camera>
Sara: Say, where is she?

Sara: Okay – Okay
DIRTY

No more stinky diaper!
NO MORE DIRTY DIAPER

Let's button
BUTTON

Let's button your pants!
BUTTON GOOD PANTS

<Henry is distressed...his vocalizations rise in pitch: mm-mm-mm>

Sara: What? What's wrong? <kisses his belly>
WHAT

What?
WHAT

<Henry touches his diaper>

Sara: Oh, your pee-pee? Let me see. <checks diaper and adjusts his "pee-pee">

Sara: Ah, I know! Big pee-pee! I know!
BIG PURPLE

Okay, let's button your pants!
BUTTON YOUR PANTS

One...Two...Three!
1 – 2 – 7 (misarticulation)

Okay!
<end of clip #1>

Clip #2: In the kitchen at cousin Bart's house (July 1997)

Henry's father (Mark) videotaped this segment for me. The children were playing at their cousin's house during their family vacation. What is notable about this clip are the linguistic negotiations that occur. Mark is not only videotaping, but he is negotiating conversations with children in both spoken English and American Sign Language at the same time. As noted by the italicized utterances, 7/8 times Henry says something in this clip, another child in the room is making some sort of vocalization that draws Mark's attention, creating a tension between spoken and visual languages (See page 6, lines 19-21 of these data for an example of one time Henry's utterances do not overlap his siblings or cousins). This tension is typical of the daily interactions that occur in the Camillos' home.

Players: ✓ Mark (Henry's hearing father – he videotaped this segment for my database)

✓ Daniel (Henry's older hearing brother – he is 6-years-old)
✓ Henry (the deaf child – he is 4-years-old. Henry is sitting on the right side of the screen at the table)
✓ Madeline (Henry's younger sister – she is 2-years-old. Madeline is sitting on the left side of the screen at the table)
✓ Cousin Bart (hearing, 6-years-old. Bart is fixing drinks and snacks for himself and the other children)

☞Upper and lowercase print indicate spoken utterances and English
☞ALL CAPS indicates gestures and ASL GLOSS
☞*Italicized print indicates where two or more people are signing or speaking at the same time*

Mark: Okay – sit down over there <to Daniel>

Madeline: <directing her communication to Bart>
Be Be Bop – Be Be Boy – Be Be Boy – Be Be Boy
<Daniel looks at them and shrugs his shoulders>

Be Be Boy – Be Be Boy

Bart: <laughs and Madeline joins him>

Henry: <watching Madeline & Bart's interaction. He knows they are being silly but is not quite sure why – the cereal box may be blocking his view of Madeline's face>

Madeline: Be Be Boy – Be Be Boy

<Madeline & Bart laugh again>

Madeline: Be Boo Boy – Be Boo Boy <Madeline starts to sing her silly words>

Now you do it Daddy! Now you do it!

Mark: Me do it? No, I don't think so.

Madeline: *Do-de Do-de Do-de*

Henry: *WHY KNOW DANIEL?*
Where's Daniel?

Mark: <May have responded in sign-only off camera: WHO?>

Henry: *Daniel* <signs Daniel's name sign while drinking>

Madeline: *Ba Ba Ba*

Henry: <to cousin Bart>
CRAZY YOU (laughs)

Madeline: *Baby Bop – Baby Bop Bop* – Bop Bop

Bart: <does not verbally respond but smiles at Madeline>

Henry: <puts his hand in his cup of water and signs>
THUMB SUCKING GESTURE
You suck your thumb! (playful intent)

Bart: <laughs aloud>

Madeline: *Baby Bop and Baby Bop*

Henry: *SNATCH WATER*
Watch, I'm going to steal his water (playful intent)

Bart: <Doesn't know what Henry said. Bart responds to Madeline instead>
You're saying Baby Bop

Henry: *BABY WATER*
You're a baby, so I'm going to steal your water (playful intent)
<pretends to drinks Bart's water and laughs>

Bart: Hey don't!

Madeline: *Baby Bop – Baby Bop*

Henry: *WHO? <Henry asks his father as he points to the green cup on the table>*

Whose cup is this?

Madeline: Baby Bop – Baby Bop
<raises her vocalizations/song to get her father's attention>
<smiles broadly for the camera>

Henry: <sees his father is responding to Madeline – looks to Madeline and signs…>
DAD DRINK BART – DAD DRINK BART – DAD DRINK BART (repeats 5X)
Dad, the drink is Bart's. Dad, the drink is Bart's. Dad, the drink is Bart's.

Mark: <to Bart> *Bart, I think that's enough (cereal) Bud…*

Bart: *I know that. I wanted it all. I have more than that.*

Henry: *<continues to vocalize to get his father's attention and repeats his statement as the clip ends>*

<end of clip>

<u>Clip #3</u>: In the kitchen: Looking for something to do (July 1997)

Clip #3 is also from the family's vacation. It is raining outside and the children are restless – looking for something to do while waiting for the storm to pass. Mark (the father) is talking to his brother in the kitchen. Mark is holding Mary (one of the triplets). Other cousins are in the kitchen looking for a snack. John and Luke (two more babies) are crawling on the kitchen floor.

<u>Players</u>: Daniel (6-year-old hearing brother)
Mark (hearing father)
Henry (4-year-old deaf child)

☞Upper and lowercase print indicate spoken utterances and English
☞ALL CAPS indicates gestures and ASL GLOSS
☞*Italicized print indicates where two or more people are signing or speaking at the same time*

Mark: <to Daniel> What are you doing?

Daniel: I'm not sleeping

Mark: You don't have to – Mary's getting ready to sleep
MARY READY SLEEP

Henry: <says hello to the babies on the floor>

Daniel: Dad, there's a cool airplane game down here.

Mark: --- (indistinguishable)

Wait, talk to me.
WHAT'S-UP?

Daniel: <to Henry>
HENRY PLAY ON THAT COMPUTER
Do you want to play on the computer?

Henry: <nods YES>

Daniel: O-K
Okay.
<goes to ask his Dad if they can play on the computer>

<end clip>

Clip #4: Mary's learning to sign

Context: Family vacation (July 1997)

Players:
Sara (hearing mother)
Henry (4-year-old deaf child)
Mary (1-year-old hearing sister)

Clip #5: Revisiting: Mark & Sara's reaction to the diapering scene (February 1998)

Context: The final interview – returning to the field

Players:
Sara (hearing mother)
Mark (hearing father)
Madeline (now 3-year-old hearing sister)

Sara: I was trying so hard for my baby.

Henry's gonna laugh when I show him that.

There goes my make-up!

Appendix J

Sample Page of Indexed Videotape Interaction

Interaction with the Medina Family
7/8/97

00000 blank screen
00012 park shelter
00040 in pool
    music playing
    Mark helping Henry with his swim mask
    children and adults playing in the water
    Henry and Madeline on steps
    interaction Henry and Mark

00253 aunts and babies in water
    Henry enters pool
    Madeline dancing on steps

00410 Henry and Madeline on steps
    Sara and baby interacting with Henry

00449 Henry gets out of pool with toy
    frightened by the dog
    gets back in pool at steps
    dog tries to get into pool

00628 Henry and Bobbi interaction
    Henry gets out of pool with toy light stick
    follows cousin
    watches interaction
    goes back to pool

00733 Mark and Henry interaction as Henry splashes the babies
    Sara begins to dance in pool
    Henry continues to play on the step

00817 interaction Henry and Marie on pool steps
    cousin gets out of water
    cousin gets back into pool

00909 Henry and Marie interact on step
    He seems to be asking her to trade sticks
    She seems to ignore him and talk to Madeline

Appendix K

Informed Consent & Videotape/Audiotape Consent Forms

<u>**Project title**</u>**: "The Development of Language and Literacy Skills Among Deaf and Hard of Hearing Students in ASL-English Classrooms."**

<u>**Principal Investigator**</u>**: Carol Erting, Ph.D., Department of Education, with members of the Gallaudet Research Institute, Gallaudet University, 800 Florida Avenue, NE, Washington, DC 20002-3695 Telephone (202) 651-5339 (v/tty) Fax (202) 651-5345**

We are asking for your participation in a research study. The central question is to describe the interaction, language acquisition, and teaching and learning strategies of preschool children and their teachers in classrooms where ASL and English are the languages of instruction. There is only minimal risk to individuals who participate in this research study. Complete confidentiality is assured. The notes, audiotapes, and videotapes will be used for research purposes. We are also asking you to give written permission to use some of this material in professional presentations. In any case, we assure you that your real name will never be used in any written report or presentation. We will send you a copy of the final report if you request it.

Videotapes and written records will be kept in a secure file to which only the researchers have access. Your participation in this study is voluntary. You may withdraw at any time for any reason and without penalty.

If you have any questions about any risk to you through joining in this study contact Dr. Carol Erting (see address and telephone numbers above).

Your Name: ____________________ School: __________________

After reading the description of "The Development of Language and Literacy Skills" research study, I agree to participate. I understand that the information about me will be held in confidence and used only for the research purposes described. I know that I can withdraw at any time.

______________________________ ______________

Your Signature Date

I consent to videotape and/or audio recording of my interview for research purposes.

______________________________ ______________

Your Signature Date

I give my permission for videotapes and/or audiotapes made of me during this project to be shown to or played for people other than the researchers. I am aware that my name will not be used when the tapes are used. I know that I can withdraw my permission at any time without explanation or penalty.

______________________________ ______________

Your Signature Date

Give one signed copy to the researcher or Dr. Carolyn Corbett, IRB
Keep one copy for your own files.

VIDEOTAPE/AUDIOTAPE RELEASE FORM
for adults

I agree to be videotaped/audiotaped as part of his/her participation in the study, "A Deaf Child and His Family: An Investigation of Extended Family Relationships."

I understand that the videotape/audiotape will not have my name on it and a pseudonym or code name will be used for identification instead.

Upon my request, I understand that the researcher will erase any portion of the videotape/audiotape.

I grant the researcher, Laura A. Blackburn of Gallaudet University, Department of Education, permission to videotape/audiotape my participation in this study.

Signature

Date

I give my permission for videotapes and/or audiotapes made of me during the project to be shown to or played for people other than the researchers. I am aware that their name will not be used when the tapes are used. I know that I can withdraw my permission at any time without explanation or penalty.

Signature

Date

VIDEOTAPE/AUDIOTAPE RELEASE FORM
for children

I agree to allow my child, ________________, to be videotaped/audiotaped as part of his/her participation in the study, "A Deaf Child and His Family: An Investigation of Extended Family Relationships."

I understand that the videotape/audiotape will not have his/her name on it and a pseudonym or code name will be used for identification instead.

Upon my request, I understand that the researcher will erase any portion of the videotape/audiotape.

I grant the researcher, Laura A. Blackburn of Gallaudet University, Department of Education, permission to videotape/audiotape my child during his/her participation in this study.

______________________________ ______________________

Signature Date

I give my permission for videotapes and/or audiotapes made of my child during the project to be shown to or played for people other than the researchers. I am aware that their name will not be used when the tapes are used. I know that I can withdraw my permission at any time without explanation or penalty.

______________________________ ______________________

Signature Date

Appendix L

A Diagram of the Camillo Extended Family Tree

Cut and Paste Joe & Geneva's picture

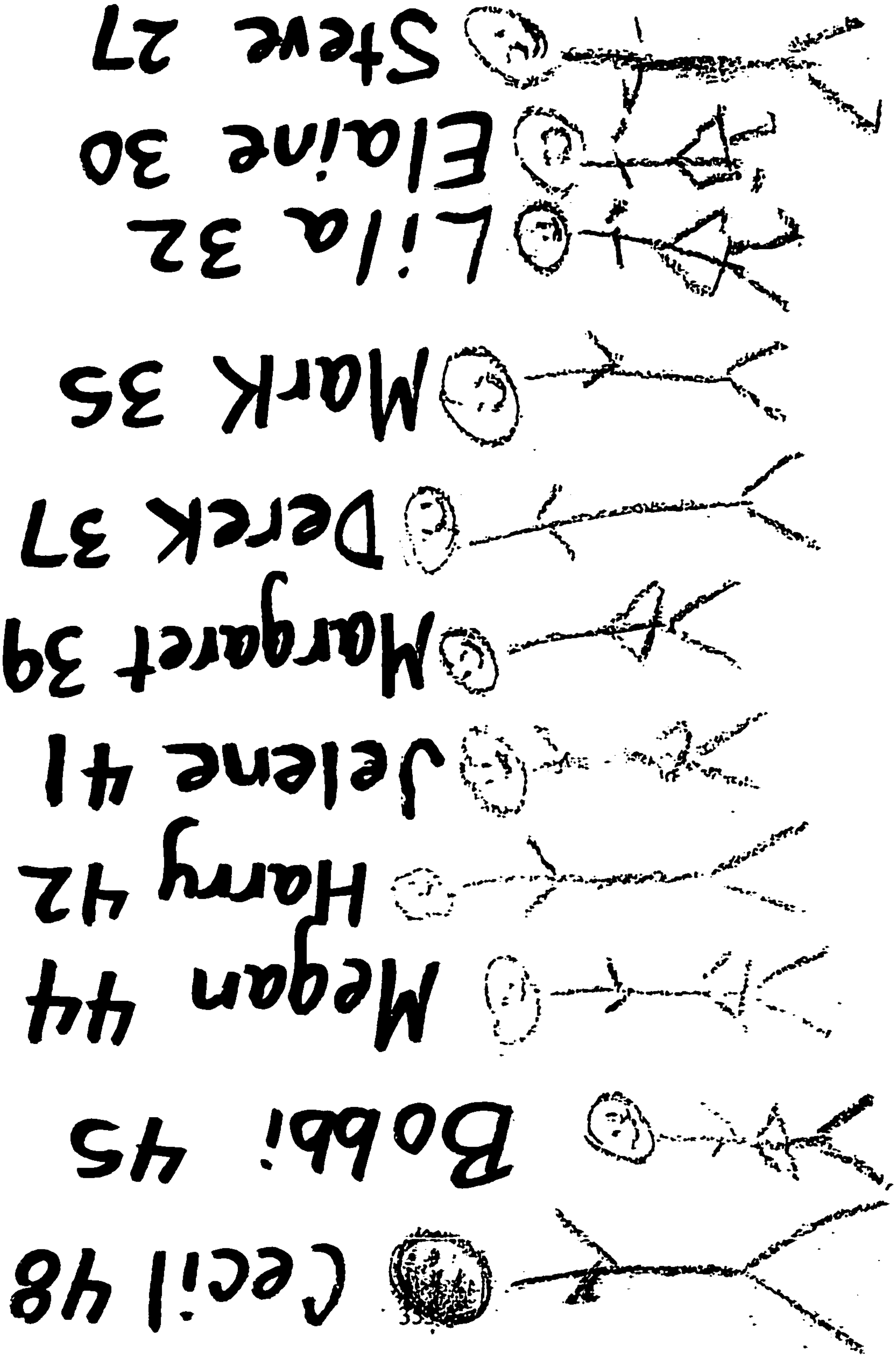
Appendix M

A Diagram of the Medina Extended Family Tree

Cut and paste Ernest & Peggy's picture

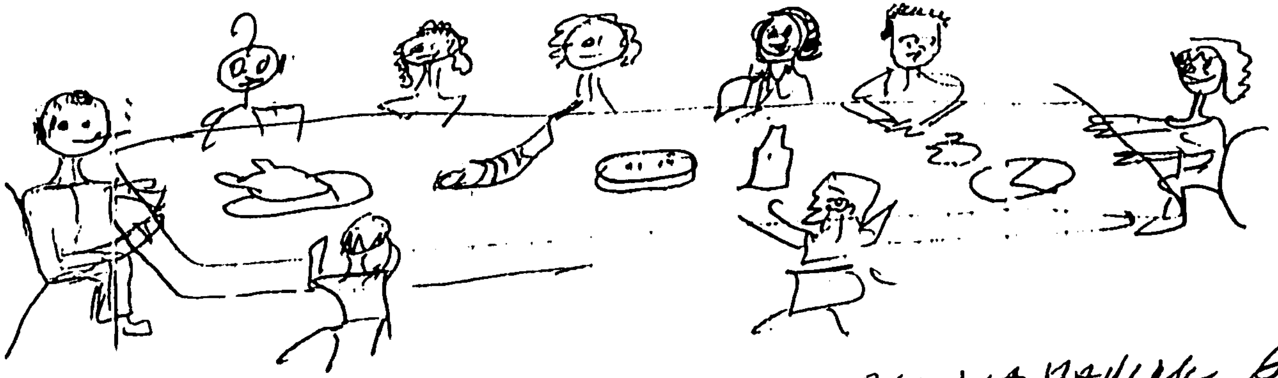
Appendix L

A Diagram of the Camillo Extended Family Tree



Appendix M

A Diagram of the Medina Extended Family Tree



ALWAYS HAVING A FEAST!

MAMA
ALWAYS
PREGNANT
'58- '60 -'62 -63 -'70

OCT-2 3,1996 (Picture by
Ernest Sr. Medina)

The Medina-Camillo Family Tree
(Picture by Peggy Medina)