

THE IMPACT OF HEARING LOSS ON MOTHER-INFANT BONDING

by

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ABSTRACT

Hearing loss is a low-incidence disability, affecting 1 to 6 per 1,000 live births. Until recently, hearing loss was not diagnosed until 2 years of age or later. In the late 1990s, a push began for Universal Newborn Hearing Screening: the ultimate goal was that every newborn's hearing would be tested before leaving the hospital.

Prior to widespread implementation of UNHS, some researchers found that hearing parents of deaf children had higher stress and atypical parent-infant interactions. More recent research, focused on parents of infants diagnosed through UNHS, is inconsistent. Some researchers have found that parents of deaf and hard-of-hearing (d/hh) children have significantly more stress than parents of hearing infants; however, some researchers have not found these differences.

Because increased stress is linked to impaired parent-infant bonding, researchers have made conclusions about bonding based on assessments of stress. The purpose of the current study was to compare the bonding of hearing mothers to d/hh infants to hearing mothers of hearing infants. A second aspect was to assess the needs of mothers of d/hh infants and to evaluate, from mothers' perspectives, how early-intervention services could be improved.

Results from the current study show that mothers of d/hh infants were not bonding abnormally. In addition, the bonding of hearing mothers to d/hh infants is not significantly different from the bonding of hearing mothers to hearing infants. On the Postpartum Bonding Questionnaire (PBQ), mothers of hearing infants were significantly more likely to feel as if their babies cried too much. Interview results show that all mothers were worried

about their children's future; however, mothers of d/hh babies had more specific worries, including those related to communication development. In addition, mothers discussed their experiences with early intervention and their valued qualities in an early-intervention provider.

CHAPTER ONE

INTRODUCTION

This chapter explains the research problem, describes its significance, offers a justification for the study, details the research questions and objectives, and discusses study limitations.

Statement of the Problem

Mother-infant bonding is of primary importance because it forms the foundation for the infant's later attachments (Klaus & Kennell, 1976). Long-term effects on mothers are not well understood; however, interruption of this emotional tie may have devastating effects on the child (Bowlby, 1988). In fact, infants who do not have secure bonds with their mothers are at risk for less satisfying relationships, as well as lower educational and cognitive abilities (Zeanah & Boris, 2000).

The parent-child relationship affects every facet of the lives of both child and parent. Attachment and bonding are two key aspects of this relationship, especially at the beginning of the child's life. The term *bonding* means the tie from parent to infant, whereas *attachment* describes the tie from child to parent (Klaus, Kennell, & Klaus, 1995). The concepts are unidirectional; however, attachment and bonding affect one another. Attachment is sometimes used in its broader context, as a feeling that binds one person to another.

In the typical mother-child relationship, signals exist between mother and child that help to organize the attachment dynamic (Cassidy, 1999). This relationship influences the

child's cognition; cognition in turn regulates behavior and affect (Main, Kaplan & Cassidy, 1985). An inborn propensity to form attachment has been demonstrated frequently. The earliest phase of parent-child attachment occurs during the first three months of life. During this time, infants' senses play a major role in their attachment (Klaus et al., 1995). Very soon after birth, infants demonstrate a predilection for the human voice and face. For example, quiet auditory stimuli cause infants to listen and be calm. When infants are deaf or hard-of-hearing (d/hh) and do not respond to the mother's voice, atypical patterns of communication and attachment may develop.

Children's early attachment affects their future emotional experiences and is therefore crucial to their emotional development (Ainsworth, Blehar, Waters & Wall, 1978). A strong sense of attachment on the part of the child leads to the development of independence and healthy relationships with others (Klaus et al., 1995). When mothers have a healthy bond with their infants, they are sensitive to their children's needs and are able to engage in high-quality interactions with them. When parent-child communication is disrupted, mothers may experience impaired bonding, which, in turn, may affect the child's attachment and future development (Willinger et al., 2005). Children's internal working models of attachment, as well as their sense of self, are directly related to the interaction they have with their parents (Bowlby, 1980, 1988; Bretherton, 1999). When a mother is sensitive to her child's needs, this sensitivity is transmitted to the child. The way a child builds a sense of self is based, in part, on internal models of attachment, as well as on a reflection of what parents say and do, and this affects the image that parents reflect back to the child about him/herself (Bowlby, 1988). Parents who are able to engage in a

free-flowing conversation with their children about trivial matters such as daily experiences, thoughts, and feelings do much to promote the attachment process. This kind of parent-child communication, even during infancy, allows children to explore sophisticated levels of affective information and to experiment with varieties of emotions, thoughts, and intentions. The parent is the secure sounding board against which the child can make these experiments. Ultimately, the conversational interchange that occurs on a day-to-day basis between parent and child is essential to the child's development.

Although some parenting behaviors may be programmed, many must be learned. Sensitive mothers regulate their behavior so that they mesh with their infants' behavior. Even during the early bonding phase, mothers lay the groundwork for conversational skills. By talking and pausing with the infant, mothers teach their infants important aspects of communication. The mother's communication sensitivity may be endangered if her stress level is abnormally high due to, for example, a disability in her infant (Jarvis & Creasey, 1991). The time immediately after birth is precarious for most mothers, but especially risky when circumstances are less than ideal. The quality of bonding that mothers form during this period affects the mother's emotional tie to her infant.

Bonding may be impaired when the parent's mental picture of their baby is disrupted because of a disability present at birth. During pregnancy, parents develop a mental picture of their baby. They think about how the baby will look and what the baby's personality will be like. They imagine interactions with their infant. They hope, above all else, for a healthy infant. Under normal circumstances, mothers of newborns go through an intense preoccupation with the baby's needs. The openness to the baby engendered by this

preoccupation is a key factor in how the mother bonds to her infant. Not only do mothers have to reconcile their idealization and the reality of their babies, but also they have to reconcile the ideas they had of motherhood during pregnancy with the reality of early motherhood. Discrepancies will always exist between the imagined infant and the actual infant. Reconciling these discrepancies under normal circumstances can be tumultuous and stressful (Klaus et al., 1995). This task becomes much more difficult when a disability or defect is present at birth. In addition, serious medical issues during infancy may induce changes in parenting behaviors. Although visible defects create more initial anxiety than problems that cannot be seen, the period of shock lasts longer in the latter case (Klaus et al., 1995). When the parents feel sorrow, depression, and anger in response to the child's birth, bonding with the infant may be affected. In fact, some mothers hold back from bonding with their new baby when a disability is present (Klaus et al., 1995).

In addition, the mother's own characteristics may put her at risk or protect her from impaired bonding with her infant. Her psychiatric history, social support, family support, family stability, infant health status, infant disability status, and the reconciliation of the idealized infant versus the actual infant all work together to create a cumulative risk for the mother. A brief time of tumultuous emotions is normal after the birth of a baby. Often called the "baby blues," this time lasts for three or four days and affects the majority of new mothers and does not affect the bonding process. However, if the mother has little support, an infant with a disability, and a history of psychiatric problems, for example, she is at high risk for postpartum depression and impaired bonding. Mother-child bonding may

range from “robust to variation”; threats to any one of these psychosocial factors might *not* result in impaired bonding.

Maternal depression and high stress levels can jeopardize the mother-infant tie (Bowlby, 1988). Experiencing the birth of a d/hh infant can cause stress and depression in parents (Brand & Coetzer, 1994; Kurtzer-White & Luterman, 2003; Meadow-Orlans, 1990, Meadow-Orlans, Smith-Gray & Dysegaard, 1995). Stress may disrupt the formation of the bond. However, we do not know if this stress or depression leads to an impaired bond between a hearing mother and a d/hh infant. Depression is of concern because depressed mothers’ interactions with their infants are of lower quality and depressed mothers do not interact with their babies as much as non-depressed mothers do (Feldman, Weller, Leckman, Kuint, & Eidelman, 1999). Secure mothers are more supportive, provide more help, and communicate in warmer ways with their children compared to insecure mothers (Crowell & Feldman, 1988).

Literature searches using the terms *bonding* and *deaf or hard-of-hearing* elicit no results of studies that examined the bonding of hearing parents to d/hh children. In the past, measures of parental stress and interaction have been used as proxies to discuss bonding. However, bonding itself has never been probed in this context.

Such studies that do exist examine bonding as it may be affected by the separation of mother from her infant due to medical reasons, as well as the threat of the infant’s death. Attachment processes are best understood from this perspective (Bowlby, 1969; Hinde, 1989; Hofer, 1995). Other causes of emotional separation (e.g., having a disabled child) are studied less frequently and may be more difficult to identify (Madrid, Skolek, & Shapiro,

2006) but are also relevant. In addition, much less attention has been paid to the bonding experience from the parent's perspective. Bowlby's initial focus, much like the focus of most of the research on bonding and attachment, explored the child's connection to the mother (Feldman et al., 1999). Scant literature describes a mother's ties to her infant.

A brief description of recent changes in the field of deafness will inform the current study, which takes place at a time when 90 percent of infants are screened at birth for hearing loss (Directors of Speech and Hearing Programs in State Health and Welfare Agencies, 2007). Until recently, only high-risk babies received screenings, and the average age of identification was 6–19 months. Universal newborn hearing screening (UNHS), now mandated in 37 states, has made it possible for children with hearing loss to achieve speech, language, and academic skills commensurate with their hearing peers. The effects of UNHS on the family are less clear.

In the US, 5000 families experience the birth of a deaf infant each year (Traci & Koester, 2003), and 90 percent of the parents in those families are hearing. Having a child who is atypical, and, consequently, learning different ways to communicate, and explaining the child's inability to hear to family, friends, and strangers are among the many variables that create stress. To provide more effective and helpful service to children with hearing loss and their families, it would behoove researchers and service providers (e.g., early-intervention (EI) specialists, audiologists, and speech-language pathologists) to identify family-system variables that may influence the functioning of the family and child. Most of the information we have on the stress levels of families of d/hh infants was assessed prior to the implementation of UNHS.

In addition, the suspicion of a disability may create problems in the bond between child and parent. Previously, mothers did not know of their infant's deafness until the children reached two to three years of age. Although the screening of 90 percent of infants at birth has led to improved speech, language, auditory, social, and academic outcomes in d/hh children, the knowledge or suspicion of hearing loss may lead to changes in feelings and/or behavior on the mother's part. Anecdotal evidence suggests that mothers may not sing or talk to their babies if they think that the child cannot hear. In addition, the stress and worry that the knowledge of hearing loss causes may affect the parent/infant bond.

Parents of children with disabilities report greater stress and depression than do parents of children without disabilities (Beckman, 1991; Fuller & Rankin, 1994; Innocenti, Huh, & Boyce, 1992; Kazak, 1987; Kazak & Marvin, 1984; Rosman, 2003). These stresses are particularly intense when income (Lloyd, 2002) or language barriers (Cho, Singer, & Brenner, 2000) exist. Data from studies of hearing mothers of d/hh children are more ambiguous. Some researchers have found that hearing mothers of d/hh children without additional disabilities were not significantly more stressed than mothers of hearing infants (Meadow-Orlans, 1994; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002). Other studies have reported that parents of children with impaired hearing were significantly more stressed than parents of hearing children (Lederberg & Golbach, 2001; Quittner, 1991; Quittner, Glueckauf, & Jackson, 1990). Parental stress and anxiety are of significant concern because parental anxiety may prevent the formation of a selective and enduring bond (Hofer, 1995).

Research Questions

This study's primary guiding research questions include:

- (1) Do hearing mothers of infants whose hearing loss was identified through UNHS and confirmed by 3–4 months of age experience impaired bonding?
- (2) Do mothers of babies who had false positives (but did not find out their babies were hearing until 3–4 months of age) have impaired bonding?
- (3) Does the bonding of either of the aforementioned groups differ from hearing mothers of infants who passed the UNHS at birth?
- (4) How do mothers of d/hh infants feel about the UNHS process and early intervention services?

Definition of Terms

Bonding is defined many different ways by different researchers. The terms *bonding* and *attachment*, although often used interchangeably, refer to slightly different but related concepts. Various scholars debate the exact definition of the two terms. Kennell and Klaus (1978) state that each concept is unidirectional; *bonding* alludes to the connection from mother to infant, and *attachment* refers to the tie from infant to mother. Attachment behaviors can be observed, whereas bonding is an internal, emotional phenomenon. For example, when two people bond, they form a close, personal relationship (Klaus, Kennell, Klaus, & Kennell, 1995).

Limitations

Certain boundaries of this study may limit generalization. All of the limitations will not be clear until the analysis is complete; however, some challenges can be anticipated. Random assignment is not possible, so a quasi-experimental approach will be applied. Hearing loss, a low-incidence disability, occurs in only 1 to 6 in 1,000 live births, and among these families, very few may agree to participate. Results from such a small sample size may not be generalizable. The characteristics of mothers who agree to participate may confound the results, as well. Mothers who feel they have the capacity to engage in a research project at this stressful point in their lives may represent those with higher coping mechanisms in the first place. This may affect the data by reflecting a highly motivated and more capable group than exists in the general population. In addition, accessing families at such an early stage during a vulnerable time may prove difficult.

CHAPTER TWO

REVIEW OF THE LITERATURE

The literature review will examine studies on typical parent-infant bonding, the effect of parental stress on infant bonding, and the impact of early knowledge of an infant's hearing loss on parent-infant bonding. In addition, the review includes the following related areas of literature: atypical parent-infant bonding due to sickness, disability, or other stressors, UNHS procedures, and the effect of UNHS on parents.

Typical Parent-Infant Bonding

Since Bowlby's seminal paper *The Nature of the Child's Tie to His Mother* (1958), which introduced the principles of attachment theory, the study of attachment systems has become one of the most productive areas of research in developmental psychology. Hundreds of experiments in humans and animals have demonstrated the inborn propensity to form attachment, the outcomes of secure and insecure attachment, and factors associated with disturbances in parent-infant attachment. Most studies, in line with Bowlby's initial focus, explored the child's developing tie to the mother (Feldman, Weller, Leckman, Kuint & Eidelman, 1999).

Klaus and Kennell (1976) describe the term *maternal bonding* as the emotional connection a mother feels toward her infant. They test the hypothesis that in the first 6–12 hours after birth, a sensitive and irrevocable period exists in which the mother has to be in touch with the child or a negative effect takes place on the ability of the mother to form a

strong emotional bond with the infant. They documented 14 mothers who had 5 minutes' contact with their babies after delivery and then were separated from their infants for 6–12 hours. They also documented, in contrast, 14 others who had an hour's contact with their infants after birth and an additional five hours each day. Each group was allowed to feed their babies for 30 minutes every four hours. The attachment bond was reviewed at one month and again at one year. While there did appear to be some element of effect on the relationship between the mother and the child due to separation, the study was not definitive because the sample size was small and attention was focused on a rather small number of negative findings rather than a large number of measurements that showed no difference in attachment between the groups.

Klaus et al. (1995) believe that the baby becomes attuned to the mother while in utero. The baby may be sensitive to the mother's sleep-wake cycles, heartbeat, hormone fluctuations, daily patterns, and voice. Such prenatal influences may affect the newborn's response to the presence, actions, and voice of the mother. In particular, adult speech has a profound effect on infants. Newborns have been found to move in rhythm and reaction to the mother's speech. The baby's movements, in turn, stimulate the mother to continue speaking and interacting. This vital reciprocal pattern begins in the first days of the infant's life. When mothers gently follow or imitate their babies, rather than lead them, babies are more responsive and likely to participate.

Because a mother's behavior has an effect on her baby, the stress experienced by the mother affects the bond between her and the baby. Currently, new mothers go home from the hospital 24–48 hours after giving birth. This is a major change from the practice

of the not-too-distant past that kept new mothers and their infants in the hospital for five to seven days. Consequently, mothers are now home, without readily accessible professional help, when the typical “baby blues” set in. The baby blues, which affect 80–90 percent of new mothers in the second to fifth day of the baby’s life, are characterized by a brief time of erratic emotions. Postpartum depression, more serious than the baby blues, affects 10–16 percent of new mothers, and in most cases begins four to eight weeks postpartum. Its symptoms include, but are not limited to: anxiety, irritability, frequent crying, feelings of helplessness or hopelessness, lack of energy and motivation that affects ability to function, lack of interest in sex, loss of appetite, sleep disturbances, and feelings of being unable to cope with new demands. These symptoms interfere with all aspects of the mother’s life, and affect bonding with the infant (Klaus et al., 1995). When the bond between the infant and the caregiver is affected, negative consequences accrue to the baby. For example, Gunnar, Brodersen, Nachmias, Buus and Rigatuso (1996) found that when caregivers respond to clear signals of infant distress, the infants develop effective stress-regulatory systems by six months of age. Stressful experiences not properly regulated by the caregiver before the infant is capable of self-regulation may influence the development of brain structures, leading to the development of anxiety difficulties and/or more anxious temperaments (Gunnar, 1998), which, in turn, affects the child’s ability to face great stressors.

Mothers who have bonded to their infants tend to be sensitive to infant signals, and sensitive mothers match their responses to the infant’s affect. Sensitive maternal responses include increasing contact or retreating, depending on the infant’s emotional signal.

Insensitive responses include a lack of response, a poorly timed response, or intrusive responses. A mother's ability to perceive her infants' emotions accurately is key in developing these sensitive patterns of communication, which influences the strength of the bond (Crockenberg & Leerkes, 2000). Emotional availability, nurturance and warmth, protection, and provision of comfort are the most salient maternal behaviors for the development of the attachment relationship. Other important, but less salient behaviors, are maternal play, teaching, instrumental care and routines, and discipline.

Experience selects and molds brain pathways in the developing child (Nelson & Bosquet, 2000). Trauma, prolonged separation from a caregiver, or interaction with a depressed caregiver may affect the infant's "lower" autonomic systems, which, in turn, affect the nervous system's neural pathways (Schoore, 1997). Physical separation can disturb parent-infant bonding. Feldman and his colleagues (1999) assessed the bonding, anxiety, and depression of 91 mothers in 3 experimental groups: (1) mothers of healthy, full-term infants; (2) mothers of low birth-weight infants born 34–36 weeks gestation; and (3) mothers of very low birth-weight infants born by Cesarean 27–32 weeks gestation (Feldman et al., 1998). Bonding was highest among mothers of the healthy infants and decreased linearly as separation or potential loss increased. Anxiety was related to maternal preoccupations of worries about the babies, and depression was related to fewer attachment behaviors.

Etzion-Carasso and Oppenheim (2000) found that children who appeared secure in infancy had better communication with mothers at age 4 and more coherent conversations at age 6. Mothers of secure infants made more positive and less controlling statements and

made more reference to feelings when discussing children's past behavior. Researchers felt this indicated that children's communication skills were influenced by the strength of the mother-infant relationship. This finding suggests that how well a mother feels bonded to her infant may affect the infant's communication skill development.

Parental Stress, Children with Disabilities, and Infant Bonding

Emotional separation (due to stress) is not as obvious as physical separation; however, when a mother fails to feel emotionally connected to her infant, bonding may suffer (Madrid, Skolek, & Shapiro, 2006). Defined as physiological, cognitive, or emotional strain or tension, stress affects everyone's life to varying degrees. High stress levels in mothers correlate with insecure bonding (Jarvis & Creasey, 1991; Pipp-Siegel et al., 2002). Although some researchers report that many families with a disabled child are able to cope and adjust adequately (Abbott & Meredith, 1986; Mahoney, O'Sullivan, & Robinson, 1992; Salisbury, 1987; Turnbull & Turnbull, 1990), many parents of children with disabilities report greater parental stress than do parents of children without disabilities (Beckman, 1991; Fuller & Rankin, 1994; Innocenti, Huh, & Boyce, 1992; Kazak, 1987; Kazak & Marvin, 1984). Mothers of children with special needs have been found to have higher levels of depression and stress than mothers of typically developing children (Rosman, 2003). These stresses are particularly bad when income (Lloyd, 2002) or language barriers (Cho, Singer, & Brenner, 2000) exist.

Mothers of children diagnosed with illness or disability often report a greater degree of problems—feelings of helplessness, a loss of confidence in the ability to be a

good or effective parent, worries over financial issues, avoidance by others after the diagnosis, and fear of inability to cope with the needs of a child with a disability—than mothers of typically developing children (Cook, 1984). Marriages are often severely tested by diagnosis of a disability or illness in a child. When the child requires follow-up or placement in an EI program, the needed services may be at a distance from the home. This sometimes requires one parent to be out of the home frequently, while the other parent tries to keep the rest of the family intact—perhaps doing so while earning a living. Couples who have a child with a disability are at higher risk for separation or divorce, and self-reports of marital distress increase (Sabbeth & Leventhal, 1997).

To determine the relationship among stress, coping, and attachment, Jarvis and Creasey assessed 32 families with a healthy 18-month-old infant, using the Parenting Stress Index (PSI), Ways of Coping, and Attachment Q-Set (1991). They found parenting stress significantly associated with infants' insecure attachment to mothers and fathers. Furthermore, psychological separation due to stress affected attachment to a greater extent than physical separation due to childcare arrangements.

Mothers of children who receive special education experience more stress than mothers of children in general education. Using the PSI (Abidin, 1990), Fuller and Rankin (1994) examined stress among mothers of children in general and special education. The PSI, a 120-item self-report questionnaire, is for use with parents of children up to 13 years of age. The assessment has two domains. The first domain, Child Characteristics, includes the child's adaptability to the environment, the acceptability of the child to the parent, the degree of bother or "demandingness" of the child to the parent, the child's mood, the

distractibility and hyperactivity of the child, and the amount of reinforcement required by the child to produce a positive response in the parent. The second domain, Parent's Personality, looks at parental depression, unhappiness, guilt, parental attachment, restrictions imposed by parental role, parent's sense of competence, social isolation, relationship with spouse, and parental health. Subscales in each domain supply a breakdown of the intensity of stress in each area. Parents who score high on the Child Domain section have difficulty coping with their child's qualities or behaviors, and parents who score high on the Parent Domain section experience abnormal levels of stress related to functioning as parents. The participants included three groups: (1) mothers of children in regular education (n=15), (2) mothers of children with learning disabilities (LD) (n=15), and (3) mothers of children with emotional impairments (n=15). All children attended Kindergarten through grades 8 in public schools. The mothers of children in regular education scored within the normal range on all subscales and domains. No significant differences were found between the mothers of children with LD and the mothers of children with emotional impairments; however, mothers of the special education children (LD and EI) had significantly more stress in their overall Child Domain scores, indicating that they had difficulty coping with their children's characteristics or behaviors. Mothers of children with emotional impairments scored significantly higher than mothers of children without disabilities on the Total Parent Domain, indicating that mothers of children with emotional impairments find the parent-child relationship very stressful. Fuller and Rankin (1994) did not give a breakdown of the ages of the children, so it is not possible to draw conclusions about mothers of young children in particular.

Leyser et al. (1996) investigated stress and adaptations in 130 parents of children with visual impairments (VI) and 78 parents of nondisabled children using a parent questionnaire and the Family Environment Scale (FES) (Moos & Moos, 1976). The FES, which measures family members' perceptions of the family social climate, has a short form of 45 items divided into three domains: (1) relationship (cohesion, expressiveness, conflict); (2) personal growth (independence, achievement-orientation, intellectual-cultural, active-recreational); and (3) system-maintenance (organization and control). Significant differences between groups were found on the personal growth dimension and the system maintenance dimension. Several chief concerns were identified through the questionnaire: parents' main concerns were for their children's futures. Providing for the children's needs, financial concerns, and the child's socialization were primary concerns as well.

Researchers in Germany used a parent questionnaire to compare the stress of 47 mothers of visually impaired children (8 months to 7.3 years) with that of 47 mothers of children who had no disabilities (Troster, 2000). Some of the children with visual impairments had additional disabilities. The questionnaire had two sections: the first section addressed demographic questions, and the second section included scales for mothers to assess their children's functional impairments, their own everyday stress, and the perceived availability of social support. The second section contained an adapted version of the PSI (Abidin, 1995). The analysis revealed that mothers of children with visual impairments had significantly more stress than mothers of children without disabilities. Mothers of children with multiple disabilities felt more stress than mothers of

children without disabilities on both the child and parent domains of the PSI. Mothers of children with only a visual impairment were significantly more stressed on the child domain than mothers of children without disabilities. When looking at only the mothers of children with vision loss, researchers found that single mothers had more stress in the parent domain than mothers consistently living with a partner. Because heightened stress related to the behavior and behavioral competencies of the children and not to parental competencies, Troster concluded that stress was not a function of maternal depression or lack of attachment.

Until recently, there was a relative paucity of research on the relationship between mothers and D/HH babies, and when problems occurred, they tended to be associated with problems in communication rather than attachment (Marsharck, 1993; Meadow-Orlans, Spencer, & Koester, 2004; Pipp-Siegel, 1998). Pipp-Siegel, Sedey, and Yoshinaga-Itano (2002) examined the stress of 184 hearing mothers of deaf children. The children ranged in age from 6 to 67 months at the time of the mothers' evaluations. The children were diagnosed with hearing loss at one year of age, and an average of 13 months had passed since diagnosis. More than 90 percent of families were receiving early intervention services. The researchers used the PSI/Short Form (derived from the full-length PSI; Abidin, 1995), Parenting Daily Hassles Scale (Crnic & Greenberg, 1990), and the Family Support Scale (Dunst, Trivette, & Deal 1988) to assess the stress of the mothers. On the PSI, mothers of deaf children scored lower on the Parent Distress subscale than did mothers in the normative sample; however, mothers of deaf children scored higher on the Parent-Child Dysfunctional Interaction than the mothers in the normative sample. No

significant difference was found in the third subscale, Difficult Child. Parental stress is at clinically significant levels when it crosses the 90th percentile mark (Abidin, 1995); 13 percent of mothers of d/hh children had clinically significant levels of stress. The authors found that three variables significantly predicted parental distress: frequency and intensity of daily hassles, amount of support, and family income. Four factors predicted Parent-Child Dysfunctional Interaction: having children with additional disabilities, a greater degree of child hearing loss, decreased child language quotient, and increased daily hassles.

Although parents of children with disabilities are more likely to suffer from stress, researchers have also noted strengths of parents of children with disabilities. Abbot and Meredith (1986) compared 60 parents (30 couples) of children with intellectual disabilities to a same-sized group of parents of children with average intellectual ability. The authors used the Family Strengths Scale, a measure of family problem-solving abilities; the Dyadic Adjustment Scale, a measure of how well married people adjust to change; the Edwards Personal Preference Scale, a personality inventory; and the Family Adjustment Survey to measure marital and family strengths, as well as parental personality characteristics. The Family Adjustment Survey was comprised of five open-ended questions that asked spouses how they were adjusting to having a child with a disability.

No significant differences were found between the two groups on the Family Strengths Scale, the Dyadic Adjustment Scale, or the Edwards Personality Profile Scale. They found that parents of children with intellectual disabilities were less critical of each other and perceived fewer family problems. On the Family Adjustment Survey, 94 percent

of parents with children with intellectual disabilities said they were getting along as well as families they knew with children without disabilities. Some challenges were noted: more difficult parenting (42 percent), greater financial burden (27 percent), worry about child's future care (25 percent), restrictions on personal and family activity (25 percent), and concern for child's lack of friends (15 percent). Significantly, 80 percent of parents indicated that they developed traditional family strengths because of their disabled child. Half of these parents said that their family had grown stronger and/or more unified as a result of having a member with a disability. Families mentioned several sources of help and support. The most important was spousal support, followed by other family members, social services, schools, and church/religious beliefs.

The Impact of Coping Strategies and Support on Parental Stress. Stress is universal; how people handle stress is not. A person's risk factors play a large role in determining the severity and duration of stressful events. However, people with the same risk factors will develop very different outcomes; some will experience adverse effects while others will not. The balance of risk and protective factors determines the ultimate impact of stressful events (Zeanah & Boris, 2000). Protective factors are circumstances that augment resilience under stressful conditions and increase buffers to future disturbances. Protective factors include, but are not limited to, close attachments to other adults, social support, feelings of parental competency, and supportive marital relationships.

Medical personnel may play a big part in helping families in stressful situations. One study found that family physicians rarely inquire about family functioning when a

child is ill (Forrest, Standish, & Baum, 1982), and this may be because the primary care team feels somewhat sidelined when the child is referred to specialty care. Forrest et al. introduced a counseling service for some of the parents with an ill child. Researchers monitored the service and compared the parents who received the counseling with those who did not. Assessment was carried out at six and fourteen months after the death of a child; researchers used semi-structured interviews as well as two self-rating scales. Of the 16 mothers within the supported group, 2 showed a psychiatric disorder at 6 months compared with 10 of the 16 mothers in the unsupported group. Those women who were socially isolated and whose marriages lacked intimacy had a higher degree of psychiatric symptoms than those who had social support. Parents reported that they appreciated it when the practitioner expressed interest and attempts to offer support, even when they knew the physician could do nothing to cure the child. It may be helpful for family medical providers or others involved in the primary care of the family to invite the family in after discharge to review how each member of the family deals with the diagnosis and future challenges and to ensure that all social support and intervention programs have been offered and are being accessed. Interaction with the staff at the time of diagnosis often can be important to the long-term attitude the parents take toward the child, and the mother's ability to bond effectively. When the child is born in a mid-to-low acuity hospital setting, there may be a relative lack of knowledge on the part of staff of how to deal with parents whose children are diagnosed with illness or disability.

Jarvis and Creasey (1991) found a correlation between parental coping strategies and attachment outcomes. Even when experiencing significant amounts of stress,

parents who used positive reappraisal techniques (i.e., reframing adverse events in positive terms) achieved healthy attachment. Parents who used avoidant coping strategies that caused them to engage in activities or mental states that prevented them from dealing with stressful events, however, were less likely to have securely attached infants. If practitioners are aware of this information and counsel parents on positive coping strategies, a further reduction in impaired bonding and attachment may be realized.

Learning that her baby may have a hearing loss can be a stressful event in a mother's life. How this news is communicated may influence how a mother copes. Because positive test results on newborn hearing screenings are relatively rare, the staff may be inexperienced in clearly or effectively communicating with the family. Family members in turn may want to turn to staff members during the hospitalization for more information on their child's condition—information that staff may not feel able or knowledgeable enough to give.

A study in the United Kingdom (Rahi, Manaras, Tuomainen, & Hundt, 2004) reviewed the needs of parents at and around the time of the diagnosis of disability in their children. The parents had children who had ophthalmic disorders; specifically, they were blind or severely vision impaired for life. Rahi et al. introduced the concept of “family-centeredness,” in which there was a recognition that the care given to the child comes not only from the care team, but also from the parents. In-depth interviews were completed to evaluate what parents perceived as most helpful during the peri-diagnostic period. In each case, a specifically assigned “key worker” who helped the family by acting as an advocate in the issues of care and referral, was found especially effective. In post-surveys, families

indicated the importance of care provided in a compassionate and emotionally supportive manner; those parents who reported fair to excellent degree of adjustment one year post-diagnosis also reported that they felt they had excellent social and medical support networks. These data indicate parents need support and education, as well as mobilization of a social support network to help them deal with their own issues, which in turn appears to help them care for and bond with their own disabled children.

A correlational study reviewing the coping strategies of parents who had children with cancer reported that coping mechanisms did not appear related to race or gender (Davies et al., 1986). However, parents who achieved a good relationship with medical staff tended to use coping mechanisms such as denial, acceptance, and reliance on religion. The more highly educated the parents, the more likely they were to use information seeking as a coping skill for dealing with issues surrounding the child's health or prognosis.

Resources and social support may affect perceptions of stress. Hill, Murray, Woodall, Parmar, and Hentges (2004) investigated the stress levels of mothers of babies with cleft lip (with or without cleft palate) in relation to the professional support the parents received. Hill et al. assessed perceived professional support, parental bonding, and the general health of the 102 mothers when the infants reached 2, 6, 12, and 18 months old. Mothers' perceptions of professional support strongly related to their perceptions of the quality of care they received from their own mothers. In addition, current depression did not influence perceived professional support. Hill et al. offered the following three reasons for perceptions of inadequate professional support: (1) vulnerable parents may perceive

their circumstances differently from parents who are not as vulnerable, (2) professionals may treat these families differently, and (3) these parents may be less amenable to professional guidance. The possibility that a mismatch exists between parents' perceptions of professional support and the reality of the support needs to be considered. However, in some cases, the support may not actually be adequate to meet the parents' needs.

It is vital for early interventionists to understand coping mechanisms across cultures and for all ethnicities, so that service delivery can be specifically tailored to the family's needs to promote an optimal level of support and development. Hanline and Daly (1992) examined the relationship between maternal perceptions of family coping strategies and family strengths in Hispanic, African-American, and Caucasian families of young children with and without disabilities. The 206 participants, recruited from early intervention and childcare programs in Florida and California, completed the Family Crisis Oriented Personal Evaluation Scales (F-COPES) and the Family Strengths questionnaires. Within all three ethnic groups, the use of internal family coping strategies predicted family strengths better than the use of social support outside the family. No differences existed in family coping strategies and family strengths between Hispanic families of children with and without disabilities. One difference related to social support among African-American families and multiple differences among Caucasian families. The negative effects of parenting a child with disabilities within Hispanic and African-American families were mediated through the use of coping strategies. These minority groups have experienced high levels of stress due to their exclusion from full participation in the majority society, and, consequently, they may have well-developed coping strategies. Although these

families still struggled with the challenges of raising a child with disabilities, adverse results were buffered when parents used coping techniques such as reframing (i.e., seeing positive aspects of challenging situations). Furthermore, minimizing reactivity positively—passive appraisal techniques (i.e., avoiding confronting an issue)—related to family accord in African-American families. This technique negatively related to family accord in Caucasian and Hispanic families and is generally viewed as an ineffective coping strategy.

Jo, Singer, and Brenner (2000) assessed the adaptation and accommodation of Korean and Korean-American families to their children with developmental disabilities. They used a demographic form and an interview to assess the experiences and attitudes of 16 Korean mothers living in Pusan, Korea, and the experiences and attitudes of 16 Korean-American mothers living in Los Angeles. All mothers were interviewed twice, and five Korean-American mothers were interviewed three times. The news of a child's disability initiated a crisis for all parents. Mothers described feelings of shame, self-blame, sorrow, and anger. Approximately 35 percent of the mothers were distressed for the first several months of their child's life, and 46 percent reported that the distress lasted for a year. A high level of negative emotion lasted for two years in 13 percent of the mothers. Even though 44 percent of mothers admitted contemplating suicide, all participants ultimately reported positive, loving feelings towards their child. Many mothers (63 percent of Korean mothers and 83 percent of Korean-American mothers) found that their negative emotions returned during stressful times. Common triggers were challenging child behaviors and difficulty obtaining disability-related services. The process of adaptation was strongly mediated by religious views. More than a third of the Korean-American participants were

not religious before giving birth; however, all had joined immigrant churches by the time of this study. They reported that their church affiliation represented a huge amount of emotional and spiritual support. Consequently, many mothers felt a dramatic reduction in their feelings of hopelessness and self-blame.

Several themes emerged regarding sources of stress that led to experiences of strain in the Korean and Korean-American families: (1) challenging behaviors of children, (2) difficulty obtaining information and resources, (3) reminders of typically developing children, and (4) worry about the effect on siblings. Inappropriate social behaviors, the leading cause of stress, made mothers feel drained, ashamed, and embarrassed. In addition, the challenging behaviors of the children made it difficult for the mothers to find respite care, which further affected the mothers' fatigue as well as their social networks. Mothers in both groups avoided situations with relatives and, especially, situations with strangers; however, Korean mothers reported a much higher incidence of public negativity than Korean-American mothers.

One major difference between the Korean and Korean-American mothers was the availability of formal social support (e.g., medical specialists, public education, case workers, school bus services). The support these professionals gave seemed to have a substantial impact on how families adapted to having a child with a disability. Lack of adequate social support frustrated the Korean mothers and increased the difficulty of parenting.

Through all the difficulties, families still found benefits of having a child with a disability. Most parents were positive about the overall quality of their lives. Feelings of

sorrow and worry were mixed with feelings of love and gratitude for personal and spiritual growth. Initial negative reactions gradually transformed into positive attributions and emotions. The scope and breadth of the transformation seemed highly dependent on environmental demands, perceptions of stress, social support, and coping skills.

Parental coping strategies affect school-aged children as well. Researchers have found that mothers' personal resources, including coping strategies, moderate the effects of their children's learning disabilities. Al-Yagon (2007) examined the role of maternal personal resources (mother's attachment style, coping strategies, and affect) in subduing the effects of learning disabilities on children's socioemotional and behavioral adjustment, as well as on their secure attachment. Mothers' low use of avoidant coping strategies and close relationships with significant others lessened the effect of their children's disabilities on the children's level of loneliness, feelings of hope, and secure attachment.

Mothers experiencing high levels of stress need coping strategies, some of which can mitigate the effects of stress and reduce the mother's chance of experiencing poor attachment and bonding. Positive reappraisal techniques (attaching positive thought to a negative experience) help parents experiencing stress avoid attachment problems.

Avoidance, however, is usually an ineffective coping strategy. People using avoidant coping strategies engage in activities like withdrawal or alcohol use that prevent them from addressing their stressors. When mothers couple heightened stress with effective coping strategies, they have a better chance of avoiding negative attachment outcomes.

Early Identification of Disabilities

Emotional Responses to Having a Child with a Disability. In 1961, Solnit and Stark first advanced the theory that mothers of children born with disabilities go through a mourning process similar to that of mothers who experience a still birth or another type of perinatal loss. Now it is widely accepted that the parent of any child who suffers from illness or disability will likely feel grief in the neonatal period. While the child is not lost, the parents did lose the healthy ideal child that they anticipated and idealized during the pregnancy. After the diagnosis, parents are often left in a state of shock. The initial phase of diagnosis is often defined as then time when the parents realize that no curative treatment exists for their child. One researcher noted that in this peri-diagnostic time, family members may maintain the mutual pretense with the parents that nothing is out of the ordinary with the child, thereby negatively affecting the social network (Bluebond-Langner, 1978).

UNHS has changed the process of the diagnosis of deafness from a parent-initiated model to an institution-initiated model. Prior to the widespread implementation of UNHS, the diagnosis of a hearing loss confirmed parents' suspicions. Now, having a child with a hearing loss is something parents may have never contemplated prior to learning the results of the screening. Consequently, the grief process begins earlier and more abruptly.

Although the initial phase of shock may be more jolting among parents who learn of their child's hearing loss early, the subsequent phases are likely similar to what parents experienced prior to UNHS. How parents handle the stages of shock, disbelief, sadness, anger, anxiety, equilibrium, and reorganization in the first several months of the child's life

affects the amount of stress the parent feels; the amount of stress the parent feels, in turn, affects how the parent bonds to their new baby.

It may be difficult to separate the mother's reactions to the hearing loss from how the infant's behaviors affect the mother-child relationship. From birth, an infant's facial expressions, body posture, vocalizations, and skin color communicate the child's state of comfort, distress, readiness to engage in interaction, and interest in objects or events (Prizant, Wetherby, & Roberts, 2000). Mothers' tone of voice elicits enhanced attention from the child and increased mutual attention. If a child develops atypically, especially if the child does not react to the mother's voice, fundamental patterns of communication may be disturbed that could negatively influence the mother-child relationship.

UNHS and Its Effects on Parental Stress and Bonding. As mentioned earlier, UNHS has drastically changed the process of identifying hearing loss. Typical babies have a well-developed sense of hearing when they are born. Soon after birth, most babies can distinguish between types of sound, loudness, pitch, various voices, and familiar versus unfamiliar noises. Severe–profound congenital sensorineural hearing loss, defined as impairment >60 decibels (dB), whose root cause lies in the cranial 8th nerve or the inner ear, is considered educationally significant because hearing loss at this level is associated with greater than average deficits in verbal abilities compared with non-verbal abilities, up to 25 intelligence quotient points (Yoshinaga-Itano, 1998). Prior to the advent of UNHS, most children with severe-profound deafness were not identified until approximately two years of age. Data collected for 709 children born between 1980 and 2003 show that screened children were diagnosed significantly earlier than children who were identified

through referrals (Durieux-Smith, Fitzpatrick, & Whittingham, 2008). Children screened through UNHS were diagnosed at 6.3 months on average, whereas children who were diagnosed through referrals were diagnosed at an average of more than 3.5 years of age.

Knowledge of hearing loss early in life has changed many aspects of life for deaf children and their families. UNHS and subsequent early intervention has made it possible for children with hearing loss to achieve speech and language milestones commensurate with their hearing peers. For these reasons, 37 states and the District of Columbia and Puerto Rico have statutes related to UNHS. Two-thirds of the statutes have been passed since 1998, so the large-scale effects of UNHS on language, speech, academic, and social-emotional skills of D/HH children have only recently become more evident, as these children reach middle school age.

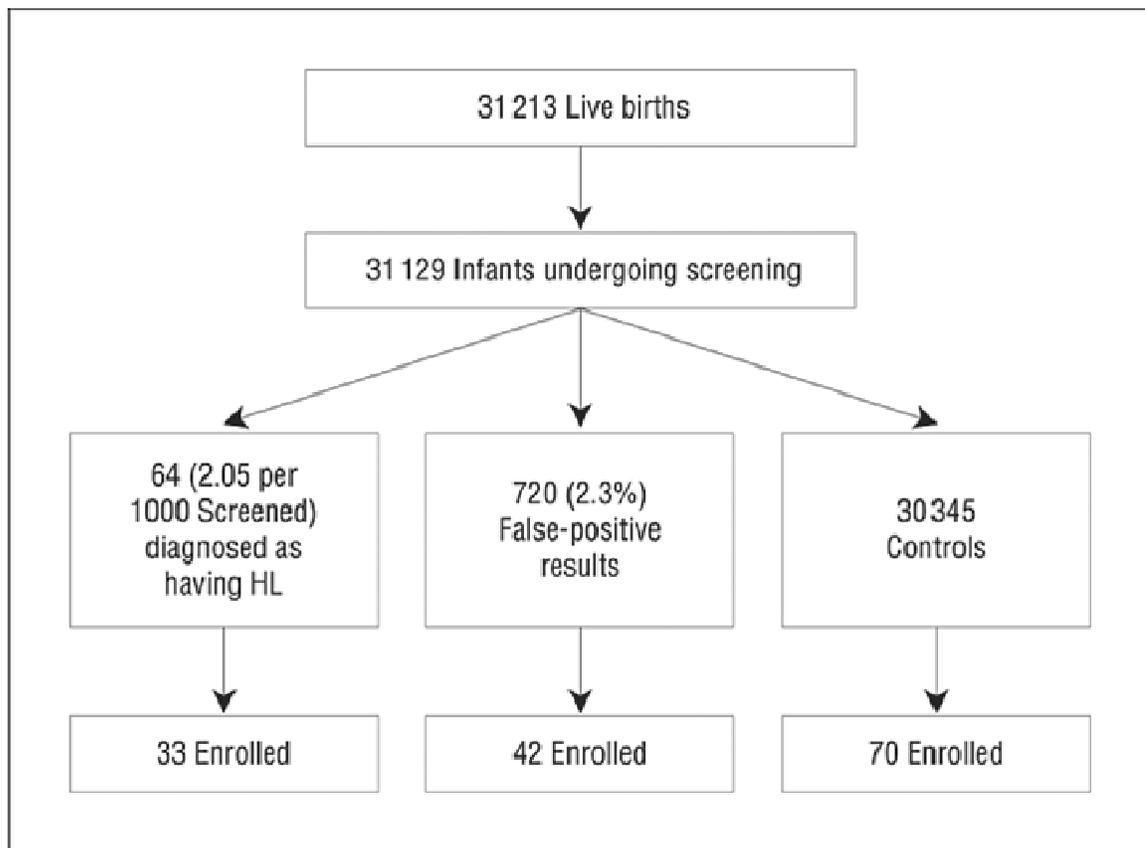
Approximately 90 percent of newborns born in the United States receive hearing screenings before leaving the hospital (Directors of Speech and Hearing Programs in State Health and Welfare Agencies, 2005). Prior to UNHS, screening was performed in the neonatal period only if risk factors were present. One literature review (Johnson et al., 2003) indicates that 19-42 percent of children with profound hearing loss in the neonatal period would go undiagnosed if screening were based on risk factors alone.

Hearing screening procedures vary from birthing center to birthing center. The screening tests consist of the detection of otoacoustic emissions (OAEs) and/or automated auditory brainstem response (AABR) testing. Most screening programs use a two-tiered process in the evaluation of neonates who have indeterminate or unclear results on the first

test. The second test is performed soon after the first test, and if no clear response is found, the infant is then referred for audiological evaluation (Davis, Bamford, & Wilson, 1997).

Hearing screening results can be either false positive (i.e., identifying a hearing loss when none is present) or false negative (i.e., not identifying a hearing loss when one is present). Of those who screen negative, less than 1 in 10,000 have a false-negative result. False positives occur more frequently, between 2.2 percent and 11.7 percent of the time (McPhillips, Thompson, & Davis, 2000). Although using two kinds of otoacoustic emissions testing (CEOAE and TBOAE) shows promise in reducing the amount of false positives (Zhang, McPherson, Shi, Tang, & Wong, 2008), current figures indicate that the majority of infants who do not pass UNHS have hearing within the normal range. This means that of the infants who leave the hospital with inconclusive hearing screening results, most eventually pass the diagnostic testing.

Figure 1: Rhode Island recruitment pool from October 15, 2002, to January 31, 2005.



Source: Vohr, B. R., et al., *Archives of Pediatric and Adolescent Medicine* 2008; 162:205-211.

False positives are of concern because of possible stress the results may cause parents. False-positive results occur for a variety of reasons, with noise (e.g., instrument, environmental, or infant related) listed as the most common cause (Muller & Kompis, 2002). In a prospective longitudinal study Vohr (2008) matched a cohort of infants who underwent screening for hearing loss between 2002 and 2005. These children were tested using the standard two-step protocol. To assess the effect of the child's hearing loss on

family change, researchers used the Impact on Family-Adapted Version G (Stein & Reissman, 1980). Infants with confirmed hearing loss were compared to false-positive infants as well as hearing infants. The PSI (Abidin, 1990) was used to assess stressful interactions in the parent-child relationship. False-positive status alone did not contribute to family stress; however, when paired with an NICU stay, family stress increased.

Magnuson and Hergils (1999) interviewed the parents of 26 children (49 parents total) who had false-positive UNHS test results in Sweden. Eleven of the children passed the first screening, ten passed the second test, and five had to be screened more than twice. Four children were found to have a hearing loss. Parents of children who passed the first test felt the test was done smoothly and efficiently. Parents of children who did not pass the first test but passed the rescreen were satisfied with the explanation that fluid in the middle or inner ear could cause the inconclusive result. Parents of children who did not pass on the first retest expressed more anxiety than parents in the other two groups. Parents of children who had to be tested more than twice said that they would do the test again if they had another child, even though they experienced anxiety before learning the final results. Once parents had the results and could develop an action plan with professionals, they felt decreased anxiety. In the present study, none of the children were diagnosed with hearing loss, so no comparisons to mothers of babies with hearing loss could be made.

Poulakis, Barker, and Wake (2003) assessed parent-reported effects of false-positive hearing screens through a retrospective survey. This Australian study used a risk-based screening program. Parents had been questioned about eight risk factors for hearing loss, and if one risk factor was present, the infant was referred for a diagnostic audiological

evaluation. Parents generally completed the survey six months after diagnostic audiological testing. They reported that they felt anxiety before the diagnostic test but also reported that these negative emotions resolved once they found out their child did not have a hearing loss. This indicated that stress caused by a false-positive diagnosis resolves when parents find out the child does not have a hearing loss. It should be noted that inherent differences might exist between medical hearing screenings (OAE, ABR) and risk-based referrals.

Although each parent will have a highly individualized experience with UNHS, researchers can find themes within and among groups. Parents endorse UNHS because of the benefits the knowledge affords their children's future. Many parents experience heightened stress when their infant does not pass the screening before leaving the hospital; however, whether or not this stress significantly affects the mother-infant bond is unknown.

The Effects of Early Knowledge of Hearing Loss on Parents. A relatively new area of research investigates how knowledge of a hearing loss or the suspicion of hearing loss very early in an infant's life affects the child's family. Young and Tattersal (2007) conducted 27 interviews in which they probed parents' feelings about knowing early that their child was deaf. The 27 interviews included 45 caregivers: a combination of mothers, fathers, and grandparents. In 21 of the interviews, caregivers responded in an emphatically positive manner about knowing early; however, in each of these interviews, caregivers described feelings of grief, shock, or loss. The turmoil created by the knowledge of the hearing loss was mitigated by benefits accruing from early identification. In these 21

interviews, parents expressed the value of beginning intervention as early as possible. In five of the interviews, however, caregivers felt less positive. These parents had originally felt as positive as the other families, but they had experienced intense frustration and disappointment with professional services. These families had hoped that early identification would lead to immediate and consistent services, but instead felt the benefits of early identification restricted by the lack of progress with equipment and related services. Two mothers wished that they had not known that their child was deaf. They expressed their desire to enjoy their baby as a healthy, typical child before discovering the deafness.

When learning of a hearing loss, parents may become concerned about their child's future. When Young and Tattersall (2007) probed caregivers about their children's futures, 10 mothers expressed joy regarding their child's likelihood of being normal and competing in the mainstream. In eight interviews, caregivers expressed relief at avoiding abnormal development. These parents focused on avoiding problems associated with deafness. Caregivers based their notions of what life would have been like for their children—had it not been for early identification and intervention—on stories told by people providing services.

Between the first hearing screening and the point of audiological referral, parents know that the possibility of a hearing loss exists. For up to three months, they live in a state of limbo regarding their children's hearing loss. Parents who receive this inconclusive message fall into three major categories: (1) parents who have little or no concern; (2) parents who are concerned about the ambiguous message, and their concern is not tied to

the process of the screening itself; and (3) parents whose concerns are tied directly to the process of the screening.

Young and Tattersall (2005) reported on findings from the same study and found that the 14 parents who did not have concern about the inconclusive results of the hearing screening cited that the screeners did their jobs in a very satisfactory way and that the explanation given for rescreening the baby did not cause them concern. These parents focused on both the screeners' professional behavior as well as their personalities. Parents preferred to be reassured that the hearing test itself might be flawed and not their child's hearing. Even though all these parents ended up having a baby with a hearing loss, they were still glad that they did not worry unnecessarily until they had to. Parents had more anxiety when the message of the inconclusive screen was given in a vague manner, without much context or reason.

Six of the families (Young & Tattersall, 2005) said that although the news of the inconclusive screening was communicated well, worry was attached to this news. These parents attribute their anxiety to deafness in the family, heightened medical knowledge, additional needs of the child, or instinct. These families had more concern between the hospital screening and the diagnostic screening than some families in the study; however, they did not blame the screening process itself or the professionals encountered during this time for the additional worry.

Some families identified the screening process itself as the cause of their anxiety. Seven families in the Young and Tattersall study (2005) fell into this category. Three of these families wished that the screener had not downplayed the possibility of deafness as

much as they did, leaving the parents' fears unacknowledged. Two families left the screening believing they had received a diagnosis of deafness and that they were being left alone to sort it out. A few families did not understand why the test was inconclusive. They felt misled and disappointed that the test had not had the capability to diagnose a hearing loss. Whether this misunderstanding stemmed from the parents' failure to grasp the information or the screener's failure to convey the information is unclear.

To determine if the presence or suspicion of a hearing loss increased stress and impact on family, Vohr and colleagues (2008) assessed three groups: mothers of infants with confirmed hearing loss, mothers of infants who had false positives, and mothers of infants who passed the initial screening. Using a prospective longitudinal study of matched cohorts of infants, Vohr et al. obtained data when children were aged 6 to 10 months (n=101), 12 to 16 months (n=126), and 18 to 24 months (n=123). They used the Family Support Scale, which measures parents' satisfaction with the support they receive in raising a young child; the Family Resource Scale (FRS), which determines the extent to which different types of resources are adequate in the households of young children; the Impact on Family-Adapted Version G Scale, which measures the effect of the child's condition in producing change in the family; and the PSI. Total stress was similar for all groups at each of the three assessment points. The financial impact score was significantly higher for mothers of infants with hearing loss at 12 to 16 and 18 to 24 months of age when compared to the control group. Furthermore, total (negative) impact (on the family) and caretaker burden scores were significantly higher at 18 to 24 months of age compared with the control and false-positive groups. Greater family resources (for all groups) were

associated with decreased stress and impact on the family. The authors speculated that the increased availability of hearing screening and early-intervention services has mitigated the potential negative and stressful impact of hearing screenings and having an infant with a hearing loss, although parents of infants who had hearing loss felt some negative impact.

When children identified as D/HH in the neonatal period are compared with children identified later in life, mean language scores for the neonatally identified children tend to be 18-20 points higher and within the range for hearing children (Yoshinaga-Itano, 2003). Because language development affects cognition and social-emotional development, much is gained by reducing the typical language difficulties that D/HH children may experience. Children with hearing loss would be at a lesser risk for such delays if UNHS and associated early intervention programs were the standard (JCIH, 2000). Time is critical when diagnosing these children. Children identified with hearing loss between months 6–12 do no better in speech and language development than those children who are diagnosed later in life (Yoshinaga-Itano, 2003).

Despite the possibility of increased stress that early detection of hearing loss may bring to the parents, substantial benefits to the child have been realized. Therefore, any negative effects should be balanced against the benefits. Researchers hypothesize that if more children were identified before six months of age, average language outcomes would continue to improve (Calderon & Naidu, 1998; Moeller, 2000; Yoshinaga-Itano, 2003). Furthermore, these authors hypothesize that better language development is associated with less parental stress and better parental bonding (Yoshinaga-Itano, 2003). *The Joint*

Committee on Infant Hearing: Year 2000 Position Statement endorses this hypothesis and calls for UNHS across all 50 states (JCIH, 2000).

Early identification is unlikely to have an impact if families cannot enroll in high-quality EI programs. In one study, parental involvement had the strongest impact on language outcomes (Moeller, 2000), supporting JCIH's position that EI programs must be designed around a team model, including educators of the deaf, speech and language pathologists, audiologists, and families (2000). A dichotomy, however, still exists in service provision (e.g., fitting hearing aids, speech/language therapy), and it is not unusual to find programs unprepared to deal with children under 18 months of age (Kennedy, McCann, Campbell, Kimm, & Thorton, 2005).

The prognosis for D/HH children concerning intellectual, emotional, language and speech development increases significantly when intervention occurs before 6 months of age (Yoshinaga-Itano, 1998). When screening programs are not in place, the diagnosis is most commonly made after six months of age. Another retrospective study of the efficacy of EI and treatment for hearing loss showed that, after an adjustment for familial involvement, degree of hearing loss, and nonverbal IQ scores, children enrolled in an intervention program prior to 11 months of age had better reasoning skills and a larger vocabulary than those who started at a later age (Moeller, 2000). Clearly, early diagnosis and intervention positively affects many outcomes of D/HH children. However, whether this early knowledge has an impact on the mother-infant bond is unknown because UNHS is still relatively new.

Conclusions and Implications

The best kind of intervention is preventive (Crockenberg & Leerkes, 2000), and it may include fostering natural communication, creating a plan for equipment and appointment management, increasing support, and increasing the mother's level of comfort with her infant. EI professionals have the powerful opportunity to help create and support environments that foster healthy bonding. A finding of impaired bonding may imply that the behavior of the mother may have to be altered. Mothers' behavior changes may require continuous, sensitive, and appropriate intervention and may include increasing emotional and social support.

Any mother or father who learns her/his child has a disability goes through a period of grief and loss. Depending upon pre-existing coping skills, some parents make the change from the idea of the perfect child to that of a D/HH child, realizing that it is the same baby with new challenges. If parental needs go unidentified and unaddressed, and if social support systems are not in place, the parents will have significant difficulty dealing with their own needs and perhaps the needs of the children. Sometimes the stress level of parents of children with disabilities is higher than that of parents of children without disabilities. Stress can lead to impaired bonding, so it is imperative to obtain more information on the impact of early identification of hearing loss on bonding in mothers.

CHAPTER THREE

METHODOLOGY

This study compared the quality of bonding between mothers of deaf infants who were identified through the UNHS process, and mothers of hearing infants who passed the UNHS screen. The original study was designed to also include mothers of babies with false positives, but unfortunately no such mothers participated. A quasi-experimental design that included both qualitative and quantitative methods was used. Participants could not be randomly assigned to groups because the independent variable (infant's status of deafness) could not be manipulated. However, measuring a single concept in multiple ways is a strong approach (Berg, 2004). Such triangulation offers convergent validation (Campbell, 1956) and a means of mutual confirmation of measures and validation of findings (Berg, 2004; Leedy, 2001).

Recruitment

Participants were recruited from three populations: (1) mothers of hearing infants who passed the newborn hearing screening (MoP), (2) mothers of D/HH infants (MoD), and (3) mothers of infants who did not pass the UNHS but who passed the follow-up exam (had false positives) (MoFP). The infants' ages ranged from 3 to 18 months. All participants were offered \$25 VISA or American Express gift certificates as compensation for participation. Participants were recruited through diagnosing audiologists, EI specialists, and flyers posted at a university. Mothers were given information that included information about the study as well as the researcher's contact information. Audiologists

and EI specialists did not know which mothers chose to participate in the study. Consequently, mothers did not have to consider whether or not their services would be affected by their choice to participate in the study. Participants often wish to stay anonymous, especially when sensitive topics are being discussed, and privacy is a chief concern (Berg, 2004). Audiologists and EI specialists gave the potential participants information about the study. After the participant contacted the principal investigator, the PI sent the consent forms through the US Postal Service (USPS). Once the consent was received, the PI sent the two questionnaires to the participant through the USPS. If the participant was chosen for an interview, the PI contacted the participant to schedule a phone interview when the PI received the questionnaires.

Participants

The MoP group consisted of eight participants, and the MoD group consisted of six participants. Mothers of infants who had false-positive newborn hearing screening results (MoFP) were recruited; however, none of these mothers participated. All participants were comfortable speaking, reading, and writing in English. The infants' ages ranged from three to 18 months.

Mothers of Infants Who Passed the Newborn Hearing Screening (MoP) and Their Infants. Mothers in this group have babies who passed the newborn hearing screening at the birthing hospital. These participants were recruited through flyers posted at the University of Arizona, as well as by word of mouth. All participants in this group were either married or have long-term partners. Six participants were Caucasian, and two were

Hispanic. All had some postsecondary education: Two had doctoral degrees and one was working on her doctoral degree. Three had one older child in addition to the infant, and five were first-time mothers. All infants passed UNHS before leaving the birthing hospital. Four infants were male, and four were female. Five were three to six months of age, two were seven to nine months of age, and one was ten to twelve months of age.

Mothers of Infants Who Were Deaf and Hard of Hearing (MoD) and Their Infants.

Mothers of d/hh infants were recruited through early intervention centers and pediatric audiologists. All MoDs are married. Four were Caucasian, and two were Hispanic. All had some postsecondary education. Four were first-time mothers, and two had one older child in addition to the infant. MoD5 had a third child who was deceased.

Time since diagnosis ranged from less than one month to thirteen months. Two infants were three to six months of age, two were ten to twelve months of age, and two were sixteen to eighteen months of age. Five infants were male, and one was female. Three infants had profound loss, one had a moderate loss, and one had a mild loss. One had a profound loss in one ear and a mild loss in the other. One infant had a hearing loss due to a rare syndrome, one had auditory neuropathy, and two had Connexin 26. The cause of the hearing loss of the other two infants was unknown to the researcher. Five infants and their families were receiving early-intervention services. The sixth infant had just been diagnosed when his mother completed the assessments. She anticipated that services would begin soon. All infants who were eligible for cochlear implantation (three) were somewhere in the cochlear-implantation process.

Instruments

All (14) participants completed two assessments: the Postpartum Bonding Questionnaire (PBQ) and the Demographic Questionnaire (DQ). Eight participants (four from each group) completed in-depth interviews in addition to the PBQ and DQ.

Demographic Questionnaires. (See Appendixes A and B.) Mothers completed a questionnaire designed to gather basic demographic information (e.g., amount and length of services, number of children, and work status). The demographic information helped to determine commonalities and differences among the groups. The DQ permitted the PI to be more knowledgeable about the participants, allowing for a more familiar and comfortable starting point for the interviews.

Postpartum Bonding Questionnaire. The Postpartum Bonding Questionnaire (see Appendix C) was designed by Brockington et al. (2001) in response to a need in primary care for an easily administered instrument to give early indications of disorders in mother-infant relationships. Brockington and his colleagues administered an 84-item questionnaire to 104 mothers and compared their scale score to interview data from probes from the Birmingham Interview for Maternal Health (3rd edition). Several of the questions from the Birmingham interview used in the current study's interviews are based on these same probes. Brockington et al. found four factors of clinical relevance and constructed four scales; they then reduced the questionnaire to 25 items.

The questionnaire consists of 25 statements (e.g., "I feel close to my baby," "My baby irritates me," and "I am afraid of my baby") and respondents must chose a response from a 6-point (0-5) Likert scale. The choices are Always (0), Very often (1), Quite often

(2), Sometimes (3), Rarely (4), and Never (5). The PBQ has four subscales: Impaired Bonding (12 items), Rejection and Anger (7 items), Anxiety about Care (4 items), and Risk of Abuse (2 items). Low scores indicate formation of a good bond. I eliminated the Risk of Abuse Scale from the assessment, making the questionnaire 23 items in length. The Risk of Abuse scale has been found unhelpful in identifying mothers considering abuse. In addition, mothers may feel more comfortable completing the assessment if these items are omitted.

Brockington et al. found that the Impaired Bonding Scale has a sensitivity of .93, identifying over 90 percent of mothers with bonding disorders and distinguishing them from normal mothers and depressed mothers with a normal bond. They found that the Rejection and Anger Scale has a sensitivity of .57 but identified almost all those with severe disorders and distinguished them from all other groups, including mothers with mild bonding disorders. The Anxiety About Care Scale has a sensitivity of .43. The authors found that this scale often showed abnormal scores in severe disorders but was not sensitive enough to be useful in screening. The authors found that the Risk of Abuse subscale has a sensitivity of .18 and accounted for just 3.4 percent of the total variance. The authors stated that self-report is not the most effective way to identify incipient abuse. Reliability scores were .95, .95, .93, and .77 for the four scales.

Wittkowski, Wieck, and Mann (2007) assessed internal consistency as well as validity of the PBQ. For the total PBQ scale, internal consistency (Cronbach's alpha) was .76. For Impaired Bonding, Rejection and Anger, and Anxiety About Care, the internal consistencies were .79, .63, and .63, respectively. The internal consistency for subscale

Risk of Abuse could not be determined because of the zero variance between the two items. With the exception of Risk of Abuse, all PBQ subscales were significantly and positively correlated with each other and with the PBQ total score ($p < 0.01$).

Wittkowski, Harvey, and Wieck (2007) examined the acceptability of the PBQ by surveying the mother and baby inpatient facilities in the United Kingdom to determine the kinds of psychological assessments that were used and what the staff thought of the various assessments. Two benefits of the PBQ as identified by hospital staff administering the assessment emerged: it focused on mother-infant bonding and a remediation plan could be created directly from the assessment. The staff felt, however, that mothers were anxious about the staff members' motivation for administering the PBQ as well as the potential for social service involvement based on the results (Wittkowski, Harvey, & Wieck, 2007). These concerns were not relevant to the current study, as everyone in this study received the assessment and the study did not take place in a ward for postpartum issues; thus, mothers were not be singled out. In addition, the Incipient Abuse subscale (only two items) has been found unreliable (Wittkowski, Wieck, & Mann, 2006) and was not used.

Interviews. Four mothers from each group completed phone interviews. The interviews probed further the concepts addressed in both the PBQ and the DQ. The interviews offered both a validation of the information provided on the PBQ and also additional unique contributions.

The interview questions were based in part on probes from the section of the Birmingham Interview for Maternal Health (3rd edition) dealing with the mother-infant relationship. The PBQ was developed based on these probes. Only probes under the

headings of *Infant characteristics* and *Mother's emotional response to her infant* were used; probes related to rejection or aggression were not used. Abnormal bonding could be detected without these probes. In addition to the questions on infant characteristics and mother's emotional response, the interview included questions designed to elicit feelings and experiences regarding the Early Hearing Detection and Intervention (EHDI) process as well as feelings specific to having a d/hh infant. Mothers of infants who passed the initial hearing screening were also asked about their experiences with the UNHS process. They were asked if they knew of the testing and how they felt about it. A portion of the interview questions were based on probes from the section of the Birmingham Interview for Maternal Health (3rd ed.) that deals with the mother-infant relationship. In addition, the interview included questions designed to probe feelings and experiences regarding the Early Hearing Detection and Intervention (EHDI) process, as well as salient challenges specific to having a d/hh infant. Mothers of infants who passed the initial hearing screening were also asked about their experiences with the UNHS process. (Interview questions are included in Appendix D.) (For the complete interview questions, see Appendix D.)

Data Collection

Whenever possible, research should be as unobtrusive as possible (Berg, 2004). As such, I designed this study so that all measures were obtained remotely. That way, participants took part in the study when and where it was convenient for them. This is important for all new parents, but especially important for families of special needs children. They may be overwhelmed by the diagnosis of deafness as well as the associated

appointments (e.g., meetings with audiologists, speech language pathologists, and early interventionists). Mothers completed the PBQ and DQ on their own time, and they chose the time of the interviews.

Four mothers per group were chosen for in-depth interviews. The first mothers from each group who agreed to participate were asked to complete interviews. All mothers who were asked agreed to participate in interviews. All interviews were conducted via telephone. Although telephone interviews are not always ideal because the interviewer loses nonverbal cues that may aid in the rest of the interview (Berg, 2004), the benefits outweigh the concerns. One main reason to conduct phone interviews is if the sampling population is in geographic diverse locations. Because deafness is a low-incidence disability, the only way to access a sizable population is to recruit mothers from disparate geographic locations. In addition, phone interviewing offers the participants the opportunity to remain relatively anonymous.

Questionnaires were sent through the mail, and interviews were conducted on the telephone. The reason for this was twofold: (1) a sufficient number of subjects would not have been found in the local population because hearing loss is a low-incidence disability, and (2) (relative) anonymity may have made mothers feel more comfortable and willing to participate. Mothers completed all instruments on their own time and in the location(s) they chose.

Berg (2004) delineates three important aspects of conducting phone interviews: (1) establish legitimacy (e.g., send a letter before the interview explaining the study and allowing the participant to set up an appointment), (2) engender in the participant a sense

that her participation is important, and (3) ensure that information obtained is sufficiently detailed.

Data Analysis Procedures

Postpartum Bonding Questionnaire Data. A t-test was used to test the differences between the two groups on the PBQ. The status of screening is a quasi-independent variable because it has not been manipulated. This type of comparison is appropriate when there are two or more varying levels of the factor (screening status). The t-test indicated if the difference between treatments was caused by the treatments' effects (i.e., the effects of the screening and status of having a deaf infant). Effect size was measured by r^2 , and the percentage of variance accounted for. An equal number of participants in each group would have been ideal for purposes of statistical analysis; however, more mothers of hearing babies agreed to participate than mothers of d/hh babies. Because the disparity between the groups was not extreme, the t-test can account for unequal Ns and provide a valid assessment of mean differences (Gravetter & Wallnau, 2005).

Demographic Questionnaire Data. The DQ was designed to help the PI become familiar with the participants. No participant indicated difficulty with DQ completion. The intention was to use chi-square analyses to compare MoP to MoD on demographic variables. However, groups were homogenous on most variables.

Interview Data. Interview data were analyzed with the help of Nvivo software. Interviews were analyzed to find trends across all mothers, trends within groups, and trends between groups. Also, because interviews probed some of the same concepts as the

PBQ, interviews were analyzed to see if they validated or refuted responses on the PBQ. Additional themes were noted as they emerged. The PI tested the tentative categories by classifying responses in the first two interviews. Then, the PI used the final categories to code all responses. Finally, the coded responses were tallied.

CHAPTER FOUR

RESULTS

This chapter includes results of the Demographic Questionnaire (DQ), results of the Postpartum Bonding Questionnaire (PBQ), and an analysis of interview data. A total of 14 people participated in the study. Fourteen completed the DQ as well as the PBQ, and eight completed interviews. No participant had impaired bonding as measured by the PBQ, and there was no significant difference between the bonding of mothers of hearing babies and mothers of d/hh babies. The two groups' responses differed significantly on one question on the PBQ: "My baby cries too much." Mothers of hearing babies were more likely to think that their babies cried too much.

As hoped, interview data helped reveal the emotions and experiences of the eight interviewed study participants—four mothers of hearing babies and four mothers of d/hh babies. The data confirmed the PBQ results: These mothers were not bonding abnormally to their babies. In addition, struggles specific to new mothers—and some specific to new mothers of a d/hh babies—were discovered. Furthermore, interview data confirmed that these two groups of mothers were not drastically different from one another regarding mother-infant bonding. All of the interviewed mothers worried about their babies, yet all eight loved and enjoyed their babies as well. Mothers of d/hh babies experienced intense emotion when they first learned of their infant's hearing loss; however, by the time of their interviews, they were not overcome by worry or emotion.

The Demographic Questionnaire

Most of the information gleaned from the Demographic Questionnaires is included under *Participants* in the Methodology Chapter. There was little heterogeneity among participants. All participants were married or had long-term (live-in) partners. Ten participants were Caucasian and two were Hispanic. All had some postsecondary education. In addition, no participant had more than two children: nine were first-time mothers, and five had one child in addition to the infant.

Postpartum Bonding Questionnaire

The PBQ as used in this study consists of three subscales: Impaired Bonding (twelve items), Rejection and Anger (seven items), and Anxiety About Care (four items). The total score on each scale is obtained by adding the scores (zero through five) of each item.

Scores on the Impaired Bonding (IB) scale can range from 0 to 60. Any score of 12 and above indicates impaired bonding; scores of 11 and below indicate that a good bond is forming. Participants' scores ranged from 3 to 9, signifying that all mothers were forming good bonds with their babies. Scores on the Rejection and Anger (RA) scale can range from 0 to 35; any score of 16 and above signals that a mother may be abnormally angry toward and rejecting her infant. Participants' scores ranged from 0 to 3. Scores on the Anxiety About Care (AAC) scale can range from 0 to 20. Any score of 17 and above indicates that a mother is experiencing abnormal levels of anxiety about her baby's care.

Participants' scores on this scale ranged from 1 to 6. PBQ scaled scores are summarized in Table 1.

T-tests were used to assess possible differences between the bonding of the two groups as measured by three subscales of the PBQ. No significant differences were found ($p > .05$), indicating that mothers of babies who passed UNHS and mothers of d/hh babies were not statistically significant from one another on the three subscales of the PBQ. Specifically, no significant differences were found between groups on the Impaired Bonding Scale $t(12) = -1.05$.

T-tests were also used to assess possible differences between MoP and MoD on the individual PBQ questions. There was a statistically significant difference on one item $t(12) = -3.00$, $p=.01$, question 12: "My baby cries too much." MoP were statistically more likely than MoD to feel as if their babies cried too much.

In addition, t-tests were used to assess possible differences between first-time mothers and second-time mothers. A participant's status as a first- or second-time mother did not predict scores on the PBQ subscales or individual PBQ items. Using t-tests, first-time mothers (nine participants) and second-time mothers (five participants) were compared on the PBQ subscales and the individual PBQ items. No significant differences were found: Impaired Bonding $t(12) = -.47$, $p=.65$; Rejection and Anger $t(12) = 1.64$, $p=.13$; and Anxiety About Care $t(12) = .73$, $p=.48$. Significance levels for individual PBQ items ranged from $p=.09$ to $p=.93$.

Table 1

Postpartum Bonding Questionnaire Scale Scores

Mothers of babies who passed UNHS (MoP)										
	MoP 1	MoP 2	MoP 3	MoP 4	MoP 5	MoP 6	MoP 7	MoP 8	Mean	Std. Dev.
Impaired Bonding	9	4	9	6	1	4	9	3	5.63	3.11
Rejection and Anger	2	0	1	2	1	2	5	3	2.00	1.51
Anxiety About Care	3	2	3	2	2	2	1	5	2.50	1.20

Mothers of babies who are d/hh (MoD)										
	MoD 1	MoD 2	MoD 3	MoD 4	MoD 5	MoD 6			Mean	Std. Dev.
Impaired Bonding	3	8	0	4	7	1			3.83	3.18
Rejection and Anger	3	3	0	1	2	0			1.50	1.38
Anxiety About Care	1	6	3	1	3	0			2.33	2.16

Note. Scores on Impaired Bonding can range from 0-60. Any score 12 and above indicates impaired bonding. Scores on Rejection and Anger can range from 0 to 35. Any score 16 and above indicates a problem with rejection and anger. Scores on Anxiety About Care can range from 0 to 20. Any score 17 and above indicates abnormal anxiety.

$p=.31$; Rejection and Anger Scale $t(12) = -.64$, $p=.54$; or the Anxiety About Care

Scale $t(12) = -.19$, $p=.86$.

Variability. Some questions had no variability, while responses on other questions ranged among four categories. Standard deviations ranged from .0 to .954. There was no variability on questions 6, 9, or 15 ($M = .0$, $SD = .0$). These questions are on the IB Scale. All participants answered “never” on question 6: “This baby does not seem to be mine.” All participants answered “always” on question 9: “I feel happy when my baby smiles or laughs.” All participants answered “never” on question 15: “I resent my baby.” The question that had the most variability ($SD = 1.01$) was question 7: “My baby winds me up.” Three participants answered “never,” five answered “rarely,” four answered “sometimes,” and two answered “quite often.” Question 12, “My baby cries too much,” had the second most variability ($SD = .95$). Six participants answered “never,” five answered “rarely,” two answered “sometimes,” and one answered “quite often.” In response question 25, “My baby is easily comforted” ($SD = .816$), three participants answered “always,” nine answered “very often,” one answered “quite often,” and one answered “sometimes.” The questions with the highest variability had four responses, meaning that participants’ answers ranged among four out of six possible categories. A detailed description of item variability can be found in Table 2.

Interviews

Four participants from each group, for a total of eight participants, were interviewed: MoP1, MoP2, MoP3, MoP6, MoD1, MoD2, MoD3, and MoD4. MoP4 and MoP5 agreed to be interviewed, but scheduling their interviews was not possible, so MoP6

was interviewed. Interviews ranged from 30 minutes to 80 minutes. The only interviews that lasted more than an hour were with mothers of d/hh babies.

Participants were interviewed by phone. Conversations were recorded on an audio recorder, and files were saved as MP3 files. A colleague and four undergraduate students in education transcribed the interviews. The PI then checked the transcriptions for errors. Transcripts were uploaded into NVivo and then coded.

Prior to obtaining interview data, anticipated interview themes were established in NVivo, a qualitative software package. These themes, known as *nodes*, were based on (1) established interview questions from the Birmingham Interview for Maternal Health (3rd ed.), (2) previous literature, and (3) the Early Hearing Detection and Intervention (EHDI) process. Once an interview with a mother of a hearing baby and a mother of a d/hh baby was completed, themes were combined and organized into final categories. The major nodes modeled after the Birmingham Interview for Maternal Health were infant characteristics, mother's emotional response to her infant, (mother's) future expectations (of her infant), professionals, and support.

Even though no research was found that is completely analogous to the current study questions, several themes were suggested from the previous literature review as well. These themes included postpartum adjustment and possible depression, bonding effects, support, experiences with hearing screening, and coping strategies. The assumption was that all of these factors would contribute to the mother-infant bond. Another assumption was that discovering mothers' perceived strengths and weaknesses of the EDHI system would help strengthen the diagnosis and early intervention process for babies with hearing

Table 2

Variability of Postpartum Bonding Questionnaire Items

Item	High score	Mean score	Standard deviation
1. I feel close to my baby	1	.21	.43
2. I wish the old days when I had no baby would return	2	.64	.75
3. I feel distant from my baby	2	.43	.65
4. I love to cuddle my baby	1	.14	.36
5. I regret having this baby	1	.15	.38
6. The baby does not seem to be mine	0	.00	.00
7. The baby winds me up	3	1.36	1.01
8. My baby irritates me	2	.86	.66
9. I feel happy when my baby smiles or laughs	0	.00	.00
10. I love my baby to bits	1	.07	.27
11. I enjoy playing with my baby	1	.21	.43
12. My baby cries too much	3	.86	.95
13. I feel trapped as a mother	2	.57	.85
14. I feel angry with my baby	1	.07	.27
15. I resent my baby	0	0	.00
16. My baby is the most beautiful baby in the world	1	.14	.36
17. I wish my baby would sometimes go away	2	.43	.65
19. My baby makes me anxious	2	1.21	.80
20. I am afraid of my baby	1	.07	.27
21. My baby annoys me	2	.43	.65
22. I feel confident when changing my baby	1	.07	.27

23. The only solution is for someone else to look after	1	.14	.36
25. My baby is easily comforted	3	1.00	.78

loss and their families, thus facilitating stronger mother-infant relationships. Themes from previous literature, interview questions, and early interviews were combined for four final categories: (1) developing feelings for infant, (2) sources of support, (3) coping strategies, and (4) expectations. Questions regarding mother's developing feelings for her infant elicited information about mother-infant bonding and how mothers' feelings developed for her baby after delivery. In addition, questions in this category were designed to draw out feelings of depression, if they existed. Questions regarding sources of support elicited information about how spouses, family members, friends, and professionals supported the mother in the months immediately after the infant's birth. Questions related to the EHDI process were included in this category. Questions about expectations elicited information regarding concerns, expectation, and hopes about the mother-infant interactions and the infant's future.

Developing Feelings Toward the Infant

A mother's bond to her infant is one of the strongest and most important of human attachments (Klaus, Kennell, & Klaus, 1995). These developing feelings are so intense that they allow mothers to make frequent sacrifices that would normally be too overwhelming. Examples of such sacrifices are soothing the crying infant for hours at a time and feeding the infant in the middle of the night, even when the mother's need for

sleep is enormous. With regard to developing feelings, the interviews in the current study focused on the mother-infant bond and how the identification of a disability, particularly hearing loss, affected how the mother's feelings for her infant developed.

Bonding. Even mothers of healthy infants tend to be acutely absorbed by their baby's demands (Klaus & Kennell, 1976). The mother's reaction to this preoccupation is a key factor in how the mother bonds to her infant. MoP1, a first-time mother, reacted to the beginning of her daughter's life: "I was one of those people who didn't bond with their baby immediately ... so many things were happening at once ... it took maybe a good week to settle on the idea that I am a mom."

MoP3, reflecting on the beginning of her second child's life, gave some perspective on the difference between bonding with her first and second child:

I bonded with him right away ... I think maybe it happened a little sooner [than with her older daughter]. I think with [her daughter] I was a little more in shock that this person came out of me.... [T]he second time around I knew a little more of what to expect.

This trend continued. MoP6, another first-time mother, said that it felt "surreal to see the ... little creature that's been inside you for nine months." First-time mothers (MoP1, MoP6, MoD1, MoD2, MoD3, MoD4) expressed a slightly delayed bond compared to second-time mothers (MoP2, MoP3) who indicated that they bonded as soon as their babies were born.

MoD1, a first-time mother (of twins), expressed sentiments similar to those of other first-time mothers:

I didn't feel like I had this immediate really strong bond ...
overwhelming to have twins ... bond developed over time
instead of immediately ... I feel like we have been really,
really bonded to them for a really long time, so I don't know
when exactly it happened.

All mothers expressed having positive feelings toward their babies soon after birth, even when the bonds were not immediate. This was a good indicator that all mothers bonded normally with their babies, which reflected the results of the PBQ. However, the second-time mothers who were interviewed expressed a faster onset of their bond. This trend was not substantiated by the PBQ results; number of children (e.g. whether a participant was a first- or second-time mother) was not related to bonding scores on the PBQ. Only two of the mothers who were interviewed had another child in addition to their infant, and both of those mothers had hearing babies. Consequently, any trends indicated by these participants should be interpreted with caution.

The Effect of a Disability on Bonding. Bruno Bettelheim (1972), summing up how an infant's disability can affect the parent-infant bond, said:

Children can learn to live with a disability. But they cannot live well without the conviction that their parents find them utterly lovable.... If the parents, knowing about the [his child's] defect, love him now, he can

believe that others will love him in the future. With this conviction, he can live well today and have faith about the years to come.

Kennell, Klaus, and Kennell (1995) found that the effect of a disability on the parents depended on many factors, including how visible the disability was. Although some mothers of infants with disabilities struggle to initiate loving responses while experiencing feelings of rejection, MoD in the current study did not seem to be too affected by this challenge. In fact, three of the four MoD participants interviewed indicated that they felt closer to their children as a result of the hearing loss. MoD1 said, “I think the diagnosis made us feel closer to him ... You want to protect him.” MoD2 stated, “And I don’t know why I was the one chosen to carry this gift. Some may see it as a burden.” MoD3 articulated the most on this topic. Even though MoD3 and her husband had planned on putting their baby in day care, they decided not to once they learned of their son’s hearing loss:

... [H]is disability drew me in closer to him [T]he plan we had while I was pregnant was ... day care ... and (we would both) go on about our career thing I think we would be more distant to the baby if that had been the way things had worked out I feel like I’m very intuitive with him and touch is very important [I]t’s the best way to communicate—the back massage, the foot massage, the hug [techniques she’s learned through EI].

High levels of stress have been correlated to insecure bonding (Jarvis & Creasey, 1991; Pipp-Siegel et al., 2002). Although MoD expressed stress related to their baby’s

hearing loss, bonding was not impaired. These mothers felt closer to their babies as a result of circumstances associated with hearing loss. MoD1 felt more protective of her son, whereas MoD2 felt as if she had been chosen for a special purpose. MoD3 felt that the alternate childcare provisions, extra attention, and physical touch—all results of the hearing loss—brought her closer to her son.

MoD4, the only mother of a d/hh who did not speak explicitly about feeling closer to her child, did not state that her daughter's hearing loss made her feel *less* close to her. She said that family members repeatedly told her and her husband that they did not seem to be as upset as they should be. Her decision to have a second child (she was pregnant at the time of the interview), despite the fact that the child had a 25 percent chance of being d/hh, indicated that she did not feel particularly overwhelmed by her daughter's hearing loss.

Sources of Support

During the major life change of having a baby, the amount of support new parents receive can have a tremendous impact on the quality of the experience. This is particularly true when that birth is paired with unexpected, challenging events. In addition, the mother's own preexisting support network affects her bonding experience (Lester, Boukydis, & Twomey, 2000). Pipp-Siegel, Sedey, and Yoshinaga-Itano (2002) found that support significantly predicted the amount of parental distress in parents of d/hh children. If social support, family support, and family stability are strong, the mother may be protected from impaired bonding, even if she has a baby with special, unexpected needs. The four major sources of support named by participants were family, spouses,

friends/coworkers, and professionals.

Family. All interviewed mothers discussed their families as vital sources of support. MoP1 and MoP3 had recently moved. They talked about how difficult it was to not have family nearby. MoP1 said that it was a “struggle,” and MoP3 said that not having family nearby affected her daily life. Similarly, MoD2 and MoD3 found family members a great source of support, but that it was difficult when support had to be provided from a distance (as it did for these moms).

In contrast, MoP2, MoP6, and MoD1 had family nearby. They discussed how comforting it was to have family they trust and who could help from the beginning. MoD1 said that her mother, who lives less than an hour away, was “vital to (her) operation,” particularly because her mom was familiar with “all the sound stuff.”

Spouses. Mothers who feel happy and supported in their marriages demonstrate better parenting skills (Simpson, 1999). Furthermore, spousal support may act as a buffer against prenatal and postpartum stress (Goldstein, Diener, & Mangelsdorf, 1996). Seven of the eight interviewed participants, and three of the four MoDs, positively described their husband’s support. MoP1 said:

I’m not going to kid myself; I’m definitely the primary caretaker ... [but] he’s great. He’s really good with her and always willing to help out.

MoP2 said that her husband was “really good” with the children. MoP3 said that she and her husband were “good supports” for one another. MoP6 said that her husband was “a fantastic husband and ... dad.”

Parents of children with disabilities have described spousal support as the most vital type of support (Abbott & Meredith, 1986). MoD1 said that her husband was a good source of support, and when asked about her husband, MoD 3 stated:

[S]ometimes I just don't know that I have enough energy to do it ... sometimes I am resentful that I'm the working parent ... [but] ... we're best friends and eventually we talk about whatever is bothering us [P]erhaps it could be better, but ... it works out usually.

MoD4 said that she was the “emotional one” and her husband was the “rational” one, but that she and her husband were a “pretty good team” and a “great support system for each other.”

MoD2, however, revealed a different picture:

Well, it takes some people longer to adjust. He still hasn't told his other [older] children. ... We were shopping for a car, and when I mentioned that we needed one that would fit a wheelchair, he became upset and said that we wouldn't need that. ... I try to get him to sit next to me when I look at information on the Internet ... but he ignores it. ... [H]e's in denial. ... [H]is support has been ... very limited.

This was of great concern for many reasons, but women caring for children with special needs whose marriages lacked enough support have been shown to be at a greater risk for psychiatric symptoms than women who had more support (Forrest, Standish, & Baum, 1982). This mother, however, seemed to find strength from other sources and did not have impaired bonding.

Friends and Coworkers. Mothers who report having a larger number of people in their support networks are more sensitive caregivers. This may be because when mothers' emotional needs are met, they are better able to focus on their infants' needs (Goldstein, Diener, & Mangelsdorf, 1996). Seven interviewed participants mentioned friends and/or coworkers as important sources of support. MoP1 and MoP3, the two interviewed participants who had recently moved, spoke about the struggle of not having many friends yet. MoP1 had returned to work part-time and had not yet made friends she could turn to for support. Reflecting on where she previously lived, she said, "I came from a place at my old job [where] I had a lot of friends, and a lot of them had young babies, and it would have been different."

MoP3 felt a little more hopeful. She was not planning on returning to work, and she had made friends with some neighbors and had joined a playgroup. MoP4 said that she did not know what she would do without her friends from childhood and church who had babies of their own. It gave her tremendous comfort to know that her daughter's behavior and development were "normal." MoP2 did not mention friends or coworkers as a major source of support, but she did not mention feeling as if that area was lacking.

MoD1 said that friends were helpful, and MoD2 indicated that she had "fantastic"

support from her coworkers and boss. In addition, MoD2 said that an online support group dedicated to her son's syndrome—and a newsletter that members of the support group published—were very important sources of support for her. MoD3 said that friends had been very supportive, and she was very much looking forward to joining a parent support group where she could meet people who have children with hearing loss, cochlear implants, and auditory neuropathy. She said that she had met one mother of a child with auditory neuropathy who had a cochlear implant and they had seen success with the technology. MoD3 also said that although her husband was “better suited” to staying home, she at times felt jealous that he had more interaction with other parents as a result of taking their son to early intervention.

Professionals. Relationships with professionals may represent an additional source of stress rather than support (Kirk & Glendinning, 2002). New parents accept that they must work with new professionals, such as pediatricians and childcare providers. With minor exceptions, MoP were satisfied with their pediatricians and childcare providers. MoP1 said that it took a few visits for her to feel comfortable with the pediatrician, and MoP3 switched pediatricians due to a misdiagnosed ear infection. Otherwise, MoP were happy with the professionals who worked with their babies. Two of the mothers of hearing infants had their babies in day care. They worried about their children when they were in day care, but they were both happy and comfortable with the services. Overall, all four MoP were satisfied with the professionals in their lives.

Overall, MoD were more than content with their interactions with professionals, even though many more services were involved in their lives. Mothers of babies with

hearing loss not only have to learn to interact with pediatricians and caretakers but also with professionals they never thought would be in their lives, such as EI providers and audiologists. The manner in which care is provided during the diagnostic period affects the mother's adjustment post-diagnosis (Rahi, Manaras, Tuomainen & Hundt, 2004). When education is paired with compassion and emotional support, parents feel more able to bond with and care for their children with special needs. Help given by professionals should be as effective as possible and informed by a sensitive understanding of what parents are experiencing (Kirk & Glendinning, 2002).

MoD1 said that she was "quite happy" with all of her services. She said that "all the audiologists [were] great," and that she and her husband especially liked their auditory/verbal therapist (AVT), because she was creative, came to their home, and emailed them. MoD1 described her AVT as "the most important person this year." She also had services at a total communication (TC) center. She said that she liked all the professionals personally, but did not like the feeling that professionals from the auditory/oral center and professionals from the TC center did not like one another simply because of the differences in communication philosophies.

MoD2 shared that her favorite professionals were "people who [understood] the emotional piece." She said that some people treated her son like he was a "case on a piece of paper and "hardly ... looked at him," while others went "straight to him." She said it was upsetting to feel rushed or to feel that professionals were focusing on their "bottom line." MoD2 also said that at first she was just anxious to get information, and that she later

realized that all professionals had information, but not all professionals understood when and how to relay that information. MoD3 echoed this sentiment:

[The EI specialist] always tells us she's not a therapist or a counselor, but she actually often fills that role for us. We get to talk about our feelings and events related to (our son's) disability. ... [T]hat's the thing that's given me the most comfort.

Two EI teachers worked with MoD3's son. She said that one teacher's visits were more enjoyable, because she did not criticize the parents or "slap ... knuckles." Also, the two teachers came from centers with differing communication philosophies. The less enjoyable teacher made them feel as if they had to follow her communication philosophy at all times.

MoD4 said that the most important quality to her was feeling that services were flexible and tailored to her family's specific needs, and were not "cookie-cutter." She said that it felt as if some professionals were giving "a presentation rather than an interaction," whereas some professionals assessed what she and her husband already knew and made an effort to have a "dialogue." She said that she felt very lucky because her county had more resources than she could use. Her daughter had been seeing the same county therapist since she was 4 months old (for a total of 13 months). MoD4 said that going to a nearby Auditory/Oral center and seeing "kids who were born deaf and were speaking, singing, and (sounding) normal ... acting like regular kids" gave her and her husband "a vision" for who their daughter could be.

MoD4 especially appreciated that her audiologist and speech therapist worked

together and communicated with one another about her daughter. MoD4 said that this coordinated team approach made a big difference. She said that the audiologist was “terrific.” MoD4 said that although, especially at the beginning, the audiologist probably thought MoD4 was “crazy” or did not agree with MoD4’s concerns, she appreciated that “without giving us false hope, she (the audiologist) honored what we were observing rather than saying, ‘It’s not happening ... she’s not hearing it.’”

Compassionate and organized early interventionists were important to these mothers. Forrest et al. (1982) reported that parents appreciate when the practitioner expresses interest and attempts to offer support, even when professionals realize nothing could be done to “cure” the child. They found that professionals involved in the primary care of the family should discover how each member of the family is dealing with the diagnosis. Ensuring that support and intervention programs are being accessed and offered, as well as having positive interaction with the staff when the diagnosis is made, affect the mother’s bond.

Overall, participants had good support systems. Although no one had support from all possible areas (family, spouses, friends/coworkers, and professionals), strong support from a couple sources seemed to be sufficient.

Coping Strategies

Most new parents are unprepared for the challenges of parenthood (Deave, Johnson, Ingram, 2008). The idea of having a baby becomes romanticized during pregnancy; consequently, the reality of how difficult the first months can be is often

overwhelming. How parents cope with these challenges impact the quality of their marriages and relationships with their newborns (Deave, Johnson, & Ingram, 2008). Effective coping strategies can alleviate the effects of elevated stress and prevent stress from negatively impacting relationships. The use of positive, active coping strategies helped all participants manage the stressful event of having a new baby. Information seeking and reframing were coping strategies that emerged in many interviews.

Information Seeking. Information seeking is an active coping strategy that turns an unknown, stressful event into something less scary and more familiar (Ravindran, Griffiths, Merali, & Anisman, 1996). One of the greatest needs that all new parents have is acquiring information related to the challenges of having a newborn (Miller & Sollie, 1980). Seven participants used information seeking. MoP1, MoP3, MoP4, MoD1, MoD2, MoD3, and MoD4 sought out information by joining play groups or talking to friends who had recently had babies. Furthermore, MoD actively obtained information about hearing technology, communication modalities, communication development, and other topics related to hearing loss. MoD4 discussed how she and her husband learned about education options and cochlear implants:

We don't know anyone that's deaf, we had no idea what it's like to raise a deaf child seeing those kids (at the school for the d/hh) gave us a visual for what could be with her we watched literally everything we could get our hands on (regarding cochlear-implant activation) that helped just because we knew what to expect ... of just about anything

Reframing. Reframing is an active coping strategy in which people redefine a negative situation into a more positive one (Ravindran, Griffiths, Merali, & Anisman, 1996). All MoD who were interviewed used reframing. MoD3 talked about how glad she was that her husband decided to stay home with their son. She said “the plan ... was to be dropping him off at daycare ... I think we would have been distant to the baby.” One way to reframe her son’s hearing loss was that it drew her closer to her son. MoD1 and MoD4 mentioned that they were glad that they found out their children’s hearing losses were genetically caused. They were positive about the likelihood that hearing loss was the only disability. In addition, MoD1 said that she probably would not have invented so many (listening) games for her twins if her son did not have a hearing loss. She liked being so aware of her babies’ specific progress. MoD2 knew that some people would think of having a child with multiple disabilities as a “burden”. She consciously thought of him as a “gift” instead. Effective coping strategies, like information seeking and reframing, help prevent depression from developing, particularly in people experiencing high levels of stress (Scott, 2001). If these mothers continued using effective, active coping strategies, they would be more likely to avoid depression and impaired mother-infant bonding.

Expectations

Not only do mothers have to reconcile their idealization with the reality of their babies, but they also have to reconcile the ideas they had of motherhood during pregnancy with the reality of what early motherhood is like (Klaus, Kennell, & Klaus 1995).

Discrepancies will always exist between the imagined infant and the actual infant. How

mothers resolve these discrepancies impact how they bond to their infants. This section discusses mothers' general concerns, how mothers' expectations relate to and affect their interactions with their infant, worries over hearing loss cause and diagnosis, anxiety regarding cochlear implants and communication goals, worries about character development, and their thoughts about their child's future.

General Concerns. All mothers worry about their children. However, when concerns or worrying thoughts preoccupy a mother, she is at risk for impaired bonding. Mothers of hearing babies divulged some worrying thoughts, such as not spending as much time with the second child as with the first, concerns over safety, and worrying about the child's care when the mother could not be present. Fortunately, none of these mothers felt as if their worries affected their enjoyment of their baby. Although some of the concerns and worries of mothers of d/hh babies were similar to those of the mothers of hearing babies, mothers of d/hh babies had additional concerns as well.

Mother-Infant Interactions. Although reconciling imagined with real interactions under normal circumstances can be tumultuous and stressful, all MoP and one MoD discussed that they either did not have many preconceived notions or that interactions were as they imagined they would be. MoP participants talked about typical hopes and frustrations, such as "hoping that she (her daughter) just wasn't a completely obnoxious, colicky baby."

During pregnancy, mothers imagine interacting with their typically developing babies. When the mother's mental picture of her baby is challenged because of a disability present at birth, bonding may be affected (Klaus Kennell, & Klaus, 1995). Two of the four

MoD participants who were interviewed indicated that there was a larger gap between their imagined and actual infant. MoD2, whose son has multiple disabilities, reflected on this challenge: "...[W]hen you're pregnant ... you have an unrealistic view ... [I] thought I was going to deliver a healthy child Most kids A's age would be crawling around ... [M]y interaction with him is different in that way." Even though her son was 11 months old, MoD3 said, "[H]e's not ... speaking back to me like a normal kid would. I've slowed down my attempts to input words into him"

MoD1, MoD2, and MoD3 stated that their interactions with their infants were sometimes controlled by communication and other developmental goals. Even though these mothers indicated that they were not always able to totally relax while interacting and playing with their babies, they were able to reframe their experiences in a positive light. Although MoD3 indicated that her interactions were altered as a result of her son's hearing loss, she said that they were "richer than ... imagined." MoD4 said that her interactions with her child were "exactly the same" as she imagined they would be. It is worth noting that at the time of the interview, MoD4's daughter was 17 months old, bilaterally implanted, and had age-appropriate communication skills. Her memory of the months immediately following the birth may have been overshadowed by the positive progress her daughter was making at the time of the interview; however, if interactions had been particularly stressful or disappointing MoD4 would have likely remembered those difficulties.

Worries Over Hearing Loss Diagnosis and Cause. Most hearing parents have never met a deaf person; consequently, what having a d/hh infant means is entirely unknown.

All four mothers of d/hh babies who participated in interviews talked about feeling anxious when their babies did not pass the initial hearing screening. Each mother was told, however, that the reason for the “failure” was likely fluid in the baby’s ears and not hearing loss. Salient points of concern for MoD were at the time of diagnosis, wondering why their child was d/hh, considering cochlear-implant surgery, and worrying about achieving communication goals. All four mothers of d/hh babies discussed feeling upset when the hearing loss was confirmed. They used words like “shock,” “blue,” “lethargic,” “guilty,” and “crying.” Each mentioned feeling overwhelmed by not knowing anything about hearing loss.

All four d/hh babies’ hearing loss was a result of genetic factors. Two mothers in particular (MoD2, MoD3) discussed worrying about being responsible for their child’s hearing loss. They worried that they had done something wrong that resulted in their child’s hearing loss. MoD3 said: “[D]id I not take good enough care of myself during pregnancy? [W]as it the antibiotics they gave him when he was premature ... or lack of oxygen to the brain ... when he was delivered because I didn’t push hard enough?” She said that learning there was nothing she could have done to prevent the hearing loss made her feel better. Learning the reason for their child’s hearing loss can help to reduce parents’ anxiety. MoD1 reported gaining some peace of mind upon learning that her son’s deafness was due to Connexin 26, a mutation on the 13th chromosome. Connexin 26 causes hearing loss, but not additional disabilities. Therefore, MoD1 thought that once her son received his cochlear implant and caught up with his speech and language development, everything would be okay.

MoD2 echoed that sentiment. At the time of her interview, MoD2 was pregnant with her second child. She acknowledged that there was a 25 percent chance that her second baby would be deaf. While she did not wish for hearing loss, she felt that it would be okay if her second child were deaf. The prospect was not as scary to her because it was no longer unknown. In addition, because her daughter's speech and language skills were age appropriate, MoD2 felt as if typical development would be attainable if her second child were also deaf.

MoP6 said that she did not worry too much about her daughter having hearing loss, but that her participation in the study made her think about what life would have been like if her daughter were d/hh:

[B]ecause you're doing this study and I was involved in it, it's made me think how grateful I am that she can hear, because there's so many things that we do that ... if she couldn't hear would be so hard, like if she's upset I can calm her down by talking to her.

This quote demonstrates what many mothers may think before they are knowledgeable about hearing loss. MoD seemed to understand that they could use verbal communication to soothe their children, but they had been participating in early intervention for several months. MoP6's perspective may represent how many mothers feel at the time of diagnosis.

Cochlear Implants. Literature suggests that, while the time immediately after

diagnosis is extremely stressful for parents of d/hh infants, they experience a tremendous amount of relief after the initial cochlear-implant fitting (Burger et al., 2005). This theme was found in the current study as well. Three of the d/hh babies of MoD were eligible for cochlear implants. These three mothers had concerns regarding cochlear implants; however, the substance of worries of MoD1, MoD3, and MoD4 depended on their child's stage in the cochlear-implant process. The son of MoD2 was not eligible for a cochlear implant because his loss was not severe enough. MoD1's son was nine months old at the time of her interview. He had gone through cochlear-implant candidacy, and she anticipated that doctors would schedule his surgery soon. She was worried about the surgery, but very hopeful about the future regarding her son's development. MoD3's son was 11 months old at the time of the interview, but he was not as far along in the cochlear-implant process. She was anxious about the surgery but hopeful about the prospect of her son learning to speak. MoD4's daughter had been bilaterally implanted for eight months, and her communications skills had become commensurate to her hearing peers. MoD4 was positive about the experience and was very excited that her daughter would be able to attend "regular" preschool.

MoD1 was very worried about the possibility that her son might become sick prior to the surgery, which would result in having to reschedule the cochlear-implant surgery. She was not particularly worried about the surgery itself at the time of the interview. She anticipated having more anxiety about the cochlear-implant activation. The daughter of MoD4 was 17 months old at the time of the interview; she had been bilaterally implanted at 11 months, and had age-appropriate speech and language skills at the time of the

interview. MoD4 was confident that her daughter would be able to attend a typical preschool with fairly minimal services. She reflected on how her worries had changed over time:

I think initially that when we found out that she was deaf our biggest concern was ... how it would affect her life and our lives. ... [N]ow ... she's on par on speech ... [and] ... receptive and expressive language. ... Just continuing private speech therapy once or twice ... a week (next year) and just regular preschool.

MoD4, the only mother whose child already had received a cochlear implant, said that “handing her over to someone for a major surgery” was the “hardest part.” She said that the cochlear-implant activation was not concerning. The reason for this was twofold: (1) MoD4 looked at any hearing sensation gained from the cochlear implant as a “bonus,” and (2) she and her husband had sought a tremendous amount of information regarding typical reactions and development of newly implanted babies. She said that they did not have any “grand delusions” and were “pretty relaxed,” because they “watched everything [they] could get [their] hands on.” MoD4 said that helped, because they “knew what to expect of just about anything.”

MoD3, however, was more anxious about the activation. Her son was not yet implanted, and was deaf due to auditory neuropathy. This mom did not have the same wealth of information at her disposal as MoD4 did, so the future was more unknown. At

the time of her interview, MoD2 was approximately two to three months away from her son's cochlear-implant surgery. She acknowledged that she would likely feel anxious when the time came, but she was not yet feeling overly worried. The mothers of children who were in the cochlear-implant process had varying concerns. Those concerns seemed to depend on the amount of information the mother had. The more that was known, the less worried they were. In addition, successful communication development seemed to mitigate the amount of anxiety mothers experienced.

Communication Goals. Some mothers of d/hh infants seemed preoccupied by achieving communication goals with their children. MoD1 occasionally became exasperated by trying to “get sound into” her son's head all day long. She said that she always had a mental checklist of goals that she should incorporate into everyday activities. She said that although it helped to know that other people had tougher things to go through, she did wonder when things would get easier. She talked about the struggle between knowing that she needed time away from her children and not wanting to leave them with someone who was not “trained” with the “hearing stuff.” MoD1 “finally” hired two babysitters, both of whom were graduate students in communication disorders. Her mother, whom she was also “training” in the “techniques,” was the only other person she trusted with her son. She said that she felt no one could do as good a job as she could, and that he was not “getting all the sound stuff” he needed while she was gone. Before she learned of her son's hearing loss, MoD1 was planning to go back to work when her twins were six months old. At the time of the interview, she had changed the timeline for returning to work to when they were 18 months of age, because she did not want anyone

else to be responsible for her son's auditory, speech, and language development. MoD1 no longer wanted to return to work at all, but she did not know if this was financially possible.

MoD3 talked about her worries regarding her son's future communication development:

I'm not gonna stop worrying until his speech is ... normal or nearly normal. ... [T]he technology is not 100 percent guaranteed. ... What if he is a deaf mute? ... I feel like I can't wholly enjoy baby mode. ... I'm anxious as to whether I'm doing enough to help my son grasp language and communication.

Although MoD3's son was only 11 months of age, she was quite anxious about his verbal communication. She blamed his hearing loss for his "lack" of spoken words. She was very much looking forward to the time when her son had his cochlear implant and was speaking. In contrast, MoD4 was more relaxed about communication because her daughter was developing age-appropriate skills.

Character Development. MoD1, MoD3, and MoD4 discussed their children's character. MoD1 said that she was going to raise a "confident" and "outgoing" son. MoD3 hoped her son was comfortable with his implant, and said she would let him grow his hair long to hide his external cochlear-implant equipment. MoD4 said that her baby "is not going to be a kid that goes to preschool and realizes that she is different and shrinks." Although the mothers of the hearing children discussed their wishes for their children's happiness, they did not reveal specific thoughts related to their children's confidence or

lack thereof. It is possible that MoD feared that hearing loss would impact their child's self esteem.

Expectations at Five Years Old. All parents envisage their children's milestones and what their families will look like during those points in the future. Imagining these times can be stressful for families of disabled children; understanding their new situation and building different expectations can be challenging (Russell, 2003). At the end of the interview in the current study, participants were asked to imagine their children in the future at five years old and then again at 18. The assumption was that responses would reveal how hopeful participants felt regarding their child's future.

When asked to imagine their children at five years of age, mothers of hearing babies said: MoP1: "I wonder what kind of kid she's going to be.... If she plays sports, what kind of sport is she going to play? ... Or where is she going to go to college?"

MoP2, who had not been particularly loquacious during the interview, did not hesitate when asked about her son at five years old:

I see a blond-haired ... boy with a lot of energy. I can see him running around in the backyard with his sister and ... trying to play catch with his dad and talking up a storm. ... Your typical five-year-old boy—probably scrapes all over his knees.

MoP3 said that she thought her son would be "athletic" and "a very social kid." MoP4 said that her daughter would "probably be like she is now, very active, she'll wanna run around,

play, and climb all over stuff. ... I think she'll be one to take stuff apart to see how it works."

When asked to picture her son at five years old, MoD1 stated:

I would hope that he is doing really well! I assume that there would be things that we are still working on. If he needs an hour of resource ... this ... doesn't worry me. I hope that he is mainstreamed! ... I hope he is having fun doing kid stuff. I hope that he is outgoing, and we're going to try to get him involved in sports. I know that kids with cochlear implants go through some social awkwardness. I just want him to be a happy kid and do normal kid stuff. I want him to do typical five-year-old stuff.

MoD3 had similar sentiments: "I see a child in kindergarten ... who is using technology well, and able to go through the alphabet and speak in sentences. I hope he'll still be playful and inquisitive. I think he will be."

MoD4 said she saw:

[The] same kid I see right now. I think it's in her general personality to be outgoing and friendly, and she has never met a stranger ... and I think the fact that we are pretty relaxed about [her cochlear implant] has made her relaxed about the whole thing. And her implants are bright pink, and

we chose those because we didn't want to make her feel like we are trying to hide them. We have found that it makes people more open to asking us questions. She hears us explain it to people, and we hope she will feel empowered, to not be an advocate for deaf kids necessarily, but to be an advocate for herself: "Oh, I didn't hear very well when I was born, and this is what these are and this is what they do and it's no big deal." That just kind of seems like her personality already.

All mothers hoped for a future in which their children were happy and healthy as circumstances would allow; however, the expectations and hopes of MoD were more specific. Their responses included words like "communication," "technology," and "mainstream."

This is greatly contrary to the sentiments of MoD2, whose son has multiple disabilities:

It's so hard for me. We have this online site where other families with children with the same syndrome chat and post pictures. So, I see pictures of other children at five, 10 years old. So I sort of have a picture in my mind, but this syndrome is so varied. Some of the children at 10 years old are walking, and some are in wheelchairs. So, it's hard to

know where A will be. Some children with this syndrome don't live that long, so it's hard. It's hard to think about the future, and that's kind of what got me through the first few months was people telling me not to worry about the future. Not focusing on what's going to happen tomorrow, but what I had to do to get through today.

When asked if this perspective helped her, she said:

Yeah. The first few days, I couldn't stop crying thinking about (his) funeral ... And people told me that I couldn't do that, [that] I should focus on what I needed to get through today.

Counseling mothers who have to contemplate their child's shortened life span is relatively uncommon for EI specialists working with mothers of d/hh babies. However, nearly half of all children born with hearing loss have at least one additional disability. Therefore, assessing this mother's challenges will help practitioners meet the needs of other mothers with multiply disabled d/hh children.

Expectations at Eighteen Years Old. Some mothers also pictured their children at 18 years old. MoP3 and MoP4 were able to imagine their children 17 years in the future. MoP3 said that her son would be a "schmooser." She saw him being "class president" and an "extrovert." She hoped that he would continue to be outgoing. She said that she had spent her life as an introvert and she firmly believed that life is easier for gregarious people.

MoP4 said that she hoped her daughter “has a lot of self-confidence and that she can do her own thing without worrying about what people will think,” and “hopefully she’ll be graduating from high school and ready to go on to college.... I hope she’ll be nice and kind and honest.”

Three MoD offered their thoughts on what their children would be like at 18 years old. MoD1 said:

I hope that he is heading to college, and he is really confident and self-assured, and that he is comfortable with his implant.

I hope that he is independent and happy! I think my hopes for him at 18 are the same for his [twin] sister at 18.

MoD3 said, “I hope that he’ll be graduated from high school, selecting what college he wants to go to, and feeling like a normal kid.” MoD4 said that at 18, her daughter would “definitely” be heading to college and doing “anything she wants.”

Although MoD participants’ worries were different qualitatively and quantitatively than the worries of MoP participants, the concerns did not preoccupy any of these mothers to the point where they were not able to enjoy their babies and bond normally. Overall, participants were hopeful about their children’s future. Even MoD2, whose son’s life expectancy is uncertain, was positive about her son and his skills. MoP and MoD shared many of the same hopes and concerns for their children’s future. Mothers of d/hh babies had more specific expectations, particularly regarding communication skills. But, generally, all eight interviewed participants wished for happy, healthy children.

CHAPTER FIVE

DISCUSSION

Results from the current study showed that no study participants were bonding abnormally with their children. In addition, there were no significant differences between mothers of hearing babies and mothers of d/hh babies on the three Postpartum Bonding Questionnaire subscales: Impaired Bonding, Rejection and Anger, and Anxiety About Care. First, this chapter discusses the how risk and protective factors might impact mother-infant bonding. Next, DQ, PBQ, and interview results are discussed. Comparisons among the assessments are made as well. Finally, implications and future directions are presented.

Risk and Protective Factors

As Zeanah (2000, p. 109) aptly wrote, “risk factors tend to cluster together and exert their effects synergistically.” Having one risk condition increases the risk of having another, and the amount of risk factors is a better predictor of deleterious outcomes than any particular combination of risk factors (Zeanah, 2000). Furthermore, risk factors combine with protective factors to create a cumulative effect. It was hypothesized that risk and protective factors would impact bonding. The most dangerous risk factors for mother-infant bonding and infant development are poverty, exposure to violence, early and unplanned parenthood, and hospitalization for prematurity or other serious health conditions (Cassidy & Shaver, 2000).

Not all factors were known, especially for participants who were not interviewed. It seems as though these mothers did not have many other risk factors in addition to their baby's disability. In fact, they had several protective factors. All participants had the protective factors of spousal support, social support, few children, education, and race advantage. When mothers have many risk factors, such as single parenthood, poverty, and a history of mental illness, and not many protective factors (like additional support), having a d/hh infant could cause enough stress to interfere with mother-infant bonding. Specific risk and protective factors will be discussed as they relate to the DQ, PBQ, and interview data.

Demographic Questionnaire (DQ)

Participants in the study were not a representative sample of mothers in the United States. All mothers in the current study had some post-secondary education and three (21.43 percent) had doctoral degrees. Their degrees were as follows: one had some college (7 percent), two had associate's degree (14.29 percent), five had bachelor's degree (35.71 percent), three had master's degree (21.43 percent), and three had doctoral degrees (21.43 percent). The doctoral degrees broke down into two groups: one J.D. and two Ph.D.s. A report from 2008 (U.S. Census Bureau) showed specific data for women 18 years and older: 17.68 percent had some college, 9.57 percent had an associate's degree, 19.17 percent had a bachelor's degree, 7.73 percent had a master's degree, and .87 percent had a doctoral degree. It is possible that mothers with more education, and thus greater financial resources, feel as if they have more time to participate in a study. Poverty is a risk factor

that is associated with many additional challenges: reduced community support, impaired family structure, reduced maternal psychological resources, and alterations in parenting attitudes and behaviors (Aber, Jones, & Cohen, 2005). Although socioeconomic status data were not collected in the current study, it is assumed that no participants were living in poverty. This assumption is based on the participants' education levels.

Single parenting is a risk factor that is associated with many detrimental effects in children, including behavior problems and poor academic performance (Beckwith, 2005). Approximately 26 percent of all parent-child situations are composed of a single mother and her child or children (U.S. Census Bureau, 2003). This is contrary to the sample group in the current study, where all participants lived with the infant's father. Twelve participants were married, and two had long-term partners. However, nationally, mothers' education levels are related to their partner's presence; the higher the mother's education level, the more likely she is to be married or have a live-in partner (U.S. Census Bureau, 2008). If the current study had included an educationally more representative sample, it is likely that more participants would have been single mothers. Again, mothers with husbands or partners are more likely to feel they have the time and emotional reserves to complete study assessments.

The racial demographics of the current study were close to the national averages. Caucasians in the current study comprised 84.62 percent and Hispanics comprised 15.38 percent of the study population. Nationally, Caucasians make up 74.1 percent of the nation and Hispanics comprise 14.7 percent (U.S. Census Bureau, 2008).

The number of newborns nationally with some form of congenital hearing loss is one to six per thousand; newborns with profound loss average one to two per thousand and the others have milder forms. In the current study, three infants had profound loss, one had a moderate loss, and one had a mild loss. One had a profound loss in one ear and a mild loss in the other. There are some reasons that could account for the incongruities. Although false negatives are quite rare (1 in 10,000), UNHS is less likely to identify babies with mild losses as opposed to more severe losses. This is because some screenings are set to detect losses over 40 dB only. Screenings set at this level will miss babies with mild losses. Furthermore, parents of babies with mild loss may be less likely to be enrolled in EI programs. All but one MoD in this study were recruited from EI centers; the other mother was recruited from a diagnosing audiologist. Although EI referrals for families of babies with mild-moderate losses have increased, anecdotal evidence suggests they are not referred proportionately to families of babies with severe-profound loss.

An intention of the study was to compare groups on marital status, education level, ethnicity, and other demographic variables. However, due to the homogeneity on demographic variables, no differences existed, so those tests were not conducted.

The Postpartum Bonding Questionnaire (PBQ)

No mothers in the current study experienced impaired bonding as measured by the PBQ. Furthermore, no statistically significant differences were found between MoP and MoD on any of the PBQ subscales: Impaired Bonding (IB), Rejection and Anger (RA), and Anxiety About Care (AAC). Due to a small sample size, the statistical test had low

power and could not capture these nuances. It is difficult to detect statistically significant differences, even if they really exist, when power is low (Gravetter & Wallnau, 2005). Although there could have been significant differences between the two groups of participants that were not uncovered, interview data seem to support the idea that there were not significant differences between the groups. That MoD did not experience impaired bonding, and that their bonding was not significantly different from MoP, is encouraging. Although population predictions cannot be made from the current study sample, these results illustrate that the early knowledge of a hearing loss did not disrupt the mother-infant bond for mothers with few risk factors.

All participants responded identically on items 6, 9, and 15. On item 6, “This baby does not seem to be mine,” participants answered “never.” On item 9, “I feel happy when my baby smiles or laughs,” participants answered “always.” On item 15, “I resent my baby,” participants answered “never.” The lack of variability in response to these items lends further weight to the notion no mothers in the group had bonding challenges with their babies. The two groups of participants differed significantly from one another in response to one PBQ item: “The baby cries too much.” Mothers of hearing babies were more likely to feel as if their babies cried too much. Five out of six MoD answered “never,” and one answered “rarely.” Conversely, only one MoP answered “never,” four answered “rarely,” two answered “sometimes,” and one answered “quite often.” Broader issues related to the hearing loss may overshadow a challenge such as crying. Additionally, three of four MoD who were interviewed indicated that their child’s hearing loss made them feel closer to and/or more protective of their children. Consequently, MoD may be

more likely to rate crying as a minor annoyance when placed against the backdrop of the diagnosis of a disability. It is possible that, on a larger scale, issues related to hearing loss may minimize other typical motherhood challenges. However, in the current study, the only significant difference was related to crying so no other comparisons could be made.

Interviews

Eight participants, four from each group, were interviewed. Four major themes emerged: (1) developing feelings to infants, (2) sources of support, (3) coping strategies, and (4) expectations.

Developing Feelings Toward the Infant

Bonding. As mentioned in the literature review, the widespread implementation of UNHS has changed a parent-initiated event into an institution-initiated event. In the past, parents were suspicious that their child was d/hh prior to the diagnosis and had likely already bonded with their infant. When the news is unexpected, it has the potential to disrupt the mother-infant bond. Etizio-Carasso and Oppenheim (2000) found that the strength of the mother-infant bond can influence communication skills at ages 4 and 6 years. Although infant communication skills were not assessed in the current study, the fact that mothers were bonding normally to their infants heightens the chance that strong communication skills will develop.

How mothers of babies with false positives bond to their babies was part of the original study inquiry. Separating the effects of inconclusive hearing screening results

from the effects of a diagnosis of hearing loss would help clarify what impacts are specific to families of d/hh children. Some researchers have discovered that parents experienced anxiety related to their baby not passing UNHS, especially when the baby was tested more than once and still did not pass (Magnuson & Hergils, 1999; Poulakis, Barker, and Wake, 2003). However, parents reported that anxiety resolved once the baby was found to be hearing. Direct comparisons cannot be made to the current study as previous researchers did not include parents of d/hh babies and no MoFP participated in the current study. Nevertheless, MoD did reflect on the time period between receiving inconclusive results and confirmation of hearing loss. Mothers who were aware that their babies were tested more than once expressed some anxiety; however, all MoD who were interviewed said that any major anxiety they felt came after the diagnostic testing was completed and hearing loss was confirmed. This indicates that the stress parents feel during the peri-diagnostic and diagnostic periods is a result of the reality of hearing loss in their baby, not just the possibility of this outcome.

Number of Children. People tend to feel more comfortable and thus, less stressed when confronted with issues with which they are familiar. An unexpected theme that emerged from the interviews was the effect of the number of children a mother had. For example, MoP who had an older child in addition to the baby said that having the second baby was less daunting and that they bonded to the second baby more quickly than to the first. No MoD who were interviewed had older children; one MoD had twins. It would be interesting to assess if having an older child would impact how a mother bonded to her d/hh infant. Additionally, the mother of the twins, one d/hh and one hearing, mentioned

that she sometimes felt as if she paid too much attention to her d/hh child at the other baby's expense. However, MoD4, who was pregnant with her second child, was relaxed about the prospect of having another d/hh child.

Impact of a Disability on Bonding. Previous studies that made assumptions about bonding of parents to their children with disabilities assessed stress levels. Because high levels of stress are correlated with insecure bonding (Jarvis & Creasey, 1991, Pipp-Siegel et al., 2002), when previous researchers have assessed stress, they have made conclusions about bonding as well. Researchers have reported that parents of children with special needs are more stressed than typically developing children (Fuller & Rankin 1994; Troster, 2000; Leyser et al., 1996). The current study aimed to directly probe the concept of bonding, rather than using stress as a proxy. Although more research is needed, the current study suggests that mothers of d/hh babies are not bonding abnormally to their children.

MoD1 and MoD3, and MoD4 discussed their children's personality and self esteem development. Although the mothers of the hearing children discussed their wishes for their children's happiness, they did not reveal specific thoughts related to confidence or lack thereof. MoD were likely more specific about their hopes and fears because they were aware of the typical challenges that d/hh children face. They hoped that their children would achieve goals typical of hearing children. MoP6 said that her participation in the study made her contemplate what life would have been like if her daughter were d/hh. She said that she was "grateful" because many things, like bringing her daughter comfort by talking to her, would be "so hard." This frame of mind likely reflects the reaction of most parents when they learn of their child's hearing loss.

Mother-Infant Interactions

Anecdotal evidence suggests that some parents may alter their behavior towards their baby when they learn of the baby's hearing loss. For example, the researcher has interacted with some families who mentioned that they did not talk or sing to their d/hh babies as much as they wanted to because they did not see the purpose of doing so. This phenomenon was not expressed in the current study. The d/hh babies in the current study were diagnosed in the first few months of life; consequently, parents have been encouraged from early in their child's life to utilize different methods to develop their child's communication skills. They are coached to develop optimal communication skills, including singing and talking to their babies.

All four MoD who were interviewed indicated that they spoke to their d/hh child as they would a hearing child. However, MoD1, MoD2, and MoD3 admitted being extremely aware of communication goals while interacting with their infants. They were able to enjoy interacting with their infants most of the time, but used phrases like "always trying to get sound into his head" and "have a checklist in my head while talking to him." This vigilance is likely to help advance communication skills; and apparently did not impair the enjoyment that mothers felt interacting with their children. In fact, one mother described her interactions as "richer" than she imagined, even though she imagined a hearing infant.

Sources of Support

Previous literature revealed that the amount of stress that parents of d/hh children experience is significantly related to the amount of support parents receive (Pipp-Siegel, Sedey & Yoshinaga-Itano, 2002). Furthermore, support directly impacts mother-infant bonding (Lester, Boukydis, & Twomey, 2000), and some researchers have suggested that parents of children with disabilities receive more support than parents of children without disabilities and thus have a greater buffer against impaired bonding (Peterson, 1984; Pipp-Siegel et al. 2002). Conversely, other researchers have found that mothers of d/hh children had less contact with support people and smaller social networks as compared to mothers of hearing children (Quittner et al., 1990). Conclusions regarding impaired bonding as it relates to lack of support cannot be made from the current study. However, although causation cannot be assumed, it is clear that mothers in this study, both MoP and MoD, were forming healthy bonds to their children. The possibility that the healthy bonds were related to ample support should be considered. Participants found that the bulk of their support came from family, spouses, friends, coworkers, and professionals.

Family. All interviewed mothers identified their families as important sources of support, whether the support was offered in person or from a distance. Mothers who had local family support spoke of the comfort they felt when they were able to leave their infant with someone they could intimately trust soon after birth. This seemed particularly important for MoD1, whose mother helped care for the infant twins. MoD1 said that she did not feel comfortable leaving her d/hh baby with anyone who was not “trained” in how to interact with her son in a way that would foster his communication development. MoD2, MoD3, and MoD4 did not have family close by. MoD3’s husband decided to quit

work and be a stay-at-home father. Although this helped, MoD3 mentioned that she did not want to leave her son with someone who was not well-versed in hearing loss. MoD4 stayed at home with her daughter, and she mentioned that initially she did not want to leave her daughter “with just anyone.” Because her daughter was speaking and developing age-appropriate communication skills, she was becoming more comfortable with the idea. Her additional worry was leaving her daughter with someone who was competent at managing cochlear implants.

Spouses. Spousal support may be the most effective defense against postpartum stress (Abbott & Meredith, 1986; Goldstein, Diener, & Mangelsdorf, 1996). All interviewed participants were either married or living with their infant’s father at the time of the interview. Seven participants, all but MoD2, identified their spouses as essential and strong sources of support. MoD3 discussed how she felt lucky, but at times resentful, that her husband stayed at home with their son. Data vary, but the U.S. Census Bureau (2008) estimates that about 25 percent of all children aged 0-4 with an employed mother have a stay-at-home dad. This suggests that it is not uncommon for primary parent receiving EI services to be the father, so early-intervention providers should be prepared to provide services to fathers as well.

Professionals. Young and Tattersall (2007) discovered, through interviews, that caregivers of d/hh children felt that the benefits of receiving intervention as early as possible outweighed their feelings of grief, shock, and loss. On the other hand, a few caregivers were not as positive about early diagnosis, especially when they had experienced delays in EI enrollment. No participants from the current study expressed any

major frustrations with their EI services, although other researchers have found that some EI programs are not equipped to deal with children younger than 18 months of age (Kennedy et al., 2005). All MoD who were interviewed valued their EI services. Like the participants in the Young and Tattersall study, MoD expressed hope that EI services would help their children avoid abnormal development and compete in the mainstream.

Professionals, including medical personnel, may help mitigate the anxiety that families experience in stressful situations. It was found that when physicians offered emotional support, even when there was nothing the doctors could do to improve the child's "condition," families were positively impacted. In addition, Rahi et al. (2004) found that families of visually impaired children were better adjusted one year post diagnosis when care had been provided compassionately. That trend was found in the current study as well. When information was offered from early interventionists, audiologists, and surgeons in a sensitive way, mothers were more comfortable and able to cope. In addition, feeling as if intervention was tailored to their specific needs rather than "cookie-cutter" improved mothers' experience with EI. When a child is diagnosed with a hearing loss, the experience is unique to the parents. It is possible that their grief could be invalidated if they feel as if professionals are providing services in a routinized manner.

One assumption was that the manner in which the news of a positive UNHS test is communicated to parents may influence how much stress parents experience. In the current study, only interviewed participants were asked about how this news was communicated. The stress levels of interviewed mothers of d/hh babies seemed to be related to the number of tests their babies "failed" at the hospital. If the babies were

retested before leaving the hospital and still did not pass, worry increased. However, mothers expressed an overall low amount of anxiety because they were told that the “failure” was likely a result of fluid in the middle ear. Mothers showed mixed feelings about the misleading information and expressed that it made them feel less prepared for the final diagnosis. While it would not be helpful to worry parents needlessly, it might be useful for parents to know that there is a real chance their child may have a hearing loss.

Coping Strategies.

Coping strategies refer to methods that people use to manage and defuse stressful events (Ravindran, Griffiths, Merali, & Anisman, 1996). A person’s reaction to a stressful event is determined, in part, by the magnitude of the event and the circumstances of the person’s life when the event occurred. A correlation exists between parents’ coping strategies and their children’s attachment outcomes. Parents who used positive reappraisal techniques achieved healthy attachment relationships with their children (Jarvis & Creasey, 1991). The current study did not examine how attached infants behaved towards their parents. However, infant attachment is related to mother-infant bonding. Spinetta et al. (1987) found that parents of children with cancer were more likely to use coping strategies when they had achieved a good relationship with medical staff. Furthermore, the parents’ education level was related to their use of information seeking as a coping strategy. In the current study, the relationship of parents to medical and early intervention staff was known only for the interviewed participants. The same is true regarding employed coping strategies. Although the current study did not show a causal relationship between MoD use

of coping strategies and MoD relationship with professionals, this idea warrants further investigation.

Although mothers of d/hh babies experienced an initial phase of shock, once they received information and the future felt less unknown, they experienced some sense of relief. In addition, a couple of participants used reframing, a positive reappraisal technique. MoD2 described her son as a “gift.” MoD3 said that she liked to think of time with her son as “richer” than it would have been. In addition, after her son was diagnosed, she and her husband decided that one of them should be a stay-at-home parent; she said that all of their lives were improved as a result of her husband staying home. These parents decided to see the favorable aspects of their situations.

A theme of empathy and information seeking emerged with almost all interviewed participants. Seven mothers had either joined or were in the process of reaching out to friends, playgroups, or support groups. All mothers of d/hh babies had joined parent support groups or were in the process of reaching out to other parents of d/hh children. They talked about the comfort that they felt by knowing they were not alone. In addition, reading and hearing about older d/hh children gave the mothers hope and helped them feel less scared about the future.

Expectations

Feldman and his colleagues (1998) found that bonding was highest among mothers of healthy infants and increased as separation or potential loss increased. Furthermore, anxiety was related to preoccupying, worrying thoughts and depression was related to

fewer attachment behaviors. Only one mother in the current study, MoD3, had a baby with severe medical concerns. Even though MoD3 knew that her son's life expectancy was shortened, she did not show any signs of impaired or decreased bonding, intense anxiety, or depression. She became sad when contemplating her son's funeral and her husband's lack of involvement, but her day-to-day attitude appeared very positive and hopeful. She had the feeling that she gave birth to her son for a purpose. In addition, she had strong support from her family, friends, and coworkers.

MoD2 and MoD3 admitted feeling guilty when their children were first diagnosed. These feelings were alleviated once the mothers learned that their child's hearing loss was hereditary and that they had done nothing to cause the loss. MoD3, whose son was eleven months old at the time of her interview, said that she would relax once her son started speaking. This supports the idea that communication development is the primary concern (related to hearing loss) for mothers of d/hh babies. Other researchers have found that when hearing loss is identified early and increased language abilities are achieved as a result, parents' perceived stress is indirectly reduced (Chaffee et al., 1990; Pipp-Siegel et al., 2002; Yoshinaga-Itano et al., 1998). Seeing other children in the same situation, and especially having their own child achieve communication milestones, does much to mitigate the anxiety caused by having a child diagnosed with a hearing loss.

Interview questions regarding the mothers' future expectations of their children were based on the PI's experience as a teacher of the d/hh. She found that many of her students' parents were focused on how their children would develop. Would they go to a special school? College? Have a girlfriend? In their minds, hearing loss had the power to

affect nearly every facet of their child's life. Mothers in the current study had similar worries, but they expressed hope as well.

Limitations

Recruitment. Participant recruitment was extremely difficult. The first roadblock was getting EI centers and audiology clinics to agree to distribute study information. Some schools and audiology clinics, especially those housed in hospitals, had their own Internal Review Boards which delayed the approval process and, at times, made it impossible due to financial requirements on the part of the PI. More than thirty EI centers and clinics were contacted in three countries. Eleven agreed to be recruitment sites and were all in the United States. From these centers, only six MoD agreed to participate and no MoFP agreed. All MoD participants were recruited from EI centers; only one came from audiology centers. To avoid any feelings of coercion on the part of the mother, EI specialists and audiologists were asked to give potential participants an information sheet about the study. That way, professionals did not know which mothers decided to participate, and mothers did not have to worry that their services would be impacted by their decision, or lack thereof, to participate in the study. Two challenges were created by this recruitment procedure. The first challenge was that it was impossible to monitor or even encourage consistent distribution of study information. The second challenge was that the researcher could not follow up with potential participants. New mothers often feel overwhelmed. Mothers of d/hh babies are particularly likely to be overwhelmed. Even those with adequate support and coping skills may not feel like they have the time or

resources to participate even though a major time commitment was not required (a maximum of two hours, including an interview). Future researchers might consider covering child care expenses or providing child care while mothers were completing assessments. This might be challenging to arrange at audiology centers, but would be feasible at EI centers. If EI specialists had agreed to provide childcare while mothers completed the questionnaires and interviews, mothers with fewer resources, might have been more likely to agree to participate.

Selection Bias. All mothers who chose to participate were married and had at least some post-secondary education. Mothers who had more risk factors, and consequently more stress, did not participate in the study. Mothers who felt too overwhelmed to participate are likely the very ones who needed the tailored intervention the most. Also, the EI centers who agreed to help recruit were auditory/oral centers. Although some of the families were still going to TC centers and/or learning some sign language, the primary mode of communication for all families was spoken language. This is likely part of the reason that MoD were focused on spoken language goals and mainstreaming. Furthermore, information gleaned from this study about how mothers bond to their d/hh babies cannot be assumed to apply to mothers of babies who are learning to use sign language as their primary mode of communication.

Interviews

Broad generalizations cannot be made from interview data. Even though the aim was to assess bonding at the moment of assessment, interviewed mothers were largely reporting retrospectively. Some participants' babies' hearing losses had been diagnosed for almost 16 months (MoD4), while others had been diagnosed for only three months. Many parents of d/hh babies worry about their child's communication development. MoD4's daughter was already talking, so her memories of the beginning phases may have been clouded by her current positive experiences.

Implications and Future Directions

Clinical Implications. The diagnosis of hearing loss turns an already precarious time into a potentially overwhelming one. Although there is no need to worry parents needlessly when most babies will eventually pass diagnostic testing, communicating the possibility of hearing loss more strongly is worth consideration. In addition, helping parents explore coping strategies is a good place to begin intervention. Giving parents thoughtful information, but not too much at one time, is one way to relieve anxiety. Assessing what families know, before beginning intervention, would help assure that intervention is neither too repetitive nor too advanced. Educating families about their communication options in an unbiased manner is another responsibility of professionals. Two MoD expressed frustration over feeling that early interventionists were exerting too much pressure regarding choosing a particular communication philosophy. In addition, MoD discussed having interactions clouded by achieving communication goals. In fact,

MoD did not feel comfortable leaving their d/hh infants with people who were not familiar with hearing loss. While it is good that mothers grasp the importance of structuring the environment so that communication with their d/hh is optimal, families of d/hh children might be best served if they were encouraged to take time for themselves as well. In particular, parents should know that it is fine to leave their infant with someone who is not an expert in hearing loss and/or communication disorders and that progress will not be undone just because a non expert cares for the d/hh child for a short time.

Clinicians should remember that parents are balancing many domains: meeting their own needs, meeting the needs of their disabled child, and explaining a disability to others that they may still not fully understand or be comfortable with. Reading information online and talking with early interventionists and other parents may ease the overwhelming feelings of fear and isolation. Using some of the (current study) interview questions, when appropriate, at early home visits or appointments may help EI specialists and other professionals who work with d/hh children and their families to assess the parents' state of mind regarding their relationship with their child.

Hearing loss impacts an infant's fundamental patterns of communication. If a child does not react to his mother's voice or develop joint attention, the mother-child relationship may be negatively impacted (Prizant, Wetherby, Roberts, 2000). The families of d/hh children in the current study were receiving early intervention services.

Communication facilitation is a main focus of EI services for families with d/hh children and parents are typically taught how to elicit and develop optimal communication skills. EI specialists educate families about typical difficulties. When parents know that infants may

not respond to their voices but that they should continue communicating as if they were, there is a better chance for the mother-infant relationship to develop typically.

Multiple Disabilities. The incidence of additional disabilities in children who are d/hh ranges from 25% to 34% (Holden-Pitt & Diaz, 1998; Karchmer & Allen, 1999; Meadow-Orlans, Smith-Gray & Dyssegaard, 1995; Moores, 2001; Schildroth & Hotto, 1996). Learning disability, intellectual disability, cerebral palsy, attention deficit disorder, and emotional/behavioral disorder are the most common concomitant disabilities (Luckner & Carter, 2001; the Gallaudet Research Institute, 2006). Nine percent of deaf children have two or more additional disabilities (Schildroth & Hotto, 1996). One participant, MoD2, had a child with additional disabilities. In terms of stress, her worries extended well beyond those engendered by the impact of hearing loss alone. Her bond to her son was within the normal range, however. Although MoD2's son's syndrome was extremely rare, her experiences and needs are informative regarding what a mother of a d/hh child with additional disabilities goes through. Results from the current study reaffirm the need for teachers of the deaf and EIs to become proficient in supporting families of d/hh children with additional disabilities. The skills of the children with additional disabilities and the experiences of their families will likely be different from d/hh children without additional disabilities, and specialists need to have the skills to work with both populations. Overall, mothers were very positive regarding their EI services. It appears that interventionists were doing a good job of serving these families.

Fathers. Researchers have found that fathers' involvement at the time of the transition to parenthood predicts the fathers' accessibility during preschool years

(Shannon, Cabrera, Tamis-LeMonda, Lamb, 2009). If interventionists encourage fathers' participation, fathers may be more likely to be involved later. In addition, the current study illustrates the need for professionals to be ready to provide services to fathers, especially when the father is the primary caregiver. Although similar goals should apply to fathers (as they do to mothers), some additional considerations should be taken into account. Men may find it more difficult to accept the role of stay-at-home parent. Furthermore, effective counseling techniques for fathers may be different than techniques traditionally used with mothers.

When mothers feel resentful or feel that the baby is not theirs, as items 6 and 15 on the PBQ would indicate, additional negative feelings are usually present as well. Both of these feelings should be red flags for EI specialists. If a mother expresses these thoughts, professionals should help the mother find psychological counseling as these thoughts, even when not accompanied by impaired bonding, are precursors for problems in the mother-infant relationship (Seifer & Dickstein, 2000).

Research

In order to deepen the understanding of how we can best serve young children with hearing loss and their families, the topic of early bonding warrants further exploration. Replicating this study with a more diverse population and a larger sample would make the results more applicable to the general population of families with d/hh children. Assessing how a wider variety of races, education levels, and marital status affect the experience of having an infant with hearing loss would be more helpful to professionals who work with

d/hh children and their families. In addition, a study whose participants have more risk factors than the current study had would be more illustrative of the typical family with a d/hh child.

Additional Assessments. Any replication of this study should include additional assessments. The Parenting Stress Index (PSI) (Abidin, 1990) would offer direct information about a parent's stress level. The Family Environment Scale (FES) (Moos & Moos, 1976) would offer similar benefits. Although the PSI and FES would offer comparisons to previous similar research as well, the field of deaf education has changed dramatically since researchers began using the PSI and FES to assess the stress of families with a d/hh child. Overall communication skills of d/hh children have improved, possibly reducing one source of stress that families of d/hh children experienced in the past. Previous research did not always use comparison groups. Although the assessments' norming samples offer comparisons, it is useful to be reminded that some issues are ubiquitous to all mothers; when only mothers of d/hh babies are assessed, it might be tempting to attribute all their challenges to their child's hearing loss.

Other Issues. Fathers currently have more child-rearing responsibility than ever before. Assessing their stress levels and how they are bonding to their d/hh infant would add a much-needed perspective to the field of deaf education. Furthermore, the current study suggests that the number of children a mother has impacts how quickly she begins to bond to her child. No MoD who were interviewed had older children, so it was not possible to compare bonding to older, hearing children to the d/hh infant.

Conclusions

This study was intended to contribute to the understanding of the experiences of mothers of d/hh children with regard to bonding and service delivery. Service delivery formerly focused on the school-age population. Then, as UNHS became more widely implemented, the birth to three year-old population has received more attention. Along with this group, we now know that the families of these young children, particularly the parents, benefit from services. Increasing the understanding of this population is tantamount to best serving their children. The overall findings reinforce the need for a greater understanding of what d/hh babies and their families require. Even when families seem to be coping and adjusting adequately, they remain vulnerable. One researcher (Carpenter, 2005, p. 181) put it well when he wrote:

At the point of diagnosis of a child's disability, a parent's first question is hardly likely to be about the local early childhood intervention services. These families are frightened, disturbed, upset, grieving and constantly vulnerable. The role of the professionals involved with them is to catch them when they fall, listen to their sorrow, dry their tears of pain and anguish, and, when the time is right, plan the pathway forward.

APPENDIX A

DEMOGRAPHIC QUESTIONNAIRE: MoP

1. Last Name: _____
2. First Name: _____
3. Age: _____
4. Level of Education: High School GED Some College Associate's Degree
 Bachelor's Degree Master's Doctorate Other: _____
5. Marital Status: Single Married Separated Divorced Widowed
6. Number of children: _____
7. Number of children with a hearing loss: _____
8. Ages of children: _____
9. Date of Birth of Youngest Child: _____
10. Gender of infant: Male Female
11. Home mailing address: _____
12. Home phone number: _____ Mobile Phone: _____
13. Email address: _____ please circle your preferred mode of communication (phone, email)
14. Ethnicity: (select one): White (not Hispanic) Hispanic/Latino Black/African American
 American Indian or Alaskan Native Asian/Pacific Islander Unknown
15. Date Form Completed: _____

SERVICES (answer all questions regarding your youngest child)

16. Your child receives services in the following areas (check all that apply):

A. **Audiology:** This includes hearing testing, hearing diagnostic evaluations, hearing aid services, and cochlear-implant consultation(s).

B. **Case Management/Social Work:** A social worker coordinates, monitors, and evaluates a package of services for your child or family.

C. **Speech/Language:** Intervention specifically focused on the production of speech sounds and/or the detection of sound

Performed by: A speech/language pathologist An auditory/verbal therapist
 An audiologist A teacher of the deaf Other, please specify: _____

D. **Early Educational Services:** Intervention focused on educating the family about hearing loss and how best to promote interaction with your infant with hearing loss. This type of service most often includes direct services to your infant (e.g. speech elicitation, hearing aid maintenance, hearing detection, hearing comprehension, vocabulary development)

Performed by: A speech/language pathologist An auditory/verbal therapist
 An audiologist A teacher of the deaf Other, please specify: _____

E. **Other** (specify): _____

17. Level of early intervention service delivery (check one): No Early intervention Services Consultation

Direct services, 1-4 hours/week Direct Services, 1-2 hours/day Direct services, 3 or more hours/day

18. Type of Service/Program Placement:

19. **Center-based:** Someone takes my infant to a location other than my home (e.g. school, early intervention center) for early intervention service delivery

20. **Home-based:** Someone comes into my home for early intervention service delivery

21. **Both:** Sometimes I go to a center, and sometimes someone comes to my home

HEARING LOSS

22. Newborn Hearing Screening: my infant did not pass (referred) before leaving the hospital
 passed before leaving _____ Date of pass or referral

COMMENTS

Please comment on anything additional that you wish to discuss:

FOR OFFICE USE ONLY

23. ID Number: _____

APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE: MoD

1. Last Name: _____
2. First Name: _____
3. Age: _____
4. Level of Education: High School GED Some College Associate's Degree
 Bachelor's Degree Masters Doctorate Other: _____
5. Marital Status: Single Married Separated Divorced Widowed
6. Number of children: _____
7. Number of children with a hearing loss: _____
8. Ages of children: _____
9. Ages of children with hearing loss: _____
10. Date of Birth of Youngest Child with Hearing Loss: _____
11. Gender of Youngest Child with Hearing Loss: Male Female
12. Home mailing address: _____
13. Home phone number: _____ Mobile Phone: _____
14. Email address: _____ please circle your preferred mode of communication (phone, email)
15. Ethnicity: (select one): White (not Hispanic) Hispanic/Latino Black/African American
 American Indian or Alaskan Native Asian/Pacific Islander Unknown

16. Date Form Completed: _____

SERVICES (answer all questions regarding your youngest child)

17. Your child receives services in the following areas (check all that apply):

A. **Audiology:** This includes hearing testing, hearing diagnostic evaluations, hearing aid services, and cochlear-implant consultation(s).

B. **Case Management/Social Work:** A social worker coordinates, monitors, and evaluates a package of services for your child or family.

C. **Speech/Language:** Intervention specifically focused on the production of speech sounds and/or the detection of
sound

Performed by: A speech/language pathologist An auditory/verbal therapist
 An audiologist A teacher of the deaf Other, please
specify: _____

D. **Early Educational Services:** Intervention focused on educating the family about hearing loss and how best to promote interaction with your infant with hearing loss. This type of service most often includes direct services to your infant (e.g. speech elicitation, hearing aid maintenance, hearing detection, hearing comprehension, vocabulary development)

Performed by: A speech/language pathologist An auditory/verbal therapist
 An audiologist A teacher of the deaf Other, please
specify: _____

E. **Other** (specify): _____

18. Level of early intervention service delivery (check one): No Early intervention Services Consultation

Direct services, 1-4 hours/week Direct Services, 1-2 hours/day Direct services, 3 or more hours/day

19. Type of Service/Program Placement:

20. **Center-based:** Someone takes my infant to a location other than my home (e.g. school, early intervention center) for early intervention service delivery

21. **Home-based:** Someone comes into my home for early intervention service delivery

22. **Both:** Sometimes I go to a center, and sometimes someone comes to my home

HEARING LOSS

23. Newborn Hearing Screening: my infant did not pass (referred) before leaving the hospital
 passed before leaving _____ Date of pass or referral

24. Audiological Follow Up: my infant passed the screening so did not have a follow up
 my infant passed the follow up testing
 my infant did not pass the follow up and his/her hearing loss was confirmed
_____ Date of pass or confirmation of hearing loss

25. Student's hearing loss unaided:

Unilateral –

Unaided thresholds in impaired ear: **If loss is so profound that no response can be recorded, enter "120 dB" in each of Hz levels.**

_____ dB at 500Hz _____ dB at 1000Hz _____ dB at 2000Hz _____ dB at 4000Hz

Pure tone average of impaired ear: _____

Degree of unilateral loss unknown or no audiological data available.

Bilateral – **If loss is so profound that no response can be recorded, enter "120 dB" in each of the Hz levels.**

* Unaided Thresholds in:

Right Ear _____ dB at 500Hz _____ dB at 1000Hz _____ dB at 2000Hz _____ dB at 4000Hz

Left Ear _____ dB at 500Hz _____ dB at 1000Hz _____ dB at 2000Hz _____ dB at 4000Hz

Pure tone average of better ear: _____

Degree of bilateral loss unknown or no audiological data available.

26. a. My child has one or more hearing aids Yes No

If yes, complete the following:

b. Number of hearing aids: Two One

c. My child wears hearing aids 0-2 hours of the day 3-5 hours of the day more than 5 hours

27. We are considering a cochlear implant: Yes No

COMMENTS

Please comment on anything additional that you wish to discuss:

FOR OFFICE USE ONLY

28. ID Number: _____

APPENDIX C

POSTPARTUM BONDING QUESTIONNAIRE

(Adapted from Brockington, I.F., Oates, J., George, S., Turner, D., Vostanis, P., Sullivan, M., Loh, C., Murdoch, C., 2001)

	Always	Very Often	Quite Often	Sometimes	Rarely	Never
1. I feel close to my baby	0	1	2	3	4	5
2. I wish the old days when I had no baby would come back	5	4	3	2	1	0
3. I feel distant from my baby	5	4	3	2	1	0
4. I love to cuddle my baby	0	1	2	3	4	5
5. I regret having this baby	5	4	3	2	1	0
6. The baby does not seem to be mine	5	4	3	2	1	0
7. The baby winds me up	5	4	3	2	1	0
8. My baby irritates me	5	4	3	2	1	0
9. I feel happy when my baby smiles or laughs	0	1	2	3	4	5
10. I love my baby to bits	0	1	2	3	4	5
11. I enjoy playing with my baby	0	1	2	3	4	5
12. My baby cries too much	5	4	3	2	1	0
13. I feel trapped as a mother	5	4	3	2	1	0
14. I feel angry with my baby	5	4	3	2	1	0
15. I resent my baby	5	4	3	2	1	0
16. My baby is the most beautiful baby in the world	0	1	2	3	4	5
17. I wish my baby would sometimes go away	5	4	3	2	1	0
19. My baby makes me anxious	5	4	3	2	1	0
20. I am afraid of my baby	5	4	3	2	1	0
21. My baby annoys me	5	4	3	2	1	0
22. I feel confident when changing my baby	0	1	2	3	4	5
23. I feel the only solution is for someone else to look after my baby	5	4	3	2	1	0
25. My baby is easily comforted	0	1	2	3	4	5

Impaired Bonding Scale: Items: 1, 2, 6, 7, 8, 9, 10, 12, 13, 15, 16, 17

Score range: 0-60; 0-11 normal

Rejection and Anger Scale: Items: 3, 4, 5, 11, 14, 21, 23

Score range: 0-35; 0-16 normal

Anxiety About Care Scale: Items: 19, 20, 22, 25

Score range: 0-20; 0-10 normal

APPENDIX D
INTERVIEW QUESTIONS

Infant characteristics

1. Please tell me what your baby is like.
2. How would you describe him/her?
3. How is your baby sleeping at night?
4. How is your baby eating?
5. How is your baby responding to you?
6. Is there anything else about his/her characteristics that you would like to tell me?

Mother's emotional response to her infant

7. How did your feelings for (name of baby) develop after delivery?
8. When did you first experience positive feelings and love towards him/her?
9. When did he/she first become a person to you?
10. What do you and your baby do together?
11. What does he/she like?
12. What makes him/her smile?
13. Describe how you talk to your baby?
14. Do you like to sing to him/her?
15. How do you feel when you are away from (name of baby)?
16. How do you feel when your baby cries?
17. How do you feel when your baby wakes you at night?
18. Have you had any worrying thoughts about your baby?
19. What are your biggest concerns?
20. Tell me about a typical afternoon with (your child).
 - a. What are the interactions like?
 - b. What do you do with him/her?
 - c. How does he/she respond?
21. Are these interactions different than you imagined they would be?
22. How do you feel when interacting with (your child)?
23. Are there things you wish you could do with your baby but don't do?

If child did not pass hearing screening at hospital....

24. I see here on the questionnaire that you filled out that (your child) did not pass the initial hearing screening. Can you tell me a little bit more about that?
 - a. What were your thoughts/feelings related to this event?

25. I see here that your child's hearing loss was confirmed (#) weeks later. Please tell me more about this.
 - a. What happened next?
 - b. What were your concerns at this time?
 - c. What are your concerns now?
 - d. Do you know the reason for her hearing loss?

26. I see that you participated in (services on questionnaire). Please tell me more about the services. Were they provided at home or a center?
27. Who or what was the most helpful to you at that time? Why?
28. What were your interactions with these professionals like?
29. Is there anything that you wish would have been different (with these professionals)?
30. Describe your other sources of support.
31. Whom do you turn to?

If parents are considering cochlear implantation

32. I see that you are considering cochlear implantation. Describe what that has been like so far.

Now, I would like for you to picture your child in the future.....

33. If you had to picture (your child) at 5 years old, tell me what you see.
34. If you had to picture (your child) at 18 years old, tell me what you see.
35. Is there anything else that you would like to add?

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