CURRENT TRENDS IN EARLY HEARING DIAGNOSIS AND INTERVENTION IN NORTH CAROLINA

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ABSTRACT

Aneesha Pretto: Current Trends in Early Hearing Diagnosis and Intervention in North Carolina
(Under the direction of Melody Harrison, Ph.D., CCC-SLP)

In North Carolina, the eligibility criteria for enrollment in Part C early intervention services do not exclude infants and toddlers based on the severity or laterality of hearing loss. As such, the state’s early intervention population represents a widely diverse array of children ranging from those with minimal to profound hearing losses. While universal newborn hearing screening (UNHS) has led to earlier diagnosis and intervention for most families of children with hearing loss, others struggle to attain desired services based on the unique needs of their child or family. Prior to the state-mandated establishment of UNHS in 1999, national surveys reported disparities in the provision of early intervention based on child-related factors such as severity of hearing loss (Harrison & Roush, 1996; Meadow-Orlans, Mertens, Sass-Lehrer, & Scott-Olson, 1997). For many families, this reduced access to desired intervention services can critically jeopardize the benefits of early detection and/or amplification. The present investigation reports current trends in Individualized Family Service Plan development and early intervention service provision from 100 parents of children with hearing loss who were enrolled in or are currently receiving services in North Carolina. It examined whether child-specific factors (e.g., unilateral hearing loss, presence of additional special needs) predicted delays in access to diagnostic and intervention services for families. The investigation also considered how family-related factors, such as racial-
ethnic background, educational attainment, and the amount of perceived social support, related to later access to diagnostic and intervention services. The study found that most families had positive experiences with early intervention even when delays in care were observed. Results also revealed that children with unilateral hearing loss or those from non-White families had an increased likelihood for a delayed start to intervention. Children with associated conditions in addition to hearing loss were more likely to start intervention within the first six months of life although they had greater odds for delayed diagnosis. The findings from this project will help to identify priorities to improve the access of comprehensive and coordinated follow-up care for families of infants and toddlers with hearing loss.
ACKNOWLEDGEMENTS

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CHAPTER 1

Introduction

Every day, approximately 33 babies are born in the United States with a permanent hearing loss predisposing them to greater risk for speech, language, and academic failure. However, with amplification and intervention services before six months of age, children with congenital hearing loss are more likely to enter first grade with language skills 1 to 2 years ahead of those who receive these services later (Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). In the last 20 years, a shift in public health and special education policy to include the interests of individuals with special needs, particularly those with hearing loss, has increased the odds that families might realize these outcomes for their children.

Early Hearing Detection and Diagnosis

Historical Overview. Early detection of hearing loss has steadily gained national support since the 1990s. In that time, both the National Institutes of Health Consensus Panel (1993) and Joint Committee on Infant Hearing (JCIH, 1994; 2000; 2007) issued recommendations to conduct hearing screenings of all infants born in the United States. The U.S. Department of Health and Human Service’s national health initiative (Healthy People 2010; 2000) also endorsed the JCIH’s guidelines for early screening by 1 month of age, confirmation of hearing loss by 3 months of age, and receipt of intervention services by 6 months of age. By the late 1990s, the number of birthing hospitals that provided newborn hearing screening (NHS) rose from 60 facilities in 1994 to 2453 hospitals in 2002 (White,
As a result of this support, newborn hearing screening is now the standard of care in 42 states; and more than 90% of children born each year, that is roughly 3.5 million births, are screened for hearing loss.

**Program Structure.** While NHS has diminished the foremost threats to late diagnosis of hearing loss, comprehensive and collaborative follow-up services are necessary to extend the benefits beyond early detection. By 1999, 53 states and territories had obtained federal funds from the Centers for Disease Control and Maternal and Child Health Bureau to establish Early Hearing Detection and Intervention (EHDI) programs. EHDI programs consist of the following recommended components:

- Screening of all newborns prior to discharge within the first 30 days of life.
- Confirmation of hearing loss no later than 3 months of age
- Receipt of intervention services no later than 6 months of age
- Systematic data tracking, surveillance and integration
- Coordination of care with the newborn’s medical home
- Culturally-competent support and inclusion of families throughout follow-up

(White, 2003)

Other programmatic features include financing and reimbursement for NHS services and periodic early childhood screenings in Head Start and community health care settings. Many EHDI programs also receive recommendations and advocacy from an Advisory Board comprised of otolaryngologists, audiologists, early interventionists, educators, hospital administrators, family care physicians, parents of children with hearing loss, and/or individuals who are deaf or hard of hearing.
**Impact on Early Diagnosis.** Prior to national NHS, Harrison and Roush (1996) documented the median ages of identification and intervention using parent report from a national sample of 331 families of children with hearing loss under 5 years of age. They found that 50% of children with severe-to-profound hearing loss were diagnosed by 12 months of age and began early intervention at 16 months of age. Children with milder hearing losses were identified and enrolled later. The most often cited sources of delayed intervention related to third-party payment, childhood illness and ear infection, a need for additional audiologic testing, and the length of the hearing aid fitting process.

Similarly, Meadow-Orlans and her colleagues (1997) corroborated findings of late diagnosis in a survey sample of 404 parents of 6- and 7-year old children with hearing loss. The mean age of diagnosis occurred at 14.5 months for children reported as deaf and 28.6 months for children identified as hard of hearing. In that sample, the average age of intervention occurred much later, near 30 months of age for children described as deaf and 36 months of age for children reported as hard of hearing. Another national survey of 252 sites also documented that only 15% of programs surveyed had an average age of intervention of less than 6 months (Arehart, Yoshinago-Itano, Gabbard, Stredler-Brown, & Thomson, 1998).

By 2002, newborn hearing screening programs had been instituted nationwide, with a record 2453 hospitals employing some form of screening protocol (White, 2003). While several state-specific studies have demonstrated that NHS can effectively lower the age of diagnosis of children with hearing loss, nearly one-half of children with permanent congenital hearing loss still receive later diagnosis (i.e., after 3 months of age; Mehl & Thomson, 2002; Dalzell et al., 2000; Harrison, Roush, & Wallace, 2003).
**Challenges in the System of Care.** For most babies with congenital hearing loss, a hospital-based screening serves as the primary entry into the EHDI process. Still, the multiple points of service *after referral from the initial screen* can stymie efforts to determine whether appropriate diagnostic and intervention follow-up were received by the child and family. Most states qualify infants who do not receive or complete the diagnostic and intervention process as *loss to follow-up (LTF)*. Those babies without documented diagnosis could include newborns (1) who remain under diagnosis, (2) who are deceased, (3) whose family relocated to another state, (4) who are not residents, (5) whose caregivers were unresponsive to referral, (6) whose parents declined services, (7) who had invalid contact information, or (8) whose status is unknown (ASHA, 2008). States may report some or all of these events in their designation of LTF. Today, most EHDI professionals acknowledge that some infants do receive continued care although the EHDI program has no record of appropriate follow-up. This condition, termed *loss of documentation (LTD)*, commonly applies to cases where the family has relocated or has sought services in a neighboring state. It may also include infants whose legal name changed after birth. Given the varied use of the terms, some advocates have offered the term *loss to system* to denote both instances of LTF and LTD (ASHA, 2008).

**Early Intervention**

*Historical Overview.* Like EHDI programs, early intervention programs also emerged or were expanded across the United States during the 1990s as a result of the Education for All Handicapped Children Act of 1975 (P.L. 94-142). This seminal legislation safeguarded the right to a free and appropriate education for all children with disabilities from age 5 to 21 years old. Its purview was later expanded at its reauthorization (P.L. 99-
457) to include program options for special education preschool services (i.e., children 3 to 5 years of age) and for infants and toddlers aged birth to 2 years, inclusive. Here, notably, parents were ascribed an active role in the planning and execution of their child’s special education services; thereby demarcating a landmark shift in special education policy from a child-centered to a more integrated, family-focused approach. Today, infant and toddler services are authorized under Part C of the Individuals with Disabilities Education Improvement Act (IDEIA, P.L. 108-446; 2004) and guaranteed the provision of early intervention services for all children with a diagnosed condition or children with, or at risk for, a developmental delay under the age of 36 months. Nonetheless, states have the autonomy to set the criteria that specify the severity of the presenting delay and whether a mental or physical condition poses sufficient risk of delay to warrant intervention.

Program Structure. The implementation of early intervention services varies widely across states. Smaller jurisdictions (e.g., Virgin Islands, American Samoa) opt for a unitary provider model where a lead agency assumes responsibility for the administration, supervision and service provision. Most states have adopted a public-private partnership that delegates assessment for services as well as service coordination and provision to a regional or local entity. In this model, direct contact may occur through contracts with an individual provider (e.g., as in Indiana, Illinois, Missouri, West Virginia) or a provider agency (e.g., as in Rhode Island, Massachusetts, Texas, Wyoming). Each model bears its own benefits and costs to the program quality. For example, family choices regarding services are optimized when states retain a large pool of providers. Such programs also demand sufficient supervisory and technical support to assure the efficacy of team coordination and reduce inflation in program costs. Some states (e.g., North Carolina, Virginia, Nevada, New York)
have pursued a combined strategy where local agencies manage and coordinate services within their catchment area while individual provider contracts augment service options within a given locality. The National Early Childhood Technical Assistance Center (NECTAC), funded through the U.S. Department of Education’s Office of Special Education Programs (OSEP), provides resources and support to Part C Coordinators.

**Impact on Infant-Toddler Services.** The complexity of Part C service structures underscores the need for a comprehensive and shared approach to program evaluation. The National Early Intervention Longitudinal Study (NEILS) project constituted the most extensive source of early intervention outcomes for children and families. Commissioned by OSEP, the NEILS project provides outcome data from a nationally representative cohort of 3,338 children between birth and 31 months of age and their families who began early intervention services in 1997-1998.

Findings from the NEILS project revealed areas of strength and continued need among children and families. Overall, most caregivers reported a positive impact from the services rendered to their children following enrollment, and at least 20% did not receive additional services after enrollment, with half of those no longer requiring services (Hebbler et al, 2007). Only 16% of families voluntarily terminated services prior to their children’s transition from early intervention at 36 months. In general, around 9 in 10 parents felt more competent to address concerns about their child’s services as well as meet their basic needs following intervention. All families, however, did not realize these benefits during enrollment. African-American families were more than twice as likely to have experienced less positive outcomes for their children. Similar trends also appeared for families of children...
with poorer health at transition. Ultimately, around 63% of families continue to receive special education services after transition from early intervention.

*Challenges in System of Care.* Subsequent to IDEIA’s latest reauthorization, OSEP introduced regulations in 2005 that mandated the report of educational and functional outcomes from early intervention (Section 616, P.L.108-446). It also enlisted the Early Childhood Outcomes (ECO) Center to develop indicators for the national outcome measurement system and provide technical assistance for its use (See Table 1.1). The ECO Center employed a consensus-seeking process that engaged a diverse set of stakeholders to ascertain which benefits received by the child and family provided the most salient picture of early intervention outcomes. Many Part C programs have initiated new data collection and management systems to assess these key indicators for both the child and family.

Table 1: Child and Family Indicators of Early Intervention Outcomes

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<td>Display positive social-emotional skills,</td>
<td>Know their rights</td>
</tr>
<tr>
<td>including social relationships</td>
<td></td>
</tr>
<tr>
<td>Acquire and use knowledge and skills,</td>
<td>Communicate their children’s needs</td>
</tr>
<tr>
<td>including communication, early language and</td>
<td>effectively</td>
</tr>
<tr>
<td>emerging literacy</td>
<td></td>
</tr>
<tr>
<td>Use appropriate behaviors to meet their needs</td>
<td>Help their children develop and learn</td>
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Endeavors to monitor and assess national outcomes ultimately inform decisions on financing for Part C programs nationwide. In 1999, federal appropriations for early intervention services peaked at $370 million, with an allocation of roughly $1979 per child enrolled. Since then, the demand for services has outpaced the federal appropriations. In 2009, the total enrollment reached 343,000 infants and toddlers nationwide with a funding allotment of $1280 per each child. Whether the system can sustain an increasing burden without a corresponding decrement in service quality relies heavily on the distribution of resources at both the state and family level.

Family characteristics within the early intervention population have amplified the burden of reduced resources on the current system. Over one-quarter of children enrolled in the program resided in families with annual household incomes under $15,000 (Hebbeler et al, 2007). Nearly one-half were identified as non-White, and of predominantly African-American, Hispanic, or Asian descent. Poverty and racial/ethnic minority status have been well-established as demographic risk indicators for poorer outcomes. The extent to which a strained system of care can alleviate the observed disparity in outcomes given these population factors is an ongoing concern.

Collaboration within Early Hearing Detection & Intervention

Early Hearing Detection and Intervention programs must bridge two distinct systems of care: its own NHS follow-up and referral system and Part C services for infants and toddlers. In at least 28 states the department of health serves is the lead agency for the Part C program whereas the department of education has fewer programs, around 10 (NCHAM, 2008a). In several states, EHDI and Part C share the same lead agency, a feature that
critically facilitates communication among the two entities. Where this is not the case, the Federal Educational Rights and Privacy Act (FERPA) can impede the efficient and accurate exchange of information between the two systems. This act protects the educational records of all children, including those enrolled in early intervention. Roughly 42% of states require signed parent consent prior to any disclosure of child special education services to EHDI programs (NCHAM, 2008a). In some jurisdictions, Part C and EHDI programs have undertaken an interagency agreement to expedite sharing child and family information. Such information exchange is more typical among programs established in the state department of education. Notwithstanding, over one-third of EHDI coordinators have reported serious difficulty in retrieving information regarding enrollment after referrals for services (NCHAM, 2008b). Another 60% of EHDI programs never or rarely received information about the actual services families of children with hearing loss obtained during early intervention (NCHAM, 2008b). In contrast, roughly half of EHDI programs do not contact Part C following the identification of a hearing loss (NCHAM, 2008b), and the referral is typically undertaken by the infant’s or toddler’s audiologist. Lack of an integrated and cohesive system of care heightens the risk that families will not receive timely and appropriate access to services.
CHAPTER 2
Literature Review

Ecological Development and the Family System

Early learning experiences for any child, including those with hearing loss, reflect aspects of the environmental context in which they transpire and, in turn, are influenced as the growing child explores and engages within them. This interplay between the environment and development was most thoroughly described by and attributed to Russian psychologist, Urie Bronfenbrenner (1979). He first conceptualized ‘development-in-context’ as a series of interconnected systems that define the child’s early environments. The most immediate system, the microsystem, relates to the routine activities, roles and interpersonal relationships that the child experiences; it most often describes settings in the home, school or child care facility, and his or her neighborhood. Any interaction among these settings or movement between them is pertinent to understanding how the child integrates multiple sources of learning into his or her knowledge and behavior. This interconnection is known as the mesosystem. External events, for example changes in state or national maternal and child healthcare policy or rezoning of school districts, also bear weight on the activities which unfold in each microsystem; this exosystem may not directly involve any of the child’s daily activities but in all probability will critically impact the resources and opportunities available to him or her. Though a full discussion of ecological development would extend beyond the
scope of the present review, its main tenents underscore the interdependence of the child, family, and wider context in which they live.

In 1997, Cox and Paley further explicated the theoretical underpinnings which necessitate an ecological study of human development in the daily life. Similar to the ecological development perspective, family systems theory dictates that individual functioning is indivisible from the larger entity in which the child exists. Moreover, the individual behavior of each member consistently reflects, in some part, the interdependent relationships which he or she maintains in the family. In a corresponding manner, the performance of the whole family unit should -somewhat predictably- defy description based solely on its respective parts. The family system, in effect, consists of a hierarchical organization of interdependent relationships, or subsystems (e.g., parental, marital, sibling). Ideally, each subsystem maintains clear but permeable boundaries that enable members to access resources from the whole, and yet individuals retain sufficient autonomy to guide their own behavior without persistent interference from other members. To the extent that these boundaries are not flexible and intact, interpersonal relationships will appear overly rigid or enmeshed. Over time, repeated interactions within and across subsystems evolve into ‘rules’ or patterns of interaction. These patterned behaviors, whether maladaptive or not, serve to stabilize the family unit. The process of self-stabilization helps the family achieve balance and braces it against environmental changes. However, continual or severe adverse forces to the family system can spur a (mal)adaptive re-organization of the unit as a whole. Such reformation often occurs during periods of normative (e.g., birth, marriage, death) and non-normative (e.g., financial distress, diagnosis of illness or disorder) transition.
If applying an ecological framework to the development of an infant or toddler with hearing loss, the family and intervention program would function as two distinct, yet intersecting microsystems wherein the child, caregivers, interventionists, and others interact. These interactions establish routines and roles that influence all members of the system. For example, observed delays in the child’s physiological or social development could prompt the interventionist to refer the child and/or family for additional assessments and services. The family while coping with these additional needs will have to manage the request for new services as they reorganize schedules, participate in the revision of their child’s service plan, and seek new supports (e.g., child care for siblings, community programs) to assist in this process. All of these events occur within a larger exosystem of the state early intervention program. For instance, some programs adopt a transdisciplinary approach in which services are provided to the family through a primary contact whereas others adopt a more multidisciplinary or interdisciplinary team model in which services are rendered through several providers. Though families and children have little immediate bearing on each state’s approach to professional teaming, they are undoubtedly impacted by such decisions as they will determine how many professionals the family will regularly encounter and likely bring into their home. In this way, the interconnected nature of the child and family to the larger intervention context not only reveals that no system is inherently immune to the behaviors and practices within another but also prepares a more cohesive landscape in which to explore the principles and practices of intervention that can address such complexity.

Family-Centered Principles and Practices of Intervention

A prelinguistic and permanent hearing loss diminishes the developing child’s environmental access to incidental language learning and inhibits the social and cognitive
skills that rely upon emerging verbal communication. Early learning experiences play a pivotal role in the subsequent development of children with hearing loss, such that beneficial early experiences lessen the need for more remedial intervention once the child reaches school-age (Eleweke, Gilbert, Bays & Austin, 2008; Yoshinago-Itano et al, 1998). The primacy of the environmental context, and in particular, the family system suggests that traditional child-centered approaches neglect to address intervening factors such as parent education and material or emotional family supports, that in all probability can impede child performance or destabilize newly attained skills once a ‘successful’ intervention has been discontinued. More importantly, inclusion of these contextual factors presents new options and resources for interventionists to pursue that can capitalize upon family strengths and potentially expedite developmental progress.

To date, the family-centered care philosophy epitomizes the central themes of contextually-based intervention. By most definitions, the core principles of family-centered intervention focus on the empowerment and enabling of family members with the expectation that empowered caregivers can, with varying degrees of assistance, mobilize the medical, educational and social resources to attain their own goals (Dunst, Trivette, & Deal, 1988; DesJardin, 2006; Bailey et al, 1986; Jackson & Turnbull, 2004). When offered these forms of help in the context of a family-centered setting, caregivers demonstrate an increased sense of personal control regarding their ability to influence their child’s development (Trivette, Dunst, Boyd, & Hamby, 1995). This perception of increased self-efficacy is known to mediate parenting behavior such that parents who feel empowered to meet their child’s needs are more likely to provide the learning opportunities that facilitate their child’s development (Dunst, Trivette, & Hamby, 2007). In other words, when caregivers receive
adequate information and support to demonstrate (or learn) the skills necessary to promote their own advancement, they are more likely to perceive their own agency in their ability to affect change in their lives and the development of their child with special needs.

The efficacy of a family-centered approach towards intervention with families of children with hearing loss is substantiated in the extant literature. Moeller (2000) demonstrated that family involvement in early intervention bears a greater impact on the vocabulary comprehension of 5 year olds than the age of enrollment, severity of the hearing loss, and nonverbal intelligence. Parental expectations of their child and the professionals who serve them have been also been associated with improved language comprehension (Wu & Brown, 2002), implying an inherent link between family beliefs and clinical outcomes. Moreover, caregivers who receive informational and emotional support during intervention have been reported to exhibit lower levels of stress and higher involvement in their child’s services (Eleweke et al, 2008). DesJardin (2006) also observed that maternal feelings of self-efficacy with regards to facilitating their child’s speech and language skills were positively associated with adept usage of the language facilitation techniques that enhance receptive language skills. Taken together, these outcomes lend weight to the argument that caregivers who receive the support and opportunity to engage in their infant’s or toddler’s early intervention program can positively influence their language development.

What aspects of family-centered care help families the most? As active listeners, interventionists can recognize the psychological undercurrent of a caregiver’s practical concern. Additionally, an attitude of empathy and unconditional positive regard towards families from service providers prepares the foundation for future confidence in clinical services and collaboration between parents and professionals. Notwithstanding the value of
emotional support, engaging caregiver participation in the decisions that guide the child’s management shifts their involvement from a more passive to active role. The roles parents can assume are diverse; they might complete informal reports of their child skills, assess the validity of their child’s performance during clinical evaluations, and generate goals and strategies for their behavioral management and learning. Parent preferences in this regard will vary within and across families. Some caregivers may elect to assume a highly active role while others defer more choices to their child’s team. However, clinical research has observed that the inclusion of parent participation during intervention displays a strong relationship to parent satisfaction and feelings of self-efficacy related to their child’s intervention program (Dunst, Boyd, Trivette, & Hamby, 2007). In fact, Dunst and his colleagues (2007) observed that family involvement bore a greater association to these outcomes in comparison to relational practices (e.g., active listening, empathy, respect) provided during adjustment counseling. Families and professionals should work together to determine the activities and roles best suited to the family’s goals for their child. A majority of early intervention program models have acknowledged and endorsed the role of the family in their child’s development; however, the extent to which families are involved in a manner that allows caregivers to strengthen their existing skills or develop new ones differs significantly across programs and individual providers.

In North Carolina, multiple factors related to the early intervention system, child and family can influence when families receive access to early intervention; they also impact the type of services that they receive or desire from their infant and toddler program. The following review explores relevant features of the early intervention program, child, and
family with special focus on how their unique traits create opportunities or strictures within the larger system of care for infants and toddlers who are deaf or hard of hearing.

North Carolina Early Hearing Detection and Intervention Program

North Carolina’s system of care for children with hearing loss consists of multiple agencies that are responsible for specific early detection and follow-up services. In October 1999, the North Carolina General Assembly authorized hearing screening for the estimated 130,000 births that occur each year within the state [Wilson, 2006; S.L. 2000-67, S ll.31(b)]. It provided for the establishment of a Newborn Hearing Screening Program, housed in the Division of Public Health in the State’s Department of Health and Human Services (DHHS). Under the law, attending physicians are required to order physiological hearing screenings of all infants less than six months of age, but preferably within the first month of life. The report of screening results must be submitted concurrently with the infant’s blood specimen to the North Carolina State Laboratory for Public Health. All screenings occurring within the state are reported to the NHS program quarterly. While parents retain the right to refuse screening for their newborn, their explicit consent is not required. As a result, NHS represents the standard of care for all babies born within the state. The ruling further outlined provisions for the follow-up and tracking of children pursuant to referral from screening and set guidelines for parent education and professional training regarding the screening process. An EHDI Advisory Board was founded to provide recommendations for the system of care for children with hearing loss. It meets quarterly and represents parents and professionals from otolaryngology, pediatric audiology, early intervention, family advocacy programs and public health.
According to state law, when a child has an identified hearing loss, families must receive immediate referral to BEGINNINGS for Parents of Children Who Are Deaf and Hard of Hearing, Inc. Established in 1987, BEGINNINGS is a non-profit family advocacy program that strives to provide emotional support and impartial information regarding communication options to parents of newly identified children. Funded primarily through state appropriations, the center serves families of children from birth until 22 years of age (Wilson, Alberg, & Roush, 2004). After diagnosis, a Parent Educator visits families in their home to share information and views about hearing loss, language development, communication options, financial assistance, and early intervention services. Parent Educators with native Spanish speaking skills are available as well. In the initial period following identification of the hearing loss, visits from the Parent Educator occur routinely for families of diagnosed infants and toddlers, but eventually they come to center around critical transition points (e.g., transition to pre-school special education; classroom support). BEGINNINGS’ services are accessible to families throughout the state as its parent educators travel from centers in western (Charlotte) and central (Raleigh) North Carolina.

Another critical component of the EHDI system in North Carolina, the state early intervention system, also resides in the Division of Public Health. It administers the Infant-Toddler (i.e., Part C, 0-3 years) program for the entire state, with direct involvement during the initial intake of families, coordination of services and tracking of high-risk infants. As a hybrid structure, the state early intervention system staffs both direct service providers and contractual private providers. Across the state, 18 Children’s Developmental Services Agencies (CDSAs) offer developmental evaluations and eligibility determination in addition to initial and ongoing service coordination for enrolled families. This single point of entry
based on region of residence facilitates the referral, enrollment and tracking of infants and toddlers with special needs. Referral for services can originate from the diagnosing audiologist, NHS program, primary care physician, BEGINNINGS, Inc., or the family, with audiologists serving as the most common referral source. However, once found eligible, services for infants and toddlers with hearing loss generally issue from the Office of Education Services (OES) within the DHHS, historically the administrative center for the state’s schools for the deaf (Wilson, 2006).\(^1\) Three regional directors supervise the program at the local level, while the OES Superintendent oversees the program at the state level. In each of the three regions, licensed speech-language pathologists and teachers of the deaf or hard of hearing are employed with expertise in spoken language (e.g., auditory-oral/auditory-verbal; cued speech) and manual communication approaches (e.g., Total Communication, American Sign Language). Intervention often occurs within natural environments like the child’s home and focuses on family involvement from the outset of intervention.

Additional program supports are available in North Carolina for families of children who are deaf or hard of hearing. The Assistive Technology Infant-Toddler Funds, offered through the DHHS, provide assistance in purchasing hearing aids for Part C enrolled infants and toddlers with a documented need. It serves as a last resort for families who are not Medicaid eligible but do not have coverage under their own private insurance outlet. The Assistive Technology Fund, managed by the Children’s Special Health Services Program, \(^1\) The DHHS Office of Education Services (OES) was closed on October 1, 2010 just prior to the publication of this study, and the administration of state early intervention services for infants and toddlers with hearing loss was transferred to North Carolina’s Department of Public Instruction. It is worthwhile to note that, for the sample of families described in Chapters 4 and 5 of this investigation, early intervention services were managed by OES.
also offers payment for services and technology associated with other long-term medical needs related to vision, mobility, communication and the like. North Carolina is steadily developing a robust support network at the state level to counterbalance the challenges confronted by parents of children who wear hearing aids. These resources are critical to caregivers who have been reported to perceive themselves as less likely to positively influence their child’s development when compared to parents of children with cochlear implants (DesJardin, 2005).

Key Encounters with Early Intervention

At the onset, two critical components of care characterize every family’s experience with the state early intervention system. The first element, eligibility criteria, establishes which infants and toddlers may be enrolled in the Part C program based on the type and severity of their hearing loss. From the perspective of ecological development, the eligibility criteria – which exist in the exosystem of the family unit – predetermine which services the family may access without particular input from any of its members. The second element of care, the Individualized Family Service Plan (IFSP), sets the form and content of the services the family will receive. Because the child’s caregivers can assume an active role in its development, the IFSP is more aptly conceived as a mesosystem feature that describes the relationship between the family and the professionals who provide services.

Eligibility Determination. Federal mandate of Part C services under IDEIA (P.L. 108-446; 2004) assures early intervention for “established conditions” that are likely to result in developmental delay. However, states may specify their criteria for these conditions broadly, narrowly or not at all. In actuality, only 67% of states recognize hearing loss as an eligible condition (White, 2006). Some states recognize the presence of a general “sensory
impairment” as a qualifying disability (Broad categorization) whereas others delimit eligibility based on the type, laterality, and/or severity of the hearing loss (Narrow categorization). Texas, the nation’s second largest hearing screening program, does not acknowledge hearing loss as an established condition but determines eligibility after referral (Stredler-Brown et al., 2008). Differential enrollment criteria can disproportionately exclude children with unilateral and/or mild hearing loss from needed services (Stredler-Brown et al., 2008) until a developmental delay occurs. As a result, Part C programs that routinely serve children across a broad range of hearing loss may offer different types of services than those that serve only a limited segment of the pediatric hearing impaired population.

In North Carolina, roughly 170 to 180 children enroll in Part C services each year due to an existing hearing loss; this population represents no fewer than 80 to 90% of all infants who are diagnosed annually (Centers for Disease Control & Prevention [CDC], 2007a; 2007b). On the whole, the high rate of enrollment can be ascribed to the state’s narrow yet, comprehensive definition of hearing loss. The current eligibility criteria for early intervention services read as follows:

“A child may be considered eligible either with a developmental delay or an established condition. The latter include those children with a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. Specific conditions through which a child may be deemed eligible in this category include a unilateral or bilateral permanent hearing loss.”

Stredler-Brown et al, 2008

The number of children and families receiving services rises steadily each year and has more than doubled since 2000 (U.S. Department of Education Office of Special Education
Programs [OSEP], 2005). In 2008, North Carolina’s state early intervention program served an estimated 9,971 infants and toddlers, or 2.48% of the state population of children between the ages of birth to 3 years (OSEP, 2010). A few years earlier, in 2006, state CDSA resources were overextended by the increasing demand for services, receiving about 17,000 annual referrals in that year (NC DHHS Early Intervention Services, 2006). Consequently, proposals to reduce the number of referred families resulted in modifications to the eligibility criteria for all infants and toddlers who had either developmental delay or established conditions (e.g., vision/hearing loss, autism, genetic disorder). At the time, recommendations to limit services to families of infants or toddlers with a bilateral moderate to severe-profound permanent hearing loss were put forth as well. However, families and advocates of children with hearing loss, including the EHDI Advisory Board, rallied to prevent future reductions in services and succeeded. The outcome of their campaign, in some part, gave evidence of the relative health of the overall system of care for children with hearing loss. With an open door to services for nearly all families of identified infants and toddlers, the predominating concern becomes the likelihood that caregivers can efficiently access suitable services from a burdened early intervention system.

IFSP Development. The IFSP represents an ongoing contractual relationship between families and professionals to address the concerns and needs of the child and his or her family. It outlines areas for assessment, describes family strengths and needs, and lists goals and expected outcomes for both the child and family. The IFSP is intended to serve as the framework for an ongoing conversation between parents and professionals to explore and identify needs and goals, and each party has the opportunity to present revisions for the service plan at least every six months. However, in practice, many parents may consider the
IFSP as a document created in meeting with a service coordinator and one or more specialized providers (e.g., speech-language pathologist, occupational therapist, social worker).

In 1986, federal mandate (P.L. 99-457) granted funding to states electing to expand pre-school services to infants and toddlers aged birth to 3 years old. North Carolina was among the first of five states to institute Part C (formerly Part H) services for eligible families. When more states opted to expand their early intervention services, the IFSP development process challenged the rather conventional child-centered service delivery models as professionals and families collaborated to ascertain the strengths and needs of not only the child but also his or her family. Federal regulations required that parents contribute actively and in equal measure to other professionals on the team during IFSP development; however, this role was largely unspecified in the law, allowing for varied interpretations under implementation. By the mid-1990’s, the rising attention to parental roles in the programming of early intervention services had spawned multiple empirical studies on how the IFSP process unfolded in routine practice.

Minke and Scott (1993) conducted a series of interviews and observations of IFSP meetings at newly established early intervention programs and pre-school programs that were extending services to the infant and toddler population in Indiana. While varying degrees of parental engagement were documented among programs, they reported that parents did not always play equal roles in the goal selection process. In actuality, few caregivers were observed to generate goals based on professional assessments without overt recommendations from the professionals themselves. More commonly, parents provided suggestions for goals and the professionals refined their ideas into child-specific targets. As
a result, parents often believed they had set goals that ultimately did not appear in the IFSP. Some programs did involve caregivers in the assessment process by requesting that the parents complete informal reports and summaries of their child’s strengths and needs (Minke & Scott, 1993). This strategy of parent reporting often mediated the degree of parental involvement during goal-setting such that caregivers offered more suggestions during the IFSP meeting when they had participated in the assessment process. While professionals did make some deliberate efforts to engage parents in a manner that would effectively increase their sense of control and empower them as caregivers, the parents were frequently relegated to passive roles such as listening or providing consent and other information. Furthermore, professionals seldom requested that families evaluate their child’s progress, implying a distinction between parental and professional appraisals of the child’s skills and behavior.

In 1996, Harrison, Dannhardt and Roush observed similar findings among a national survey sample of parents of children with hearing loss. They found that, while an overwhelming 90% of parents agreed or strongly agreed that the IFSP team supported them as the primary decision-maker during the process, more than two-thirds of parents did not feel their opinions were given more weight in the event of a disagreement with professional recommendations. In addition, nearly one-quarter of the sample felt or were unsure that they decided what would be written down as a family priority on the IFSP. Other investigators (Summers et al, 1990) have noted that although families may not readily prioritize their strengths and needs for professionals, families must reserve the right to determine what their child’s needs are and how they will figure in the IFSP document. This statement remains equally true for families of children with hearing loss who, because of early identification,
will typically have a longer early intervention experience than families of children with other special needs.

Since the mid-1990s, the emergence of early hearing detection programs has ushered more families of infants and toddlers towards enrollment in early intervention programs. In North Carolina, the newborn hearing screening program was established in 1999. Since its inception, family-focused early intervention programs in North Carolina have had the opportunity to enhance their responsiveness to family needs and priorities and equip providers with the skills to support parents throughout the early intervention process. At present, there is insufficient evidence to determine how parents experience the IFSP process in North Carolina and whether the state’s early intervention system has demonstrably succeeded in expanding the contribution of caregivers during the development of their infant or toddler’s service plan.

Child Factors

Unilateral Hearing Loss. Unilateral hearing loss\(^2\) (UHL) has been categorized as a form of minimal hearing loss (Bess, Dodd-Murphy, & Parker, 1998), representing approximately 22% of infants and toddlers with an identified hearing loss and 34% of all diagnosed children (CDC, 2007c, 2007d; Tharpe, 2008). Unilateral hearing loss contributes to delays in educational progress, with at least 22% to 35% of children failing one school grade (Bess & Tharpe, 1986; Bovo et al, 1988). Children with UHL have demonstrated poorer performance during sound localization tasks and speech recognition tasks of nonsense

\(^2\) Pure Tone Average at 0.5, 1.0, 2.0 kHz ≥ 20 dB or pure tone thresholds > 25 dB HL at two or more frequencies above 2 kHz in the affected ear (Bess et al, 1998)
syllables in noisy environments (Bess, Tharpe, & Gibler, 1987). Infants and toddlers with suspected UHL have increased susceptibility to loss-to-follow-up because the consequences of such hearing loss may be viewed as minimal. Some states do not recognize UHL as an established condition meriting early intervention. To some degree, variations in eligibility criteria for UHL reflect the diversity in treatment approaches that may be taken which range from a conventional ‘wait and see approach’ to the use of assistive technology such as hearing aids and FM devices. As a result, tangible aspects of the early intervention process can differ from state to state for infants and toddlers with UHL, and there is critical need to determine the services and resources that these parents access and rely upon for their child.

*Additional Special Needs.* An estimated 30% of newborns with hearing loss have at least one attendant neurodevelopmental condition, including mental retardation (Van Naarden, Decoufle, & Caldwell, 1999). By school-age, educationally significant impairments are observed among approximately no less than 40% of children who have a hearing loss (Picard, 2004). The most frequently identified conditions include, in order of decreasing prevalence: specific learning disability, intellectual disability, attention deficient and hyperactivity disorder, and visual impairment. The stability of this trend has been documented in more recent surveys of children with hearing loss as well (Gallaudet Research Institute, December 2006). Moreover, the only demographic subgroup that has exhibited a decline in prevalence since 2000 is infants with syndrome-related conditions, most typically trisomy 18 or 21. This drop may be attributable to pre-natal diagnosis and subsequent termination of pregnancy in industrialized societies (Adler & Jushnick, 1982). Some researchers (Picard, 2004) have posited that the rise in preterm births, particularly very low birth weight babies (i.e., less than 1500 grams) or those with a gestational age under 25
weeks at delivery, has in effect predisposed more infants to a range of neuromotor, sensory
and cognitive sequelae.

The vulnerability of infants with co-occurring birth defects that include a hearing loss poses challenges to timely access of hearing screening and diagnostic services, especially for those with a Neonatal Intensive Care Unit history. In Virginia, roughly 32% of infants born with at least 2 concomitant birth defects in addition to a hearing loss were likely to receive a screening after one month of age (Chapman, Lynch, & Stampfel, July 2010). Similarly, a majority of the same infants, or 83%, did not receive formal diagnosis until after three months of age. While medically fragile infants often must delay screening, it is important to defer screening no longer than absolutely necessary while educating parents on the meaning and resources for continued follow-up. The effects of an associated disability for families of children with hearing loss often reverberate throughout the family’s emotional and material support structure. Later diagnosis of an additional impairment, as with ADHD or learning disability, frequently re-activates feelings of denial or loss that a family first experienced following diagnosis of the hearing loss (Luterman, 2002). Caregivers of children with multiple challenges often have difficulty configuring services to suit their child’s multiple needs, when specialized services are warranted. On the whole, further information is needed regarding how and when parents of children with hearing loss and other special needs gain access to services for their infant and toddler.

*Family Factors*

*Demographic Factors.* At present, eligible African-American, Asian, and American Indian families access early intervention less frequently than their White counterparts (C. Gaffney, Personal Communication, February 9, 2009). Chapman and colleagues (July 2010)
reported that infants from Black, non-Hispanic families in Virginia were more than twice as likely to receive a hearing screening after the first month of life in comparison to their white counterparts. In addition, the odds that the same children had received a confirmation of hearing loss after three months of age were comparable. Some research (DesJardin, 2005) has implied that the impact of later diagnosis is associated with a reduced perception of caregiver self-efficacy, or one’s ability to succeed over time in a task (e.g., parenting a child who is deaf). Accordingly, families from racial minority groups may be less likely to thrive in a complex intervention system when they are unable to access diagnostic and habilitation services in a timely manner.

Furthermore, racial disparities in access to services are frequently confounded by the contribution of lower educational attainment among these groups. In a caregiver sample of children ages 7 to 14 years with moderate to profound hearing loss, Kluwin and Corbett (1998) observed a disproportionately higher number of African-American and Hispanic parents who had not received a high school diploma. In their sample, parents who did not complete high school were correspondingly less likely to engage in their child’s special education programs by visiting the classroom or participating in the development of their child’s special education plan (i.e., Individualized Education Program). While these trends do not directly relate to the early intervention process that often precedes enrollment in a special education program after the child’s 3rd birthday, it suggests that potential racial disparities in access to early intervention services may be perpetuated beyond transition from early intervention and exert a long-term impact on the quality of services received by children from racial or ethnic minority groups. The degree to which these differences impact racially diverse families of children with hearing loss in North Carolina is unknown.
Perceived Social Support. Informal social supports (e.g., kin, friends, community) can offset the demands of an intense intervention program by providing emotional and informational aid or tangible supports like child care. Parents who feel supported are better able to manage the stresses of a challenging early intervention system. Zaidman-Zait (2007) used critical incident interviews to examine the facilitative events that aided parents in rearing a child with a cochlear implant. In her sample of 15 Canadian caregivers, she observed that parents cited their shared experiences with parents of other children who were deaf as the most helpful source of support, after professional monitoring of progress. In fact, over 90% of parents viewed support from other parents of children who were deaf as critical to their coping in parenting a child with a cochlear implant. Asberg and her colleagues (2008) also supported these findings in a sample of 35 American parents of children who were deaf. In their study, caregivers’ level of perceived social support explained unique variance in parenting stress scores beyond the contribution of child factors (i.e., chronological age, degree of hearing loss, and age of identification).

Joint reflection with other parents of hearing-impaired children has been acknowledged as a buffer against heightened maternal stress (Calderon & Greenberg, 1999). In this regard, parent support groups also fulfill this role. Establishing relationships through these community groups offers parents a venue to confide their personal and familial histories, observe the growth of children similar to their child, and collectively explore novel approaches to resolve daily caregiving challenges. Families who have relocated to attain desired services can particularly benefit from connection to additional community resources (e.g., child care programs, etc.). Thus, the development of a healthy social support network
in the early intervention process can serve to shield families from the demands and stress of parenting a child who has a hearing loss.

The desire for these social supports among parents of children who are deaf has also been firmly documented in the literature (American Speech-Language-Hearing Association [ASHA], 2008). As early as 1996, a national survey of parents of children with hearing loss noted that informal supports (e.g., spouse, relatives, other parents, deaf adults, friends) dominated the top 10 ranks of most helpful caregiver resources (Meadow-Orlans et al., 1997). In contrast, only two professional roles (i.e., the teacher and therapist) received ranking on the list, although not prominently, and this report signified that while service providers are highly beneficial to families, assistance found within the parents’ immediate social environment can exert a more pervasive and consistent influence on daily family functioning.

The extent to which an enhanced perception of social support enables parents to attain the services they desire from their early intervention program has not yet been studied. Parents who have a healthy support system are more likely to exhibit greater synchrony between the services they seek and those they desire. It is also possible that parental needs for social support will diverge according to the unique needs of their child (e.g., multiple special needs) and his or her hearing loss (e.g., laterality).

Specific Aims

This study reports results from a mail-based survey of parents of infants and toddlers with a diagnosed hearing loss. It examines the current trends in the delivery of early intervention services for families of children who are deaf or hard of hearing, including the development of the family’s service plan. The investigation also endeavored to identify the extent to which certain factors, pertaining to the child or family, predict later access to
diagnostic and early intervention services after newborn hearing screening. These activities were considered within the structure of the following specific aims:

1. *To describe caregivers’ perceptions of the early intervention process and the types of infant and toddler services that are most commonly received by families in intervention.* This first descriptive analysis reports parent perspectives on follow-up care after screening as well as the planning and implementation of early intervention services. It will also describe the early intervention services most commonly received and desired by families.

2. *To characterize the current trends in early hearing detection and intervention services for infants and toddlers with hearing loss.* The second descriptive analysis provides the median ages of detection, diagnosis, device fitting, and intervention services based on the laterality of hearing loss and the presence of additional special needs in the child. It will include analysis of services received based on caregiver race and educational attainment. It is expected that these specific features in the child or family are related to later arrival to early intervention.

3. *To assess the extent to which child and family characteristics uniquely explain differences in the observed age of diagnosis for infants and toddlers who received a newborn hearing screening.* It is hypothesized that children with unilateral hearing loss as well as children with one or more special needs will have an increased likelihood for later diagnosis in comparison to infants and toddlers with bilateral hearing loss only. Likewise, children of non-white racial and ethnic background as well as those with parents who have not graduated from college will also have greater odds of later diagnosis in comparison to their counterparts from white, college-educated families.
4. To examine the extent to which child and family characteristics uniquely explain differences in the observed age of early intervention for infants and toddlers who received a newborn hearing screening. It is anticipated that infants and toddlers with a unilateral hearing loss as well as children with at least one additional special need will experience a higher probability of delayed access to early intervention services. Equally, it is expected that infants and toddlers from non-white racial and ethnic backgrounds as well as those with parents who have not graduated from college will exhibit increased odds of late access into early intervention in contrast to their peers from white, college-educated families.
CHAPTER 3
Research Design & Methods

Target Population

The target population included primary caregivers of children with hearing loss who have recently received or are enrolled in early intervention services provided by the Part C program in North Carolina. EHDI guidelines endorse early intervention for infants with congenital hearing loss no later than 6 months of life. In North Carolina, approximately 170 to 180 infants and toddlers are found eligible for Part C services based on an existing hearing loss each year, and since 2006, enrollment prior to 6 months of age for infants born with a hearing loss has escalated from less than 5% to 44.8% (CDC, 2007). To ensure that the majority of primary caregivers included in the sample had gained some experience with the early intervention system, only parents of children with a diagnosed hearing loss and who were at least 9 months of age at the time of survey distribution were eligible to complete the survey. Conversely, to capture respondents who held a long-term perspective of the early intervention process, caregivers of children who had either transitioned from or whose eligibility for services had expired no more than three months prior to survey distribution were also invited to complete the survey. In other words, the upper age limit for inclusion in this study was restricted to families of children with hearing loss who were 39 months of age at the time of the survey. Thus, the window of eligibility based on child age was 9 to 39 months old.
Survey Design & Administration

To gather a representative sample, a complete list of the target population is required to assure that every eligible participant has the chance to respond. However, privacy safeguards and insufficiency in tracking families after NHS preclude the creation of an accurate and unbiased frame of eligible units. Prior investigations have generated frames from membership lists of national support groups for the hearing-impaired (Harrison, et al., 2003) or longitudinal samples (Meadow-Orlans, et al., 1997). These outlets typically reflect families that demonstrate a willingness to engage social supports or participate in research, and the respondents drawn from such methods often differ significantly from the population of interest.

North Carolina statutes mandate the report and referral of children with a confirmed hearing loss to BEGINNINGS, for Parents of Children Who Are Deaf or Hard of Hearing, Inc. In this study, 460 eligible families were identified by the parent advocate organization, BEGINNINGS, Inc., and their mailing addresses were released via confidential agreement. Five addresses were found insufficient (e.g., no street number, city, state, and/or zip code information), yielding a sample of 455 family contacts. Duplicate copies of mailing addresses were not made, and packages returned unopened were stripped of identifiers.

Survey packages were prepared and sealed under supervision of the principal investigator for shipment on February 23, 2010; each package contained the questionnaire, token incentive, and a pre-addressed business reply envelope. A cover letter displayed in the interior of the survey cover invited caregivers to complete and return the survey and offered explanation of the participant selection methods, the importance of the survey, and confidentiality safeguards. It also detailed sponsorship and project contact information. The
project incorporated multiple design features related to sponsorship, postage, incentives, follow-up contact, and readability to bolster response rates from all survey recipients, especially those from minority subgroups.

**Sponsorship.** Prestige from affiliation with respected institutions has been established as the most influential factor to stimulate higher response rates (Fox, Crask, & Kim, 1998; Linsky, 2001), with a marked bias in favor of university sponsorship. Because disclosure of sponsorship is a highly evocative tool for survey participation, specific affiliations can, in some instances, negatively impact response rate relative to the population under study. This survey project was funded in part by the Division of Speech & Hearing Sciences at the University of North Carolina at Chapel Hill. The university community is well-recognized within the state among families of children with hearing loss for its hospital-based pediatric audiology and cochlear implant programs. Given the anticipated benefit from this affiliation, sponsorship for the survey was disclosed in the cover letter, which also appeared on university letterhead.

**Postage.** Delivery via metered mail, rather than bulk-rate shipping, is known to increase response rate (Fox, Crask, & Kim, 1988; Yammarino, Skinner, & Childers, 1991). Each survey package received first-class priority handling, and all respondents returned the questionnaire using the prepaid business reply envelope.

**Incentives.** Token incentives can raise response rates by eight to 10% when included with the *initial* survey mailing (Dillman, 2007). A black, ball-point pen was included in each mailed survey package to induce higher response rates. Each pen displayed the survey name as well as the name of the partnering organization that assisted in survey distribution, BEGINNINGS, Inc. BEGINNINGS, Inc., provides unbiased parent support to families of
diagnosed children, and it was expected that many families might consider their personal, and hopefully positive, experiences with the organization in their decision to complete the survey.

*Follow-up Contact.* Communication following survey receipt can facilitate a timely response to the survey requests, more so than a pre-notification letter sent to prospective participants (Linsky, 2001). A thank you postcard was mailed on March 3, 2010 to all eligible families, approximately seven to 10 days after receipt of the survey package (see Appendix A). The postcard also provided a reminder to return the completed survey and gave specific requests for participation from sample subgroups. These appeals addressed families of children with ANSD and unilateral hearing loss.

*Inclusion of Minority Subgroups.* Female caregivers represent the respondent majority in survey research regarding children with special needs (Harrison & Roush, 1996; Meadow-Orlans, Mertens, Sass-Lehrer, Scott-Olson, 1997). Cultural values may influence individual participation in social exchanges like surveys (Groves & Couper, 1998); however, these findings have not been confirmed in self-administered (e.g., mail/web) surveys (Jackson et al, 1997). Lower literacy levels among some groups (e.g., disadvantaged educational and/or socio-economic background) can also discourage individuals from participation in a self-administered survey.

In this study, two techniques were employed to enhance the participation of underrepresented groups. First, the token incentive (i.e., a ball-point pen) was included with every survey package. Token financial incentives are known to increase low-income and minority respondent representation in the sample (Kulka, 1994). Second, the readability of the document had been tailored to the fullest extent possible to accommodate a wide range of
reading levels. The Flesch Reading Grade Level test is a system which scores readability based on the average sentence length and the average number of syllables per word. The system rates the text based on a U.S. school grade level. For example, a score of 8.0 means that an eighth grader can understand the document. For most documents, a score of approximately 7.0 to 8.0 is appropriate. The Flesch Reading Grade score for the survey instrument is 4.9. This measure, although a cursory estimate, suggested that the questionnaire was comprehensible to individuals with at least a 5th grade reading level.

**Questionnaire Development**

The development of the *Survey of Infant-Toddler Services* (SITS) represented an expansion of the national mail survey of *Services for Families of Young Children with Hearing Impairments* (Harrison & Roush, 1996). The current instrument has extended the previous study with additional queries on topics such as newborn hearing screening, hearing technology, assessment for intervention services, and perceived social support.

A panel of 10 clinical experts from various fields, including speech-language pathology, pediatric audiology, cochlear implant centers, early childhood, and survey methodology from the UNC-CH community, reviewed the SITS instrument. They offered feedback on (a) the coherence of the project’s stated objectives with the survey’s actual content, (b) the inclusion or exclusion of specific questions to better address objectives, (c) the accuracy of the content for individual questions, and (d) the appropriate use of skip logic or alternate paths for question order. The finished document was a 64-item questionnaire with multiple question formats including forced choice, check-all, matrix, and open-ended styles. To reduce response burden, a patterned skip logic directed respondents to answer
questions presumed pertinent to their child’s or family’s experience. Sixteen skips appeared in the completed questionnaire. The SITS contained six sections on the following topics:

1. **Section A: About Your Child** included nine items that asked about the sex, age, and hearing of the child with a confirmed loss or disorder. It covered questions about the laterality, severity, and etiology of hearing loss.

2. **Section B: Newborn Hearing Screening & Audiologic Management** contained 13 questions on newborn hearing screening status, confirmation of hearing loss, and hearing aid fitting. This section also incorporated questions regarding potential reasons for delay in audiologic management and later cochlear implantation.

3. **Section C: Evaluation for Infant and Toddler Services** consisted of two items that asked about the role of the primary caregiver in activities related to the assessment of the child with hearing loss. Parents were prompted to respond whether they *did* or *did not* have the opportunity to participate in key elements of the evaluation. Similar approaches to rate the caregiver’s level of involvement during a multidisciplinary child assessment have been used with the infant and toddler population in North Carolina (Simeonsson, Edmonson, Smith, Carnahan, & Bucy, 1995; Crais, Poston-Roy, & Free, 2006;)

4. **Section D: Designing the Individual Family Service Plan** (IFSP) included six items with two matrices about the caregiver’s experiences related to IFSP development. This section retained six original questions from the survey conducted by Harrison and Roush (1996) with families of children who were deaf or hard of hearing. Because the state early intervention system employs both state providers and contractual private providers, some caregivers might not have been informed as to whether their child was actively enrolled in ‘Part C’ services. However, the majority of caregivers (Bailey 2004) do recall
participation in the planning of their infant’s or toddler’s services. As such, the gateway question to this portion of the questionnaire “Was an IFSP developed with your family?” served as a proxy measure for enrollment in the state early intervention program. Parents who indicated that an IFSP had been developed for their child and that they were currently receiving services were assumed to have enrolled in the Part C program.

5. **Section E: Your Family’s Infant and Toddler Services** was comprised of 21 items that discussed various aspects of service delivery (e.g., location, frequency, and start of services). In addition, it contained an adapted form of the *Family Support Scale* (FSS, Dunst, Trivette, & Jenkins, 1994), a measure of how helpful potential sources of social support have been to families. The original FSS presented 18 items that described sources of help related to six subscales: formal kinship, informal kinship (e.g., friends, other parents, church), nuclear family, social organizations (e.g., parent groups, coworkers), general and specialized professional services. Respondents rated each item on a five-point, Likert-scale response ranging from “Not at All Helpful” to “Extremely Helpful”. Respondents could write-in unique sources of help and rate them or indicate that a particular source was “Not Available.” The scale was developed for use with families of preschoolers who had physical handicaps, intellectual disability or were at-risk for other developmental delay. The modified FSS revised the sources of general professional support to inquire about four sources of specialized professional support: the family advocate program or service, the speech-language pathologist, the teacher of the deaf or hard of hearing, and the audiologist.
6. Section F: About Your Family consisted of 13 items about the caregiver and siblings of the child with hearing loss. The questions related to the racial, linguistic and educational background of the primary and/or secondary caregivers.

Data Collection & Analysis

Prior to distribution, each SITS form was coded with a numeric case ID to represent the subject ID. Returned surveys were compiled into batches and reviewed to assess the accuracy of responses. The status of the case ID for each survey was updated in a locked MS Excel spreadsheet. The taxonomy for case ID status is presented in Table 3.1.

Table 3.1: Taxonomy of Case ID Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete</td>
<td>A completed survey returned by an eligible respondent</td>
</tr>
<tr>
<td>Received Blank</td>
<td>A blank survey returned by the respondent</td>
</tr>
<tr>
<td>Ineligible</td>
<td>A returned survey that is completed by an ineligible respondent</td>
</tr>
<tr>
<td>No Response</td>
<td>A survey not returned by the EI program or a respondent</td>
</tr>
<tr>
<td>Not Distributed</td>
<td>A blank survey returned by the EI program</td>
</tr>
<tr>
<td>Not Delivered</td>
<td>A returned survey with an incorrect mailing address</td>
</tr>
</tbody>
</table>

Data from completed surveys was coded using CS Pro 4.0, a survey software package available online through the US Census Bureau. This software has programmable validation parameters to reduce data entry error. Ten percent of the coded surveys were randomly selected for manual validation to gauge the accuracy of data entry. Response rate from the mailed survey was calculated as:

\[
\text{Response Rate} = \frac{\text{Complete} - \text{Ineligible}}{\text{Complete} + \text{Received Blank} - \text{Ineligible} - \text{Not Delivered}}
\]

All statistical analyses were conducted using SAS 9.2 software.
CHAPTER 4

Results

This investigation sought to identify the services typically provided to families of infants and toddlers with hearing loss as well as to assess how factors related to the child or family predicted the timely provision of follow-up services subsequent to newborn hearing screening. For this reason, the analysis addressed two primary goals: a) a descriptive report to ascertain the variability in follow-up care for infants and toddlers with hearing loss and b) an inferential analysis of factors associated with the child or family that raised the likelihood of delays in service provision. The section that follows presents results from the descriptive analysis while inferential statistics are addressed in the latter half of this chapter.

Sample Characteristics

Response Rate. Data collection for the SITS began on February 22, 2010 and concluded on September 22, 2010. From the 455 mailed survey packages, a total of 158 questionnaires were returned to UNC’s Division of Speech & Hearing Sciences. Of these returns, 46 surveys were received as ‘non-deliverable’ with the status of insufficient or unknown address, moved with no forwarding address, or lack of a mail receptacle. An additional 12 surveys were coded as ‘ineligible’ because the respondent’s child was over 39 months of age, the child’s age was not indicated, or the field period for data collection had ended. Two families returned surveys indicating that their infant was less than 9 months of age; their questionnaires were included in the sample as each family indicated that they had
at least 3 months of experience with early intervention services. No blank questionnaires were returned by the recipient to suggest an ‘overt’ or ‘hard’ refusal to complete the survey. A subsequent 100 surveys remained eligible for analysis, yielding an overall response rate of 25% \[=100/(455-58)\] for all delivered questionnaires.

**Respondent Characteristics.** Mothers served as respondents for the majority of the sample (92%); although 5% of the sample was reported by fathers or grandmothers. The median age for respondents was 32 years of age, with a range of 20 to 46 years. Most parents (79%) reported some experience with higher education, and 58% of the parents indicated that they had graduated from college. Only 18% of the sample had not received any post-secondary education. Approximately 78% of parents reported that another parent lived in the home; and for those caregivers, 62% had attended college or vocational school with approximately 42% attaining either an undergraduate or graduate degree. Eleven parents reported that English was not the only language spoken in the home, with Spanish as the most frequently cited addition. One-quarter of families described their area of residence as ‘rural’ whereas 59% indicated that they lived in either a small or large city. The majority of caregivers was Caucasian; and representation among African-American or Hispanic families was considerably less, around 10%. Approximately 80% of parents indicated that they were married and another 14% reported that they had never been married. Table 4.1 reports the key demographic characteristics of respondents to the SITS.
Table 4.1: Demographic Characteristics of Respondents

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Percent % (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to Child</td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>92</td>
</tr>
<tr>
<td>Father</td>
<td>3</td>
</tr>
<tr>
<td>Grandmother</td>
<td>2</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Never Married</td>
<td>14</td>
</tr>
<tr>
<td>Married</td>
<td>80</td>
</tr>
<tr>
<td>Divorced</td>
<td>3</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
</tr>
<tr>
<td>Level of Educational Attainment</td>
<td></td>
</tr>
<tr>
<td>Under 12\textsuperscript{th} Grade</td>
<td>6</td>
</tr>
<tr>
<td>High School Diploma</td>
<td>12</td>
</tr>
<tr>
<td>Junior College/Technical School</td>
<td>7</td>
</tr>
<tr>
<td>Some College</td>
<td>14</td>
</tr>
<tr>
<td>Four-Year College Graduate</td>
<td>40</td>
</tr>
<tr>
<td>Graduate School</td>
<td>18</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
</tr>
<tr>
<td>Racial/Ethnic Background</td>
<td></td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>72</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>10</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>10</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>3</td>
</tr>
<tr>
<td>Native American</td>
<td>1</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
</tr>
<tr>
<td>Language Spoken at Home</td>
<td></td>
</tr>
<tr>
<td>English Only</td>
<td>86</td>
</tr>
<tr>
<td>Spanish</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
</tr>
<tr>
<td>Geographic Location</td>
<td></td>
</tr>
<tr>
<td>Large City</td>
<td>33</td>
</tr>
<tr>
<td>Small City</td>
<td>26</td>
</tr>
<tr>
<td>Suburb</td>
<td>10</td>
</tr>
<tr>
<td>Rural Area</td>
<td>25</td>
</tr>
<tr>
<td>Unknown</td>
<td>6</td>
</tr>
</tbody>
</table>
**Child Characteristics.** As shown in Table 4.2, the age of infants and toddlers reported by caregivers ranged from 7 months to 39 months, with a median age of 26 months old. Sample representation was rather evenly divided by sex with 52% of parents reporting on males and 48% reporting on females. Thirty percent of the parents also stated that their child had at least one special need in addition to hearing loss. Over one-half (56%) of caregivers indicated that the cause of their child’s hearing loss was currently unknown. Other parents cited genetics (17%), prematurity (13%), and/or other factors (21%; e.g., meningitis, hypoxia, hyperbilirumenemia, etc.) when asked about the cause of their child’s hearing loss. Infants and toddlers with a unilateral hearing loss comprised 30% of the sample; and of those children, two-thirds were affected in the left ear, whereas 30% were affected in the right ear. Over half the sample included current hearing aid users while another 13% had at least one cochlear implant. The remainder of infants and toddlers (35%) were reported as unaided. Nearly 80% of caregivers indicated that an IFSP had been completed for their child.

**Descriptive Analysis**

This section summarizes the early intervention services received by families of infants and toddlers based on parents’ report from the SITS. It also describes age-related differences in the receipt of follow-up care based on features unique to the child or family. These results are framed in reference to the first two research questions.
<table>
<thead>
<tr>
<th>Child Characteristics</th>
<th>Percent % (n=100)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>52</td>
</tr>
<tr>
<td>Females</td>
<td>48</td>
</tr>
<tr>
<td>Additional Special Needs</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>30</td>
</tr>
<tr>
<td>No</td>
<td>70</td>
</tr>
<tr>
<td>Cause of Hearing Loss</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>56</td>
</tr>
<tr>
<td>Genetic</td>
<td>17</td>
</tr>
<tr>
<td>Prematurity</td>
<td>12</td>
</tr>
<tr>
<td>Ototoxic Drugs</td>
<td>7</td>
</tr>
<tr>
<td>Other</td>
<td>27</td>
</tr>
<tr>
<td>Laterality of Hearing Loss</td>
<td></td>
</tr>
<tr>
<td>Unilateral</td>
<td>30</td>
</tr>
<tr>
<td>Bilateral</td>
<td>69</td>
</tr>
<tr>
<td>Unknown</td>
<td>1</td>
</tr>
<tr>
<td>Severity of Hearing Loss (Bilateral, n=69)</td>
<td></td>
</tr>
<tr>
<td>Mild to Moderate</td>
<td>30</td>
</tr>
<tr>
<td>Moderate to Severe</td>
<td>7</td>
</tr>
<tr>
<td>Severe to Profound</td>
<td>11</td>
</tr>
<tr>
<td>Auditory Neuropathy Spectrum Disorder</td>
<td>5</td>
</tr>
<tr>
<td>Unknown</td>
<td>16</td>
</tr>
<tr>
<td>Severity of Hearing Loss (Unilateral, n=30)</td>
<td></td>
</tr>
<tr>
<td>Mild to Moderate</td>
<td>12</td>
</tr>
<tr>
<td>Moderate to Severe</td>
<td>1</td>
</tr>
<tr>
<td>Severe to Profound</td>
<td>13</td>
</tr>
<tr>
<td>Auditory Neuropathy Spectrum Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
</tr>
<tr>
<td>Assistive Listening Technology</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>35</td>
</tr>
<tr>
<td>Hearing Aids</td>
<td>52</td>
</tr>
<tr>
<td>Cochlear Implant(s)</td>
<td>13</td>
</tr>
<tr>
<td>IFSP Completed</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>79</td>
</tr>
<tr>
<td>No</td>
<td>18</td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
</tr>
</tbody>
</table>
Research Question 1: How do caregivers’ perceive the early intervention process and what types of services are most commonly received by families at intervention?

Timeliness of Follow-up Care after Diagnosis of Hearing Loss

Once a hearing loss is confirmed by an audiologist, families may seek assistive listening technology to maximize the audibility of acoustic stimuli for their child; particularly for children with bilateral loss, the provision of amplification is a key component of effectual auditory learning. Approximately two-thirds of infants and toddlers (64%) received hearing aid amplification following diagnosis. Over one-quarter (28%) of children who were bilaterally fit with aids following screening received amplification within 3 to 4 weeks after diagnosis, although other families experienced delays of up to 12 weeks following diagnosis. In fact, more than 32% of parents recalled that they did not receive hearing aids for their child until at least 2 months after confirmation of hearing loss. When those caregivers were queried about their satisfaction with this delay, two-thirds of them felt that it was a reasonable period of time to wait for amplification. The remainder of caregivers perceived the time between audiologic confirmation of hearing loss and hearing aid fitting as either ‘a little too long’ or ‘much too long.’ The main causes for a prolonged wait for amplification, according to families, related to a delay in third-party payments like Medicaid or private insurance or difficulty receiving reliable follow-up care. Some parents described the latter experience as “different suggestions by different audiologists,” “too many referrals,” or “misdiagnosis from other doctors.”

In regard to the start of early intervention, delays were also reported among caregivers. More than one-third (34%) of caregivers reported a duration of at least three months between their child’s diagnosis and the start of services; however, around 79% of
those parents perceived this wait as ‘reasonable.’ Very few families described the cause for delay (16%); however, the chief reasons noted were difficulty scheduling services and a lack of vigilance in the provision follow-up services (e.g., “didn’t know about services,” “not contacted by CDSA,” “too much work to find who to contact and intake”).

Assessment and Planning of Early Intervention Services

Assessment for Services. Almost all (97%) of parents reported that their child had received evaluation for early intervention services. Based on caregiver report, over 90% of those respondents felt they had shared their most important concerns with professionals, been given an invitation to attend all testing activities, and received time to provide feedback on their child’s testing performance. A similar proportion of caregivers indicated that team members had successfully ensured that he or she understood the purpose of all activities and tests during the child’s evaluation. Yet, for those parents who reported that their child had been evaluated, approximately one-quarter of them also noted that they had not completed any checklists or provided any written observations of their child’s behavior for consideration during testing.

Following assessment, planning for early intervention services by professional and family team members constitutes an integral component of the early intervention process in which concerns, priorities and goals for both the child and family are shared. This component is required under the statutes for provision of Part C state infant and toddler programs; and as such, is a tangible marker for recall of enrollment in early intervention. Caregivers who indicated that they had completed an early intervention service plan, or IFSP, and were currently receiving intervention services were assumed to have been enrolled in Part C. Nearly two-thirds of caregivers (64%) indicated that an IFSP was completed for their
family and that their child was currently enrolled or had recently transitioned from early intervention services in North Carolina.

*IFSP Development.* Caregiver impressions regarding development of the IFSP were almost uniformly favorable. The majority of parents felt that they were allowed to make decisions at their own pace during the process (93%) and were perceived as equal partners when planning goals (92%). Most caregivers agreed that they had the ability to decide their family’s priorities during planning (88%), a sufficient amount of time to read and review the IFSP document (91%), and were comfortable with the finished IFSP when they signed it (89%). Still, roughly one-quarter (26%) of families indicated that they did not have any influence regarding who would participate on the IFSP team or were uncertain if they had. A smaller percentage (17%) related that they would have preferred to be more involved in the development of their infant or toddler’s service plan. Overall, 87% of parents reported that in the event of a disagreement among team members during planning, their opinion was ‘given the more weight’ in decision-making. The remainder of families (12%), by and large, reported that they were undecided on how their opinion contributed to the resolution of any disputes during IFSP development. Parental accounts of the professional team members after the IFSP was established were equally positive. Over 90% of caregivers related that all members carried out the formalized plan and provided services in accordance with their family’s priorities. Eighty-nine percent agreed that team members also provided assistance with scheduling for services and testing. However, roughly one-fifth (21%) of parents did not feel or were uncertain if team members modified the IFSP as their child progressed. While virtually all parents (98%) indicated that their family’s schedule was considered when services were planned and that the amount of services received was ‘about right’ (95%),
approximately one-fifth of caregivers stated that they did not have a choice about how often their family received services. Similarly, another 25% of parents reported they were not sure or did not have a choice about where the family received those services. However, most parents (89%) indicated that they did have a choice about how much they participated in the services with their infant or toddler.

_Provision of Early Intervention Services_

_Components of Service Delivery._ As presented in Table 4.3, more than half of all currently enrolled families (59%) reported that they had received services for at least 6 to 18 months prior to completing the SITS. The family home was the most commonly reported location for intervention sessions (74%), followed distantly by services in a day-care center (17%). A teacher of the deaf or hard of hearing served most frequently as the primary provider seen most often, according to parent report (see Table 4.4 Professional Background of Primary Providers and Team Members). Speech-language pathologists and early childhood special educators were less prominently listed among primary providers, serving roughly 12 to 13% of families. When not acting as the primary provider, representation across team members for teachers of the deaf and speech-language pathologists was equally high. Approximately 11% of families did not report that an audiologist was included on their team. Most parents (64%) stated that their early intervention team included between 2 to 4 different professionals, although some families reported as many as 8 separate professionals on their team.
Table 4.3: Duration in Early Intervention at the Time of Survey

<table>
<thead>
<tr>
<th>Duration of Early Intervention</th>
<th>Percent %</th>
<th>Cumulative Percent %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 6 months</td>
<td>10.94</td>
<td>10.94</td>
</tr>
<tr>
<td>6 to 12 months</td>
<td>28.13</td>
<td>39.06</td>
</tr>
<tr>
<td>13 to 18 months</td>
<td>31.25</td>
<td>70.31</td>
</tr>
<tr>
<td>19 to 24 months</td>
<td>14.06</td>
<td>84.38</td>
</tr>
<tr>
<td>25 to 30 months</td>
<td>9.38</td>
<td>93.75</td>
</tr>
<tr>
<td>Over 30 months</td>
<td>6.25</td>
<td>100.00</td>
</tr>
</tbody>
</table>

Table 4.4: Professional Background of Primary Providers and Team Members

<table>
<thead>
<tr>
<th>Provider’s Profession</th>
<th>Primary Provider (%)</th>
<th>Team Member Only (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Childhood Special Educator</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>Infant-Toddler Specialist</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Teacher of the Deaf/Hard of Hearing</td>
<td>44</td>
<td>32</td>
</tr>
<tr>
<td>Speech-Language Pathologist</td>
<td>13</td>
<td>35</td>
</tr>
<tr>
<td>Audiologist</td>
<td>2</td>
<td>89</td>
</tr>
<tr>
<td>Physical Therapist</td>
<td>10</td>
<td>23</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>2</td>
<td>27</td>
</tr>
<tr>
<td>Social Worker</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>19</td>
</tr>
</tbody>
</table>

*Communication Mode.* Forty-three percent of parents indicated that they had adopted a spoken language approach for intervention with their child while just over one-fifth (21%) had decided to pursue sign language, typically in combination with spoken language (17%). When infants or toddlers with a bilateral hearing loss were considered, the proportion of families who had adopted a spoken language approach remained relatively high, around 44%. Only 11% of families stated that the primary provider who was responsible for instruction in the family’s chosen mode of communication was ‘somewhat’ skilled while the remainder cited that their provider was ‘very skilled’; no caregivers perceived their provider as ‘not at
Parents’ perception of their primary provider’s skills was relatively equivalent across families irrespective of their chosen mode of communication.

*Types of Services.* With regard to the specific activities and forms of help that occurred during intervention, a markedly high degree of compatibility occurred between the services commonly received by families and those that they desired. Table 4.5 displays rankings for the 10 most commonly provided and desired services based on parent report. These services were associated with suggested materials and strategies to facilitate language development and communication, help with assistive listening technology, and emotional or social support. Of interest, three of the 10 most highly ranked services desired by families did not appear on the list of frequently provided services. They included: a) encouraging the parent to be the major decision-maker about his or her child, b) giving the parent time to express his or her feelings about having a child with hearing loss, and c) helping the parent find community activities and programs for his or her child that were (or could be made) communication accessible. The least desired services among parents involved social supports for their family and child such as: meeting adults with hearing loss, finding funding for services, and contacting parents of other children with hearing loss.

Table 4.5: Rankings of Top 10 Most Commonly Provided and Desired Services

<table>
<thead>
<tr>
<th>Rank</th>
<th>Top 10 Most Commonly Provided Services</th>
<th>Rank</th>
<th>Top 10 Most Commonly Desired Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Show you how to use toys, books and play to develop language</td>
<td>1</td>
<td>Use your suggestions about how to work with your child</td>
</tr>
<tr>
<td>2</td>
<td>Use your suggestions about how to work with your child</td>
<td>2</td>
<td>Show you how to use toys, books and play to develop language</td>
</tr>
<tr>
<td></td>
<td>Help you feel you can positively affect your child’s development</td>
<td>3</td>
<td>Show you strategies to develop language during your child’s daily activities such as dressing or bathing</td>
</tr>
</tbody>
</table>
**Research Question 2: What are the median ages of diagnosis, amplification, and intervention for infants and toddlers identified through newborn hearing screening?**

Nearly all (93%) children had received a hearing screening at birth with at least three-quarters (77%) of those requiring referral for an additional screening. For those infants who passed their initial screening, a referral from a later hearing screening served as the most frequent cause (11%) for concern among parents regarding their child’s hearing status. Atypical speech development, poor response to acoustic stimuli, and a prolonged hospital stay were also evenly ranked (at 6% each) by parents as reasons for suspicion of a hearing loss. A few caregivers also noted that concerns expressed by their health care provider (5%) and family or friends (2%) prompted their suspicion about the status of their child’s hearing.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Top 10 Most Commonly Provided Services</th>
<th>Rank</th>
<th>Top 10 Most Commonly Desired Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Show you strategies to develop language during your child’s daily activities such as dressing or bathing</td>
<td>4</td>
<td>Help you feel you can positively affect your child’s development</td>
</tr>
<tr>
<td></td>
<td>Help you learn your child’s communication approach</td>
<td>5</td>
<td>Help you learn your child’s communication approach</td>
</tr>
<tr>
<td>6</td>
<td>Give helpful suggestions to manage your child’s behavior</td>
<td>6</td>
<td>Encourage you to be the major decision-maker about your child</td>
</tr>
<tr>
<td>7</td>
<td>Demonstrate knowledge of your child’s equipment</td>
<td>7</td>
<td>Give you time to express your feelings about having a child with hearing loss</td>
</tr>
<tr>
<td>8</td>
<td>Help you fill out forms</td>
<td>8</td>
<td>Give helpful suggestions to manage your child’s behavior</td>
</tr>
<tr>
<td>9</td>
<td>Help you find parent support groups</td>
<td>9</td>
<td>Help you find community activities and programs for your child that were (or could be made) communication accessible</td>
</tr>
<tr>
<td>10</td>
<td>Help you learn to troubleshoot the hearing aid and/or cochlear implant.</td>
<td></td>
<td>Help you find parent support groups</td>
</tr>
</tbody>
</table>

51
Referral from Newborn Hearing Screening. As displayed in Figure 4.1, infants who did not pass their newborn hearing screening were reportedly identified with hearing loss between the ages of 1 to 25 months. For children who passed the newborn screening, diagnosis occurred between 3 months and 28 months of life. One-half of those infants who did not pass the initial screening received an audiologic confirmation of hearing loss by the 2nd month of life. Children who passed their initial screening were diagnosed later, with an estimated 50% of those babies receiving a confirmation by 11 months of age.

Table 4.6 shows that the median age of hearing aid fitting for newborns who did not pass the initial screening occurred around 6 months of age. In contrast, 50% of newborns who passed the initial screening were fit after their first birthday, around 14.5 months of age. By 5 months of age, half of the infants in the subsample that did not pass the initial screening had also begun to receive early intervention services; in contrast, the median age for early intervention for newborns who passed the initial screening occurred around 11.5 months of age.

Additional Special Needs. Roughly one-third of parents (30%) in the sample stated that their child had one or more special needs attendant to a hearing loss. The most commonly reported needs related to a visual loss or impairment, developmental delays, cerebral palsy and a neurological disorder, impairment or anomaly (e.g., seizure disorder, stroke, small cerebellum). Table 4.7 reports the median ages of diagnosis, hearing aid fitting, and start of intervention for children who did not pass the initial hearing screening based on whether their parent indicated the presence of an additional special need. Figure 4.2 shows
Table 4.6: Median Ages, in Months, of Diagnosis, Hearing Aid Fitting, and Intervention based on Status After Newborn Hearing Screening

<table>
<thead>
<tr>
<th>Status After Newborn Hearing Screening</th>
<th>Pass</th>
<th>Did Not Pass</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at Diagnosis</td>
<td>11.0 (15)$^a$</td>
<td>2.0 (73)</td>
</tr>
<tr>
<td>Age at HA Fitting</td>
<td>14.5 (8)</td>
<td>6.0 (49)</td>
</tr>
<tr>
<td>Age at Intervention</td>
<td>11.5 (14)</td>
<td>5.0 (67)</td>
</tr>
</tbody>
</table>

$^a$ Sample size (n) in parentheses.
the distribution of ages for each event based on the child’s special needs status. For those children with at least one special need other than hearing loss, the median ages of diagnosis and hearing aid fitting took place around 4.5 and 11 months of age, respectively. These ages were comparatively later than children who were never diagnosed with additional special needs and a co-morbid hearing loss; for those infants and toddlers, the median age of diagnosis and amplification occurred at a corresponding two and five months of age. In spite of this, children with concomitant special needs experienced a relatively earlier start to intervention, with about half receiving services by 4 months of age. In contrast, the median age of intervention for infants and toddlers diagnosed with hearing loss only was 6 months of age.

Laterality of Hearing Loss. Approximately one-third of caregivers reported that their child had hearing loss in only one ear. Table 4.7 provides the median ages of diagnosis, amplification, and intervention based on laterality for newborns who received referral after hearing screening. Figure 4.3 displays the distribution of ages for each event for children with a unilateral or bilateral hearing loss. For children with unilateral hearing loss, confirmation of hearing loss occurred around 2 months of age and did not differ substantially from that of infants with bilateral hearing loss, half of which were identified by 2.5 months of age. Only three infants with a diagnosed unilateral hearing loss following screening received amplification; however, the age of hearing aid fitting for bilateral children referred from newborn screening was 6 months of age. The start of early intervention services was found to be earlier for children with bilateral hearing loss, with half of the sample reported to begin services by 5 months of age; however, the median age for intervention for children who were affected in one ear was somewhat later, occurring around 7 months of age.
Figure 4.2 Boxplots of Ages of Diagnosis, Hearing Aid Fitting, and Early Intervention by Special Needs Status

No = Hearing Loss Only
Yes = Additional Special Need(s)

Figure 4.3 Boxplots of Ages of Diagnosis, Hearing Aid Fitting, and Early Intervention by Laterality of Hearing Loss
Table 4.7: Median Ages, in Months, of Diagnosis, Hearing Aid Fitting, and Intervention after Newborn Hearing Screening based on Special Needs Status and Hearing Loss

<table>
<thead>
<tr>
<th></th>
<th>Special Needs Status</th>
<th>Laterality of Hearing Loss</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HL Only</td>
<td>Additional Special Needs</td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td>2.0 (55)(^a)</td>
<td>4.5 (18)</td>
</tr>
<tr>
<td>Age at HA Fitting</td>
<td>5.0 (36)</td>
<td>11.0 (13)</td>
</tr>
<tr>
<td>Age at Intervention</td>
<td>6.0 (48)</td>
<td>4.0 (19)</td>
</tr>
</tbody>
</table>

\(^a\) Sample size (n) in parentheses.
\(^b\) Median not reported due to sample size of less than 5 cases.

**Racial/Ethnic Minority Status.** Group membership based on racial/ethnic minority status in the sample was defined as identification of White or Caucasian background versus non-White racial or ethnic identity (i.e., African-American, Hispanic, Asian, or Native American). Based on this classification, exactly three-quarters (75%) of the sample was categorized as White and another 24% as non-White. Figure 4.4 displays the distribution for ages of diagnosis, hearing aid fitting, and start of intervention based on the caregiver’s racial/ethnic minority status. As seen in Table 4.8, the median age of identification for children of non-White families was at 3 months of age and later than their White counterparts, half of whom were diagnosed by the age of 2 months. Similarly, the median age of hearing aid fitting occurred at 7 months for non-White families as opposed to 5 months for White families. In this sample, the median age for start of early intervention was the same across groups at 5.5 months of age.

**Level of Educational Attainment.** Families were again classified according to the highest level of education completed by the primary caregiver who served as respondent to
the SITS. Three groups were created to describe caregivers who had a) received a high school diploma or did not complete secondary education, b) attended some college or completed a technical school/junior college degree, or c) graduated from a 4-year college or graduate school. These groups appear in Figure 4.5 and Table 4.8 labeled as ‘high school,’ ‘some college,’ and ‘college graduate,’ respectively. As shown in the table and figure, infants and toddlers of parents in the ‘some college’ group had relatively higher median ages of diagnosis and hearing aid fitting in comparison to other groups. However, their median age for the start of early intervention was comparatively lower - at around 4 months, as opposed to the median ages of 5.5 months (high school) and 6 months (college graduate) for the other groups.
Table 4.8: Median Ages, in Months, of Diagnosis, Hearing Aid Fitting, and Age at Intervention based on Racial/Ethnic Minority Status and Level of Educational Attainment

<table>
<thead>
<tr>
<th>Racial/Ethnic Minority Status</th>
<th>Level of Educational Attainment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High School</td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td>2.0 (53)a</td>
</tr>
<tr>
<td>Age at HA Fitting</td>
<td>5.0 (33)</td>
</tr>
<tr>
<td>Age at Intervention</td>
<td>5.5 (48)</td>
</tr>
</tbody>
</table>

Note: 1 = High School Diploma or Less, 2 = Technical School or Some College, 3 = College Graduate

*a Sample size (n) in parentheses.
**Perceived Social Support.** Respondents were asked to complete a modified version of the *Family Support Scale* (Dunst, 1994) that was amended to incorporate sources of professional support unique to intervention for infants and toddlers with hearing loss. In total, the scale included 20 distinct sources of support related to: kinship, friendship, the community and formal services. Parents who completed the SITS rated each source of support based on a 5-point Likert scale ranging from 1 ‘Not at all Helpful’ to 5 or ‘Extremely Helpful.’ For the purpose of analysis, data were rescaled to an absolute scale where a value of *zero* signified ‘Not at all Helpful’ and a value of 4 equaled ‘Extremely Helpful.’ Table 4.9 displays the mean score with corresponding standard deviation and the number of parents to whom each source of help was available. Of all potential sources of help, spousal support received the highest score. Of all professional sources of help, the teacher of the deaf and hard of hearing received the top ranking followed closely by the audiologist. Speech-language pathologists were only perceived as moderately helpful to families and followed closely by help from the family physician.

Four Spearman rho rank order correlations were conducted to assess the degree of relationship, if any, among two measures of support and the ages of diagnosis and intervention for each child. The first correlation showed almost no association between the number of available sources of help and the age of diagnosis (rho = 0.04, p = 0.6874); and the second revealed a small negative relationship between the number of available sources of help and the age of intervention (rho = -0.13), although it was not statistically significant (p = 0.24). For the second set of correlations, a ‘perceived social support score’ was derived as the sum of caregiver ratings across all 20 items weighted by the number of available supports (perceived social support = total sum score ÷ number of available supports).
positive relationship was found between the ages of diagnosis (\( \rho = 0.12415, \ p = 0.25 \)) and intervention (\( \rho = 0.190, \ p = 0.09 \)) and the perceived support score; however, neither was significant.

Table 4.9: Mean Scores for Caregiver Evaluations of Perceived Social Support

<table>
<thead>
<tr>
<th>Source of Help</th>
<th>Mean</th>
<th>SD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>3.46</td>
<td>0.94</td>
<td>87</td>
</tr>
<tr>
<td>Teacher of D/HH</td>
<td>3.11</td>
<td>1.04</td>
<td>56</td>
</tr>
<tr>
<td>My parents</td>
<td>2.97</td>
<td>1.18</td>
<td>70</td>
</tr>
<tr>
<td>Audiologist</td>
<td>2.85</td>
<td>1.01</td>
<td>81</td>
</tr>
<tr>
<td>My children</td>
<td>2.84</td>
<td>1.17</td>
<td>45</td>
</tr>
<tr>
<td>Daycare</td>
<td>2.68</td>
<td>1.09</td>
<td>38</td>
</tr>
<tr>
<td>My spouse’s parents</td>
<td>2.64</td>
<td>1.42</td>
<td>66</td>
</tr>
<tr>
<td>Family program</td>
<td>2.54</td>
<td>1.16</td>
<td>41</td>
</tr>
<tr>
<td>Speech therapist</td>
<td>2.47</td>
<td>1.00</td>
<td>47</td>
</tr>
<tr>
<td>Relatives</td>
<td>2.42</td>
<td>1.14</td>
<td>67</td>
</tr>
<tr>
<td>Family doctor or Pediatrician</td>
<td>2.35</td>
<td>1.09</td>
<td>82</td>
</tr>
<tr>
<td>Church</td>
<td>2.25</td>
<td>1.24</td>
<td>56</td>
</tr>
<tr>
<td>My friends</td>
<td>2.12</td>
<td>1.11</td>
<td>76</td>
</tr>
<tr>
<td>Social club</td>
<td>2.10</td>
<td>1.41</td>
<td>20</td>
</tr>
<tr>
<td>My spouse’s relatives</td>
<td>1.93</td>
<td>1.46</td>
<td>67</td>
</tr>
<tr>
<td>Parent support groups</td>
<td>1.86</td>
<td>1.15</td>
<td>28</td>
</tr>
<tr>
<td>Other parents</td>
<td>1.78</td>
<td>1.26</td>
<td>49</td>
</tr>
<tr>
<td>My spouse’s friends</td>
<td>1.73</td>
<td>1.24</td>
<td>64</td>
</tr>
<tr>
<td>Co-workers</td>
<td>1.70</td>
<td>1.28</td>
<td>43</td>
</tr>
</tbody>
</table>
Inferential Analysis

Predictors of Later Diagnosis

Research Question 3: To what extent do child and family characteristics uniquely explain differences in the observed age of diagnosis for infants and toddlers identified through newborn hearing screening?

Multiple logistic regression analyses were conducted to explore how factors related to the child and family impacted the odds that an infant who had received a hearing screening at birth would receive a diagnosis after the age of 3 months. Two analyses were performed to compare the predictive value of a model that included child predictors to a model containing predictors for the child and family. For both analyses, the data for ‘age of diagnosis in months’ were censored to create a binary variable with values 0 and 1, where 0 represented a confirmation of hearing loss at or before 3 months of age and 1 indicated a confirmation occurring after 3 months of age. Each regression modeled the log odds of ‘the event’ that a diagnosis was received after 3 months of age.

In the first analysis, the child predictors for screening results (i.e. pass versus refer status), presence of other special needs (i.e., present versus absent), and laterality of hearing loss (i.e., unilateral versus bilateral) were entered. The chi-square test for the likelihood ratio was significant [$\chi^2 (3) = 21.8154, p<0.0001$], demonstrating that at least one predictors’ regression coefficient was not equal to zero as tested under the null hypothesis that none of the independent variables have any predictive value. A Wald’s chi-square test (see Table 4.10) revealed that two child predictors, ‘screening status’ [$\chi^2 (1) = -2.23, p=0.0069$] and ‘presence of other special needs’ [$\chi^2 (1) = 1.39, p=0.0105$], were significant (p≤ 0.050). Under this model, infants who had a ‘refer status’ following hearing screening had a 2.23
decrease in their log odds of receiving a diagnosis after three months when other variables in
the model were statistically controlled. Converting the log odds to odds ratios shows that
infants referred from newborn screening have a substantial decrease in their odds of
receiving a later diagnosis; more explicitly, they are 0.107 times as likely to receive a
diagnosis of hearing loss after three months of age when other predictors are held constant.
Likewise, a child with ‘at least one special need in addition to hearing loss’ had a 1.39
increase in their log odds of receiving a diagnosis after three months of age holding all other
predictors constant. If the log odds are interpreted as an odds
ratio, then it reveals that a child with more than one special need is 4.01 times as likely to
obtain a diagnosis after three months of age. The odds of a later diagnosis did not differ
significantly for children with unilateral as opposed to bilateral hearing loss. Table 4.10
depicts the odds ratios for the regression analysis. The overall model fit reflects better than
chance levels based on model fit statistics. Without any predictors the -2 Log Likelihood (-2
Log L) = 120.352, which is a global measure of variability in the sample; however, with the
three predictors included in the model, -2 Log L = 98.537 which indicates 21.815 decrease in
the amount of unexplained variation after accounting for the child variables.

In the second analysis, a set of family variables were introduced into the existing
model to represent the caregiver’s racial/ethnic background, level of educational attainment,
and perceived level of social support. Data for educational attainment were dummy coded in
reference to the majority group, college graduates who composed 58% of the sample. Two
dummy variables were constructed: ‘high school’ defined respondents who had completed
secondary schooling up to the 12\textsuperscript{th} grade, and ‘some college’ described caregivers who had *completed* junior college or technical school or *attended but did not graduate* from a college.

Table 4.10: Logistic Regression Model for Prediction of Diagnosis After 3 Months of Age Based on Child Factors (n = 88)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>( \beta )</th>
<th>SE ( \beta )</th>
<th>Wald’s ( \chi^2 )</th>
<th>df</th>
<th>p</th>
<th>Odds Ratio ( (e^\beta) )</th>
<th>95% Wald Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>1.2217</td>
<td>0.8118</td>
<td>2.2645</td>
<td>1</td>
<td>0.1324</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refer</td>
<td>-2.2329</td>
<td>0.8264</td>
<td>7.2999</td>
<td>1</td>
<td>0.0069</td>
<td>0.107</td>
<td>0.021-0.542</td>
</tr>
<tr>
<td>Needs</td>
<td>1.3905</td>
<td>0.5433</td>
<td>6.5515</td>
<td>1</td>
<td>0.0105</td>
<td>4.017</td>
<td>1.385-11.650</td>
</tr>
<tr>
<td>Unilateral</td>
<td>-0.0720</td>
<td>0.5391</td>
<td>0.0178</td>
<td>1</td>
<td>0.8938</td>
<td>0.931</td>
<td>0.324-2.677</td>
</tr>
</tbody>
</table>

Test

<table>
<thead>
<tr>
<th>( \chi^2 )</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model</td>
<td>( \chi^2 )</td>
<td>df</td>
</tr>
<tr>
<td>Likelihood ratio test</td>
<td>21.8154</td>
<td>3</td>
</tr>
<tr>
<td>Score test</td>
<td>20.0270</td>
<td>3</td>
</tr>
<tr>
<td>Wald test</td>
<td>14.9217</td>
<td>3</td>
</tr>
</tbody>
</table>

When these predictors were entered into the existing model, the likelihood ratio chi-square test was again significant but the chi-square value did not change appreciably [\( \chi^2 (7) = 20.4713, p=0.0046 \)]. The ‘screening status’ and ‘presence of other special needs’ predictors remained significant; however, no other predictors were observed to predict changes in the log odds for later diagnosis. Table 4.11 shows the parameter estimates and Wald Chi-square statistics with related significance values for the full model. As before, the -2 Log L declined from 112.454 to 91.982 for a net decrease of 20.472, confirming that the full model predicted the log odds of later diagnosis at better than a chance level and was comparable to that with child only predictors.
Table 4.11: Logistic Regression Model for Prediction of Diagnosis After 3 Months of Age Based on Child & Family Factors (n = 82)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>β</th>
<th>SE β</th>
<th>Wald’s $\chi^2$</th>
<th>df</th>
<th>p</th>
<th>Odds Ratio (e^β)</th>
<th>95% Wald Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>-0.0144</td>
<td>1.5537</td>
<td>0.0001</td>
<td>1</td>
<td>0.9926</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refer</td>
<td>-1.9789</td>
<td>0.8554</td>
<td>5.3522</td>
<td>1</td>
<td>0.0207</td>
<td>0.138</td>
<td>0.026-0.739</td>
</tr>
<tr>
<td>Needs</td>
<td>1.5466</td>
<td>0.6192</td>
<td>6.2395</td>
<td>1</td>
<td>0.0125</td>
<td>4.696</td>
<td>1.395-15.802</td>
</tr>
<tr>
<td>Unilateral</td>
<td>-0.1689</td>
<td>0.5512</td>
<td>0.0939</td>
<td>1</td>
<td>0.7592</td>
<td>0.845</td>
<td>0.287-2.488</td>
</tr>
<tr>
<td>Non-White</td>
<td>-0.0341</td>
<td>0.7246</td>
<td>0.0022</td>
<td>1</td>
<td>0.9625</td>
<td>0.967</td>
<td>0.234-3.999</td>
</tr>
<tr>
<td>High School</td>
<td>-0.2689</td>
<td>0.7748</td>
<td>0.1205</td>
<td>1</td>
<td>0.7285</td>
<td>0.764</td>
<td>0.167-3.489</td>
</tr>
<tr>
<td>Some College</td>
<td>0.2176</td>
<td>0.6580</td>
<td>0.1094</td>
<td>1</td>
<td>0.7409</td>
<td>1.243</td>
<td>0.342-4.515</td>
</tr>
<tr>
<td>Support</td>
<td>0.3027</td>
<td>0.3631</td>
<td>0.6950</td>
<td>1</td>
<td>0.4045</td>
<td>1.354</td>
<td>0.664-2.758</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Test</th>
<th>$\chi^2$</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model Evaluation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Likelihood ratio test</td>
<td>20.4713</td>
<td>7</td>
<td>0.0046</td>
</tr>
<tr>
<td>Score test</td>
<td>18.7704</td>
<td>7</td>
<td>0.0089</td>
</tr>
<tr>
<td>Wald test</td>
<td>14.2870</td>
<td>7</td>
<td>0.0463</td>
</tr>
<tr>
<td>Goodness-of-fit test</td>
<td>6.8546</td>
<td>8</td>
<td>0.5524</td>
</tr>
</tbody>
</table>

**Goodness of Fit and Predicted Probabilities.** The Hosmer and Lemeshow test yielded a non-significant value for the child predictor model [$\chi^2 (4)=5.3240$, $p=0.2556$] and the child and family predictor model [$\chi^2 (8)=6.8546$, $p=0.5524$], implying that the estimated probabilities did not differ radically from the actual data for later diagnosis. Although both models predict patterns observed in the observed data, the parameters for the odds ratios lacked overall specificity, as confirmed by the 95% confidence limits for each estimate. Better specification of parameter estimates for the log-odds would require a larger sample size.
Figures 4.6 depicts the modeled probabilities in relation to the observed outcomes of earlier versus later diagnosis for the full model. Based on the density of observations in Figure 3.1, the predicted probabilities for the children with an earlier diagnosis typically occurred at or below p=0.40 and indicated a diminished likelihood of later diagnosis. There were very few cases in which a later diagnosis was predicted but in fact had not occurred (i.e., false-positives). In contrast, two regions of density are noted for children who had a later diagnosis, one occurring below a p-value of 0.50 and the other found above. As shown in Figure 3.1, some infants and toddlers experienced a later diagnosis (i.e., false-negatives) which the model failed to predict based on the child and family factors included in the model.

Figure 4.6 Child & Family Predictors: Predicted Probability versus Observed Outcome of Later Diagnosis

---

3 The principle of parsimony favors a model that includes fewer predictors without any increase in the error of estimation. Using this guide, the ‘child’ predictor model is preferred. However, only a few unique probabilities are estimated under this model because it has so few predictors. In fact, under the model with three predictors, the majority of the data clustered around four or five estimated values; and a graphic representation of this was not very useful. Because the full model explained approximately the same amount of variation in the data, the graph for this model is presented instead.
Predictors of Later Intervention

Research Question 4: To what extent do child and family characteristics uniquely explain differences in the observed age of early intervention for infants and toddlers identified through newborn hearing screening?

Two multiple logistic regression analyses were conducted to examine how factors related to the child and family impacted the odds that an infant who had received a hearing screening at birth would begin to receive early intervention after the age of 6 months of age. Another binary variable was created from the ‘age of intervention’ data that defined later intervention with values of 0, for ‘the start of services at or before 6 months of age,’ and 1, for ‘the start of services after 6 months of age.’ The regression modeled the log odds of ‘the event’ that early intervention services began after 6 months of age. Three child predictors were loaded into the model. To control for the contribution of later diagnosis to a delayed start of intervention, the dichotomous variable from the prior regression, ‘later diagnosis,’ was entered into the model. The previous child predictors, ‘presence of other special needs’ and ‘laterality of hearing loss,’ were also loaded into the model. Table 4.12 shows that the chi-square likelihood ratio was significant [$\chi^2(3) = 15.9821, p=0.0011$], suggesting that at least one predictors’ regression coefficient was not equal to zero as assumed under the null hypothesis. Further examination of the parameter estimates demonstrated that both ‘later diagnosis’ [$\chi^2(1) = 10.3505, p=0.0013$] and ‘presence of other special needs’ [$\chi^2(1) = 4.9339, p=0.0263$] were alone significant. Under this model, a child with a diagnosis received after three months of age had an increased log odds of 1.9653 of later start to intervention given that all other predictors in the model remained constant. When converted
to an odds ratio, this estimate conveys that these children are 7.137 times as likely to start intervention services after 6 months of age. Likewise, a child with at least one additional special need had a -1.4153 decrease in their log odds of beginning intervention services after 6 months of age; in other words, these children were 0.243 times as likely to start intervention services at an age later than 6 months. The overall fit of the model implied better than chance levels of prediction. Without any predictors in the model the -2 Log L was 109.097 and expressed the overall variability in the data; however, when accounting for the three child predictors, the -2 Log L declined by a factor of 15.982 to 93.115.

Table 4.12: Logistic Regression Model for Prediction of Start of Intervention After 6 Months of Age Based on Child Factors (n =80)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>$\beta$</th>
<th>SE $\beta$</th>
<th>Wald’s $\chi^2$</th>
<th>df</th>
<th>p</th>
<th>Odds Ratio ($e^{\beta}$)</th>
<th>95% Wald Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>-1.0754</td>
<td>0.4075</td>
<td>6.9649</td>
<td>1</td>
<td>0.0083</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Late Dx</td>
<td>1.9653</td>
<td>0.6109</td>
<td>10.3505</td>
<td>1</td>
<td>0.0013</td>
<td>7.137</td>
<td>2.156-23.633</td>
</tr>
<tr>
<td>Needs</td>
<td>-1.4153</td>
<td>0.6372</td>
<td>4.9339</td>
<td>1</td>
<td>0.0263</td>
<td>0.243</td>
<td>0.070-0.847</td>
</tr>
<tr>
<td>Unilateral</td>
<td>1.0736</td>
<td>0.5637</td>
<td>3.6274</td>
<td>1</td>
<td>0.0568</td>
<td>2.926</td>
<td>0.969-8.833</td>
</tr>
</tbody>
</table>

Test $\chi^2$  df  p

Overall Model Evaluation

| Likelihood ratio test | 15.9821 | 3 | 0.0011 |
| Score test           | 14.7520 | 3 | 0.0020 |
| Wald test            | 12.2715 | 3 | 0.0065 |

Goodness-of-fit test

| Hosmer & Lemeshow    | 1.8069 | 5 | 0.8752 |
A subsequent analysis included the family predictors of caregiver racial/ethnic background, level of educational attainment, and perceived social support. These variables were defined as in the prior logistic regression of later diagnosis. The chi-square likelihood ratio was also significant [$\chi^2 (7) = 24.2038, p=0.0010$], and specific attention to the parameter estimates revealed four significant predictors: later diagnosis, presence of other special needs, laterality of hearing loss, and racial/ethnic background (see Table 4.13). In this model, children who were diagnosed after three months of age had a 2.3952 increase in their log odds for a later start to intervention; or rather, they were 10.97 times as likely to have a later start to intervention with other predictors held constant. Children with at least one additional special need besides hearing loss had a decreased log odds, or were 0.207 times as likely to receive a later start to intervention when other predictors were statistically controlled. Furthermore, children with a unilateral hearing loss had an increased log odds of 1.7455 for a later start to intervention; or in terms of the odds ratio, they were 5.729 times more likely to experience a later start to intervention all factors remaining equal. Lastly, children with a non-White caregiver also had an 1.8315 increase in their log odds of beginning intervention services later; or more to the point, they were 6.244 times as likely to begin services after six months of age in comparison to their counterparts with White caregivers. No other variables were significant. The data support that these predictors meaningfully impact the odds of a later start to intervention services. In fact, the -2 Log L function decreased from 100.631 to 76.427, in other words by a factor of 24.204 when both child and family predictors were added to the model. This outcome implies that the present model holds better predictive value than a model based uniquely on child factors.
Table 4.13: Logistic Regression Model for Prediction of Start to Intervention After 6 Months of Age Based on Child & Family Factors (n = 74)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>β</th>
<th>SE β</th>
<th>Wald’s $\chi^2$</th>
<th>df</th>
<th>p</th>
<th>Odds Ratio (e^β)</th>
<th>95% Wald Confidence Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>-4.0914</td>
<td>1.6712</td>
<td>5.9940</td>
<td>1</td>
<td>0.0144</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Late Dx</td>
<td>2.3952</td>
<td>0.7096</td>
<td>11.3930</td>
<td>1</td>
<td>0.0007</td>
<td>10.971</td>
<td>2.730-44.084</td>
</tr>
<tr>
<td>Needs</td>
<td>-1.5739</td>
<td>0.7372</td>
<td>4.5574</td>
<td>1</td>
<td>0.0328</td>
<td>0.207</td>
<td>0.049-0.879</td>
</tr>
<tr>
<td>Unilateral</td>
<td>1.7455</td>
<td>0.6781</td>
<td>6.6248</td>
<td>1</td>
<td>0.0101</td>
<td>5.729</td>
<td>1.516-21.642</td>
</tr>
<tr>
<td>Non-White</td>
<td>1.8315</td>
<td>0.8436</td>
<td>4.7136</td>
<td>1</td>
<td>0.0299</td>
<td>6.244</td>
<td>1.195-32.622</td>
</tr>
<tr>
<td>High School</td>
<td>-0.0398</td>
<td>0.9743</td>
<td>0.0017</td>
<td>1</td>
<td>0.9674</td>
<td>0.961</td>
<td>0.142-6.487</td>
</tr>
<tr>
<td>Some College</td>
<td>-0.3696</td>
<td>0.7041</td>
<td>0.2756</td>
<td>1</td>
<td>0.5996</td>
<td>0.691</td>
<td>0.174-2.747</td>
</tr>
<tr>
<td>Support</td>
<td>0.6462</td>
<td>0.4244</td>
<td>2.3176</td>
<td>1</td>
<td>0.1279</td>
<td>1.908</td>
<td>0.830-4.384</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Test</th>
<th>$\chi^2$</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Model Evaluation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Likelihood ratio test</td>
<td>24.2038</td>
<td>7</td>
<td>0.0010</td>
</tr>
<tr>
<td>Score test</td>
<td>21.4107</td>
<td>7</td>
<td>0.0032</td>
</tr>
<tr>
<td>Wald test</td>
<td>16.5539</td>
<td>7</td>
<td>0.0205</td>
</tr>
<tr>
<td>Goodness-of-fit test</td>
<td>7.4287</td>
<td>9</td>
<td>0.5926</td>
</tr>
</tbody>
</table>

**Goodness of Fit and Predicted Probabilities.** The Hosmer and Lemeshow test was not significant for the child predictor model [$\chi^2 (5) = 1.8069, p=0.8752$] nor the full model [$\chi^2 (9) = 7.4287, p=0.5926$], suggesting that the predicted model did not differ radically from the observed data for later intervention. While each model predicted trends observed in the actual data, the specificity of parameters for the odds ratios was poor as confirmed by the 95% confidence limits for each estimate. Further specification of parameter estimates for the log-odds would require a larger sample size. Figure 4.7 illustrates the modeled probabilities.
based on the actual value in the data. As anticipated, the highest density of observations for
children who received an earlier diagnosis centered around predicted values less than 0.4. In
comparison, the majority of children who had a later diagnosis also had correspondingly
higher predicted probabilities with values greater than 0.50.

Summary of Key Findings
The list below provides a condensed review of the principal outcomes observed in this study
based on parental report.

1. Caregiver perceptions of the planning and provision of early intervention services
   appear generally favorable. Most parents reported understanding and involvement in
   the evaluation for services and felt positive about their role and decisions during the
development of their infant’s and toddler’s services plan.
2. Roughly one-third of parents indicated a wait of 2 or more months to receive amplification, and the same proportion reported that they had a 3 month delay or longer in the start of early intervention services. Despite these delays, the majority of caregivers felt that the length of their wait for follow-up was reasonable.

3. Around 20 to 25% of parents reported that they exerted less influence over choices related to the scheduling of services, location of services, and the professionals who served their family.

4. Caregiver reports of the types of help offered by the primary provider versus those that they most desired were highly similar; however, two services related to emotional support and encouragement of parental decision-making were not ranked among the top 10 received services, although they were highly desired.

5. More than half of families had elected to pursue a spoken language approach with their child. A combination of spoken and sign language was the second most popular method chosen.

6. Children whose parents reported at least one special need in addition to hearing loss had increased odds of receiving a diagnosis of hearing loss after three months of age; and, these infants and toddlers were more likely to have begun intervention before 6 months in comparison to those who had been diagnosed with hearing loss alone.

7. Children with unilateral hearing loss had increased odds of starting early intervention after 6 months of age, although the probability that they will receive a later diagnosis (e.g., after 3 months of age) is no greater than that of children with bilateral hearing loss.
8. Children from non-White families (e.g., Black, Hispanic/Latino, Asian) have greater odds of starting early intervention services after 6 months of age in comparison to White families/Caucasian families.
CHAPTER 5

Discussion

General Trends in Early Intervention Services

Based on self-report, parents value the Part C services and supports available through early intervention in North Carolina and generally enjoy a satisfactory level of participation in the planning and implementation of those services for their infant or toddler. Numerous parents also offered anecdotal testimony that endorsed these perspectives. As one mother of a 22-month old boy with a severe-to-profound hearing loss remarked:

“We are very happy and thankful for all of the resources available to our son. The advocacy and training in our state is outstanding! Our teacher for the deaf and hard of hearing accompanied with the folks at [our medical center] are a source of great strength and comfort now, and have been throughout our journey so far. We move forward with much assurance!”

In many respects, the early intervention experiences reported by parents of children with hearing loss appear to mirror trends in the larger early intervention population. According to the National Early Intervention Longitudinal Study (NEILS, Hebbeler et al, 2007), around 81% of all caregivers felt that decisions regarding outcomes for their child and family were made jointly with professionals. In comparison, 88% of parents who responded to the SITS indicated that they had the ability to decide their family’s priorities during planning for the IFSP. Such sentiments underscore the critical role of early intervention in bolstering supports for not only very young children with special needs but also for the family unit.
Parental opinions about the need for greater inclusion in the determination of their infant’s and toddler’s services from the current study revealed a high degree of similarity to the views of caregivers in the general early intervention population. Slightly more than one-fifth (22%) of NEILS families stated that they would have preferred a higher level of involvement in the decisions regarding their infant’s and toddler’s services; a comparable proportion of caregivers (17%) from the SITS indicated that they would have also desired to be more involved in the development of the IFSP. Of particular note, around 1 in 4 caregivers who completed the SITS perceived that they had little choice in who would serve on their child’s early intervention team, and roughly one-fifth of parents felt they had no impact on how often they received services. Reactions from the early intervention population at large are similar, with around 49% of families stating that the professionals made most decisions regarding services (Hebbeler et al, 2007). Partiality regarding which party should determine the intensity and frequency of services has been attributed to the need to control costs related to programming (Hebbeler et al, 2007) but may also reflect a bias in favor of professional expertise on decisions that could potentially impact the rate of developmental progress towards child outcomes. However, given that the average family receives 2 hours per week or less of direct service contact, it would be unreasonable to expect that the momentum of a child’s progress is guided exclusively – or even primarily – by the intensity of direct services he or she receives (Hebbeler et al, 2007). Such notions are likely borrowed from older service delivery models whereby the provider served as the principal change agent, and in some sense run counter to the expressed goals of early intervention, to support families in their efforts to facilitate the development of their infant or toddler.
**Perceived Social Support.** For families of screened newborns, spousal support received the highest scores, on average, of all sources of perceived help in the SITS. This ranking reflects in part the marital status of the families sampled, 80% of whom were currently married. However, the next highest average was attained for professional support from an audiologist, owing likely to the number of families who had opted to pursue spoken language instruction for their child. Other sources of family support included grandparents, the teacher of the deaf and hard of hearing, and a family physician or pediatrician.

In this study, the perceived social support score estimated the level of current social support reported by the caregiver based on the number of potential sources of support available to him or her. There was no statistically significant association between the ages of diagnosis or intervention and the current level of perceived social support as reported by caregivers at the time of survey. Since the SITS was completed retrospectively, it is unclear whether perceived social support at the time of diagnosis or intervention may have differed based on the age at which hearing loss was confirmed or that intervention began. It is likely that the diagnostic and intervention services provided to families responding to the SITS enhanced caregivers’ overall perceptions of support, as demonstrated by the relatively high rankings assigned to professionals such as audiologists and teachers of the deaf or hard of hearing.

**Parent Perspectives on Early Diagnosis and Intervention.** Based on the SITS, more than one-third of caregivers whose infant did not pass newborn screening described a wait of 3 months or longer between diagnosis of the hearing loss and the start of intervention. Parent reports could not be corroborated by a record check of the duration between referral for services and the date the IFSP was signed. As such, it is uncertain whether these delays
originated from hindrances in referral from diagnosis to Part C services, barriers within the Part C system (e.g., scheduling, pre-authorization for services, etc.) or reluctance on the part of the family to pursue intervention services and other extenuating circumstances. These trends remain consistent with those observed in the early intervention system nationally. The NEILS found that just 60% of families received an IFSP within 45 days following referral as mandated by IDEIA. Within 14 weeks of referral, or twice the mandated interval, 90% of families had completed a service plan (Hebbeler et al, 2007). Still, it is likely that multiple factors contributed to the prolonged receipt of services, including obstacles at the system level.

Children with hearing loss now have earlier ages of entry (e.g., under 12 months) into Part C programs, and this shift necessitates an increase in the staffing of skilled providers who can also address the needs of infants with a hearing loss. In North Carolina, past efforts to restrict the eligibility of children with hearing loss for Part C services – although unsuccessful – denote that some early intervention professionals may not appreciate the effects of hearing loss on language and social development or feel equipped to address the needs of a newly identified baby with hearing loss.

“The service provider seemed as though she didn’t want to do an IFSP – I got the impression that because he looked ‘normal’ she didn’t think there was a need for special services. She told me we could do one down the road if he seemed to need it – I had to push to have it done – he is profoundly deaf in one ear, moderate in the other – he needed it!”

-Mother of an 8 month old boy who was diagnosed at 3 months

Lack of provider knowledge, as highlighted by this mother, is a noted concern for families of children with hearing loss (Shulman et al, 2010). In the last 25 years, the focus of services
has moved from specialized schools for the deaf to integrated learning in spoken language environments. As the age of identification is lowered and parents seek these services earlier, providers will require additional in-service training to develop competency in how to support such families. The University of North Carolina’s Division of Speech & Hearing offers the First Years Program as an in-service option for interventionists seeking added knowledge on auditory learning for very young children with hearing loss. As an online distance education program, First Years provides professionals with a certificate for the development of spoken language following the completion of two years of coursework and mentoring. The Carolina Children’s Communicative Disorders Program also offers a two-week summer institute that provides intensive training for auditory-oral and auditory-verbal approaches in a clinic and preschool setting. These programs are vital educational resources to providers who work with families that have chosen to integrate their child into a spoken language environment or regular education setting after early intervention.

Predictors of Later Diagnosis and Intervention

Referral from Newborn Hearing Screening. Newborn hearing screening (NHS) profoundly lowers the age at which children with hearing loss receive early intervention. Prior to the advent of statewide screening programs, the median age for identification of hearing loss ranged from 12 to 22 months, and earlier identification relied heavily upon the presence of known risk factors (e.g., heredity, prematurity, perinatal meningitis) and the severity of the loss (Harrison & Roush, 1996; Meadow-Orlans et al, 1997). In the present study, newborns who did not pass the newborn hearing screening were 0.10 times as likely to receive a diagnosis after the age of 3 months when compared with those who passed the initial screening. In fact, the median age of diagnosis for children who passed the newborn
screening was much later, around 11 months age. While some of these children may not have had a presenting hearing loss at birth, the screening status of others was unknown due to complex birth histories such as adoption.

In a study of NHS programs in the United States, Shulman and her colleagues (2010) noted that a lack of service-system capacity frequently undermined efforts to provide newborn screening and effective follow-up care to very young children with hearing loss and their families. For most NHS programs, the chief obstacle to sustaining a reliable system of care was faulty screening equipment in the birthing hospital (Shulman et al, 2010). Where possible, some facilities may maintain auxiliary equipment; however, these resources are unavailable or severely limited for most hospital-based programs, including those in North Carolina. Families in hospitals without sufficient screening equipment may be asked to return to the hospital or a re-screening clinic which elevates the likelihood of a missed screening.

To complicate matters, a resident pediatric audiologist who offers continued support and training to nursing or volunteer staff is not often represented within the NHS programs at most facilities in North Carolina; instead, the equipment manufacturers typically conduct the primary screening training for hospital staff. The state’s Division of Public Health also employs six Child-Health Audiology Consultants (CHACs) who are responsible for in-service training, technical support and compliance with NHS protocols at regional hospitals within their state district (Alberg, Wilson, & Roush, 2006). Unfortunately, demanding nursing staff schedules or regular staff turnover may undercut the benefit of the periodic trainings delivered by CHACs to hospitals in their region.
With the inclusion of a pediatric audiologist in the screening process, NHS programs could guarantee ongoing training to maintain hospital staff competency with screening procedures, which would presumably reduce the false-positive refer rates (i.e., newborns who screen positive but have normal hearing) and the number of infants requiring follow-up. The audiologist could also ensure that parents of referred newborns receive notification about their baby’s screening results and the need for follow-up at an outpatient clinic in a compassionate yet accurate manner before hospital discharge. Although the involvement of a pediatric audiologist when delivering screening results to a family whose newborn did not pass the in-hospital screening (Roush, 2000) or at the time of outpatient rescreening (Gravel & McCaughey, 2004) is an acknowledged component of family-centered NHS care, a shortage of audiologists trained in pediatric services often precludes their regular participation at many birthing facilities in North Carolina. As such, the stage between in-patient hospital screening to outpatient re-screening represents a critical juncture in NHS care during which newborns remain vulnerable to loss to follow-up care or delayed diagnosis.

Later Diagnosis. In the SITS sample, roughly 57% (50/88) of infants who did not pass their initial screening received audiologic confirmation of a hearing loss at or before 3 months of age; this finding suggests a rise in the proportion of infants with congenital hearing loss who receive an early or ‘on time’ diagnosis (i.e., diagnosis by 3 months of age), which was previously reported at 39 to 48% in recent years (CDC, 2007c-d). Later diagnosis also predicted a later start to intervention and signified that obstacles encountered during the NHS follow-up process have a cumulative impact that is not easily recouped at diagnosis. Efforts to promote timely follow-through from in-hospital screening to subsequent audiologic assessment and early intervention have called for broader consideration of outpatient re-
screening as a key step in the diagnostic process (Gravel & McCaughey, 2004). This approach would also necessitate direct communication between the birthing facility and, ideally, the diagnostic clinic where the re-screening occurs. In many instances, a diagnostic center offering pediatric services may be relatively distant or inaccessible to families; under those circumstances, it is preferable to encourage parents to return to the birthing hospital’s outpatient clinic for re-screening, if one exists. In any event, a focused effort is needed to reduce the number of separate facilities to which the family must return for follow-up.

Coordinated care from in-hospital to outpatient screening requires further support from the infant’s medical home. The American Academy of Pediatrics (AAP) conceptually defines the ‘medical home’ as the provision of accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent healthcare services (AAP, 2002); the primary care provider (PCP), as the seat of the medical home, can assist parents in navigating the EHDI system given regular contact with the family. In practice, however, parents sometimes have not identified a long-term PCP for their infant before hospital discharge. When the PCP is known, he or she may not receive notification of results from the hospital-based or outpatient re-screenings if the appropriate documentation is not accessible in the child’s medical records at his or her facility. More regrettablly, even when documentation is submitted and reviewed by the PCP, some pediatricians adopt an outlook of ‘wait-and-see’ towards newborns referred from screening; this last concern is a growing issue for nearly one-half of screening programs nationwide (Shulman et al, 2010). Added encouragement from PCPs to follow through with an outpatient re-screening could serve as a vital resource for parents who confront challenges during the NHS process:
“After failing the newborn hearing screening, the nurse was to schedule a follow-up appointment but did not. We thought it was fluid and took a few weeks to schedule. After the local audiologist confirmed a problem, she called [a diagnostic clinic] to schedule a follow-up appointment. [The diagnostic clinic] never called so we followed through. This was all fine for us because we wouldn’t have let it go. It was very easy for us to say to ourselves, “Well it’s probably just fluid. I’m sure she can hear, but we’ll make sure.” Other families may just be dismissive without pressing ahead with appointments.”

-Mother of a 38 month old girl with a severe to profound hearing loss

The consequences of uncoordinated care, as implied by this mother from the SITS, can have a lasting impact on infants with hearing loss and their families. To respond to these concerns, the North Carolina EHDI program joined a national learning collaborative in 2009 to enhance follow-through from the initial newborn screening to the outpatient rescreening. The learning collaborative arose from a partnership among the Health Resources and Services Administration Maternal and Child Health Bureau, NCHAM, and the National Initiative for Children’s Healthcare Quality (NICHQ); it convened a group of EHDI programs from geographically diverse states to address loss to follow-up after NHS. Member states in the collaborative applied a quality-improvement approach to assess and share strategies that set specific goals which addressed common sources of loss to follow-up in their state. Each state team set objective targets for improvement, devised strategies and measures to achieve them, and tested small scale changes brought about by the intervention and then revised their methods accordingly. This cycle to ‘plan an intervention, then do it on a small scale, study any resulting change, and act upon the findings’ was conceptualized as the PDSA (i.e., Plan Do Study Act); over rapid cycles, PDSAs allowed EHDI teams to
obtain, assess and apply incremental changes that improved the quality of NHS care within their state.

For its part, North Carolina’s team targeted aims related to the outpatient re-screening program, the medical home, and education for parents of screened newborns as central components of loss to follow-up and delayed access to diagnostics and intervention services. PDSAs for these components of care were field tested within two at-risk hospital-based NHS programs, one a large medical center, and the other, a comparatively smaller community hospital. The NC team joined together EHDI stakeholders from the state’s NHS program, CHACs, parents of children with hearing loss screened at one of the at-risk facilities, hospital nursing staff and administrators, a PCP, an EHDI researcher from UNC-CH (the author) and a pediatric audiologist who managed a hospital-based NHS program.

From the collaborative, the NC team implemented several interventions targeting re-screening, the medical home, and parent education about NHS. Re-screening programs were established at the birthing facility or families were directed to another medical center that could provide outpatient rescreening and diagnostic evaluation, if necessary. Likewise, in an effort to enhance follow-through to diagnosis, scripts were created for re-screening staff to read to parents that provided accurate and culturally sensitive information on the results of their baby’s secondary screening. To curtail the number of false-negatives due to multiple in-hospital screenings, laminated cards with instructions listing follow-up activities for staff to complete prior to discharge for referred newborns were given to the NHS programs for posting. With regards to the medical home, nursing staff at the birthing facility were responsible for faxing results from the in-hospital screening to the PCP’s practice manager; in addition, the PCP’s information would be verified periodically by telephone. In addition,
all PCPs, especially those with an identified child with hearing loss in their practice, were to receive notebooks to share with families detailing the NHS process and diagnostic and intervention options available in North Carolina. To educate parents about the NHS process and their newborns results, it was recommended that staff provide a letter in English or Spanish at discharge describing their baby’s results. These interventions, if implemented on a large scale, have the potential to substantially reduce the number of ‘late arrivals’ to diagnostic and intervention services across the state.

Additional Special Needs. Specific factors, such as the presence of one or more special needs in addition to hearing loss, can affect the age at which children receive diagnostic and intervention services. Thirty percent of parents responding to the SITS indicated that their child had at least one additional need in conjunction with hearing loss; this figure likely underestimates the incidence of additional disability within the infant and toddler population in North Carolina as most parents reported medical conditions (e.g., cerebral palsy, vision loss, neurological impairment or disorder) present at or near birth for their child. In the general population, developmental or behavioral conditions such as learning disability, intellectual disability, and attention deficit disorder with or without hyperactivity comprise roughly 28% of the additional special needs observed among children with hearing loss (Roush, Holcomb, Roush & Escolar, 2004). Given that these conditions are typically identified well after the first year of life (Hebbeler et al, 2007), parents in the SITS sample were unlikely to observe and report their existence in their infant or toddler.

Very young children with multiple needs arising from a medical condition often require hospitalization in a neonatal intensive care unit prior to discharge, and their medical management must often take precedence over audiologic services of diagnosis and
intervention. Prince and her associates observed that newborns in Hawaii weighing less than 2500 grams at birth were twice as likely not to complete screening and later follow-up in comparison to their normal weight peers when controlling for factors such as maternal education level, race, and birthing facility (Prince, Miyashiro, Weirather, & Heu, 2003). Although the SITS did not investigate the impact of NICU status or birth weight, infants and toddlers from the SITS with other special needs unrelated to hearing loss had disproportionately higher odds of receiving a confirmation of hearing loss after 3 months of age. In fact, half of children with such needs were not diagnosed with hearing loss until after 4.5 months of age.

In contrast, infants or toddlers with multiple presenting needs including hearing loss were found to start early intervention at comparatively earlier ages (i.e., at or before 6 months of age) with regard to their peers identified with hearing loss alone. Earlier ages of intervention may in some respect reflect the predominance of medical conditions reported by the sample. Medical conditions with resulting physical impairment awaken suspicions of special needs inciting prompt referral to early intervention. In the SITS sample, approximately half of these infants and toddlers began early intervention services before a hearing loss was confirmed by the audiologist, and half of parents reported that their infant had started early intervention by 4.0 months of age. On the contrary, some researchers have suggested that children who are at-risk for multiple disabilities due to low birth weight are twice as likely not to receive a referral to early intervention and, therefore, more susceptible to loss to follow-up (Liu, Farrell, MacNeil, Stone & Barfield, 2008). Clearly, additional evidence is needed to determine the risks posed to children with other special needs and hearing loss with respect to timely diagnosis and intervention.
Roush and his colleagues (2004) outlined a family-centered framework for addressing the needs of children with multiple disabilities (Roush, Holcomb, Roush & Escolar, 2004). Although the medical fragility of an infant or toddler at birth can preclude immediate screening and follow-up within the NICU, an added emphasis on care coordination can assure that delays in diagnostic and intervention services are not magnified by poor communication among medical specialists. According to JCIH guidelines (2007), infants requiring a NICU stay who do not pass their initial ABR screening should receive a prompt referral to an audiologist for re-screening and diagnostic assessment, if necessary.

Audiologists must rely upon their battery of physiologic measures (e.g., auditory brainstem response, auditory steady state response, otoacoustic emissions, and acoustic immittance) to determine the child’s hearing status. Close consultation with the otolaryngologist and pediatrician is also necessary when considering decisions regarding sedation for testing; when necessary, audiologic evaluation involving sedation or general anesthesia may be combined with operating room procedures of other medical specialties in an effort to conserve the resources of time and energy on the part of the infant and his or her family. These efforts can have a lasting impact on parent to professional rapport and motivation to pursue additional follow-up after diagnosis.

Unilateral Hearing Loss. Infants and toddlers with unilateral hearing loss had an increased likelihood of delayed start to early intervention although their age of diagnosis was statistically equivocal to those of children with bilateral hearing loss. Population-based studies from other states have corroborated findings of later intervention for these infants and toddlers at different points in the continuum of care following NHS (Spivak et al, 2009). In New York, infants referred from newborn screening who had unilateral hearing loss...
confirmed later were more likely not to receive hearing aid fitting, when appropriate, until after 6 months of age (Spivak et al, 2009). In a Massachusetts study, newborns who did not pass screening and later had a confirmed unilateral hearing loss were 2.47 times more likely to not receive a referral to early intervention services (Liu et al, 2008). The same study reported that they were no less likely than their bilateral counterparts to not receive audiologic evaluation.

Even though infants and toddlers with unilateral hearing loss are eligible for Part C services under North Carolina’s eligibility criteria for hearing impairment, parental uncertainty regarding the consequences of this type of loss can impede the rate at which newborns who do not pass initial screening will subsequently enroll in services. Unilateral hearing loss results in deficits in sound localization, hearing at a distance, speech perception in noisy environments, and behavioral problems (Holstrum, Biernath, McKay, & Ross, 2009); and so, the unique strengths and needs of these infants and toddlers differ importantly from their bilateral peers. Parent education is necessary to assist families in facilitating their child’s auditory skill development and in providing environmental and acoustic modifications to reduce the burden of listening in the home and/or child care settings. Providers should also encourage families to pursue frequent audiologic monitoring to assess the stability of hearing thresholds in both ears given the higher incidence of progressive hearing loss among children with unilateral hearing loss (McKay, 2006).

**Family Factors.** The current study offers perspectives on early intervention experiences and delays in diagnosis and intervention from a sample of predominantly white, married, college-educated parents of infants and toddlers with hearing loss. Caregiver race or ethnicity, educational background, and perceived level of support did not significantly
impact the likelihood that an infant or toddler would receive a diagnosis of hearing loss after
3 months of age. From an ecological standpoint, the influence of factors comparatively distal
to the child such as caregiver race, educational level, and support may not be relatively
apparent in a system where the age of diagnosis is as heavily controlled as it is for infants and
toddlers with hearing loss. To discriminate among these factors, a larger sample than the one
presented in the current study would be necessary. Other studies have corroborated the
presence of disparities in access to NHS and audiologic evaluation based on racial or ethnic
background. In Hawaii, newborns from White families were 1.8 times more likely not to
complete newborn hearing screening (Prince et al, 2003). These findings seem atypical but
reflect the racial composition of a state where non-Hispanic Whites constitute a minority as
roughly 25% of residents. In New York, non-White newborns referred from NHS were
found 1.5 times more likely not to receive an audiologic evaluation.

In regards to early intervention, a relatively elevated proportion of newborns who did
not pass the initial hearing screening actually began services after six months of age
according to the SITS (42%), and equally high rates have been reported for North Carolina’s
population of infants and toddlers with hearing loss (55.2%; CDC, 2007a). Thus, it appears
that external factors outside of the EHDI system of care exert substantial effect upon the rate
at which newborns arrive from NHS to early intervention; even with a sample size as modest
as the one presented here, disparities that related to caregiver race or ethnicity were
observable. As seen on the SITS, infants and toddlers with non-White caregivers had greater
odds of a delayed start (i.e., after 6 months of age) to early intervention. No other family-
related factors statistically predicted a later start to early intervention.
Delays in follow-up care and access to early intervention for racial-ethnic minority groups often tarnish later perceptions regarding the efficacy of intervention services for culturally-diverse caregivers. Parental satisfaction with early intervention services is customarily poorer among non-White families of infants and toddlers with special needs (Hebbeler et al, 2007), including those with hearing loss (Meadow-Orlans et al, 1997). Moreover, this relationship may be mediated by the age of diagnosis such that families of non-White children diagnosed later express greater dissatisfaction than those children whose hearing loss was identified earlier (Meadow-Orlans et al, 1997). Given that most early intervention providers are hearing, female, White and English-speaking in North Carolina, efforts to train culturally competent professionals who provide care to racially and linguistically diverse families is a recognized challenge for the Part C system (Alberg, Wilson, & Roush, 2006).

*Study Limitations: External Validity*

Several features of the survey methodology limit the extension of its key findings to the early intervention experience of all infants and toddlers with hearing loss in North Carolina. In some respects, these drawbacks are universal to the nature of self-administered survey research. Self-administered questionnaires can enhance the reliability of responses to sensitive questions and provide coverage for respondents who are less accessible by telephone or in-person visits. It also typically represents the most inexpensive method of data collection in contrast to other interview-based modes (e.g., telephone, face-to-face formats). These benefits, unfortunately, can prove costly with regards to non-response at the unit (e.g., respondent) and item (e.g., question) level. A discussion regarding how non-response threatens the external validity of results from the current study is presented here.
Self-administered questionnaires often display lower response rates in comparison to other traditional survey modes that include the presence of an interviewer either by telephone or in-person. Traditionally, response rates for mailed surveys range from a conservative 30% to 60% in contrast to telephone and face-to-face modes that typically achieve responses from 60% to 80% or more of the surveyed population (Goyder, 1985; Hox & de Leeuw, 2002). In this study, the response rate reached 26.5% of all delivered surveys and is comparable to earlier studies of EHDI services with families that attained rates ranging from 27% to 35% (Harrison & Roush, 1996; Meadow-Orlans et al, 1997; Harrison, Roush, & Wallace, 2003). This rate yielded a relatively small sample of 100 families, once ineligible surveys were excluded, due to the size of the population under study.

Reduced sample sizes cannot fully capture the range of minority subgroups that constitute a heterogeneous population like that of children with pediatric hearing loss. In this instance, families of children with less common diagnoses like Auditory Neuropathy Spectrum Disorder and unilateral hearing loss were not equally represented among respondents. Likewise, children who had received extensive intervention (e.g., cochlear implants) were also underrepresented. Moreover, parents who had elected to pursue intervention with the less popular communication modes (e.g., Signed Communication, Cued Speech) or belonged to an at-risk demographic minority (e.g., non-White, lacking college education) also responded less favorably to requests to complete the SITS. Under-representation of the minority subgroups in question constrains the interpretation of findings related to the caregiver’s race or ethnicity, level of educational attainment, and perceived social support within the current study.
The dilemma of unit non-response plagues all survey research, particularly when response rates remain low. In such cases, efforts can and should be made to ascertain the extent to which the population of ‘non-respondents’ differs from the population of ‘respondents.’ More often than not, a significant difference between the populations exists owing to the characteristics of the non-respondents who are less predisposed to comply with requests to complete the questionnaire. In fact, these individuals may have to overcome a higher burden for survey compliance due to a variety of factors, including: a) speaking English as a second-language, b) a low level of English literacy, c) inaccessibility due to frequent changes in address, and d) strained family and work schedules. In the SITS project, questionnaires were completed anonymously and no records of prospective respondents were managed by the investigator. For this reason, endeavors to gather information about the geographic or demographic characteristics of non-respondents were not permissible. Furthermore, the agreement of confidentiality for release of respondent mailing addresses did not afford tracing of those families with incorrect contact information whose survey packages were ultimately returned as non-deliverable. These constraints prohibited efforts to learn more about those individuals whom were unable or unwilling to complete the SITS questionnaire. Accordingly, considerable caution should be taken not to extend the results of this study to families not sufficiently represented in the survey sample.

Another point of concern arises in the consideration of the response quality for the SITS data. Self-administered survey instruments customarily exhibit a higher proportion of item non-response, that is, single questions or statements to which the respondent gave no answer (Groves et al, 2004). This propensity is largely predicated upon one of three behaviors on the part of the respondent: a) poor comprehension of the item, b) disregard for
instructions in the survey, or c) refusal to provide an answer (Groves et al, 2004). In the SITS data, item non-response for child and family data ranged from 1 to 15%. When possible, missing data values were imputed if a single response option was known to be correct. The missing data values largely occurred for items that requested specific knowledge (e.g., severity of hearing loss) and or those that fell near the end of the survey, suggesting some respondent fatigue.

Additional Methodological Concerns

The SITS study endeavored to identify relevant trends in the provision of diagnostic and intervention services for infants and toddlers with hearing loss and to detect any disparities in access of these services based on child and family factors. To accomplish this goal, a multi-layered approach to the design and administration of the survey was necessary to induce response across all groups in the population. Although techniques such as instrument validation, follow-up notification, and token incentives were applied, the following modifications to the SITS development and distribution process would have enhanced the response rate to the survey:

Instrument Translation. A Spanish version of the SITS questionnaire would have certainly facilitated the comprehension of the survey and elevated the response rate among families who speak it as their primary language in the home. In the southern United States, more than one-fifth of children with hearing loss who are under the age of 18 years reside in homes where Spanish is spoken. In the SITS sample, 10% of the respondents indicated that they were of Hispanic/Latino origin and 8% of those stated that they spoke Spanish in the home. A Spanish form for the SITS would have undoubtedly stimulated a higher rate of return in this group as several inquiries regarding translation were made by Spanish-speaking
caregivers when the SITS was in-field. Because a Spanish version was not available, parents were counseled to rely upon proxy translation through a family member, friend or professional. Still, the presence of a third-party –particularly a professional- undermined the anonymity of the responses and potentially biased responses among these families. Questionnaire translation, when used, significantly alleviates the burden of survey completion and, conversely, introduces a new source of response error and bias (Harkness, Pennel, Schou-Glusberg, 2004). The goal of a translation is to achieve a ‘cultural equivalent’ of the instrument that renders the meaning of concepts presented in the original document (Marin & Marin, 1991). Difficulty often arises when a concept has no linguistic counterpart in the target language, particularly when translating attitudinal scales (e.g., “sometimes helpful”, “generally helpful”; “very helpful”). To the extent that such items are not equivalent, discrepancies in responses across the separate language versions could present spurious differences within the surveyed population. Although several approaches to survey translation exist, the preferred method, ‘back translation,’ encourages the use of at least two independent translators. One individual translates the document from the original language to the target, and the second translates that version back into the first language. This process occurs iteratively until a second version that represents the ‘cultural equivalent’ of the original survey has been achieved (Marin & Marin, 1991). When the resources of time and personnel are available, ‘back translation’ or a similar method promotes the inclusion of culturally-linguistic diverse populations within the sample.

**Respondent Contact.** All SITS participants received two requests to participate in the survey: the initial questionnaire mailing and a follow-up reminder postcard. Survey methodologists advocate the use of multiple contacts to spur higher response rates, and to
this end, attempt to contact prospective participants at all phases of the survey process, including before and after the receipt of the questionnaire. In this project, the use of a pre-notification letter to inform potential respondents of the coming survey may have increased response rates across all segments of the target population. Earlier literature, including meta-analysis, has validated the utility of pre-notification for the purpose of inducing response (Linsky, 1975; Fox, Crask, & Kim, 1988). The implementation of a pre-contact letter could have not only lent more weight to the completion of the SITS but also exposed inaccuracies in the mailing address database at a reduced cost prior to the survey mailing. Although follow-up communication has demonstrated a greater rate of return in comparison to pre-notification techniques (Linsky, 1975), the employ of both techniques in conjunction with a mail-based survey remain ideal in stimulating survey return.

**Study Limitations: Internal Validity**

Potential threats to the internal validity of the SITS originate from the imperfect nature of measurement. Noted threats relate to the identification of the early intervention population and the restricted variance of question items relating to service provision. The impact of these threats and recommended alternatives to measurement that could have enhanced the internal validity are described below.

*Part C Enrollment.* In the SITS study, family enrollment in the state’s Part C program was determined based on the development of the IFSP. Parents who reported that an IFSP was developed for their child were assumed to have enrolled in state early intervention because it is a requisite component of service provision. The IFSP was selected as a proxy variable for enrollment since it occurs with the counsel of professionals and is typically associated with a salient event, the IFSP meeting. A direct query about enrollment
in Part C services could have provoked more respondents to mistakenly deny enrollment as many caregivers are less familiar with the term ‘Part C’ or the manner in which their services are coordinated, particularly when private providers are involved as in North Carolina. At least 90% of families with children with hearing loss ultimately enroll in services after referral to early intervention in North Carolina (CDC, 2007a-b). So, it is reasonable to expect that the 79% of parents who stated in the SITS that an IFSP was developed for their child represented families who had actually enrolled in Part C services. Nonetheless, in families where an IFSP has been developed, approximately 18% of parents do not report any awareness of a ‘written plan that describes goals for their child and the services he or she should receive’ (Hebbeler et al, 2007). Given that families received the SITS as much as six to nine months after their last IFSP was developed, some parents may have erroneously indicated that they had not completed an IFSP when in fact they had. This bias might account for the slightly lower representation of family enrollment in Part C services that was noted in the SITS sample. The anonymous administration of the SITS precluded any attempts to validate parent reports of IFSP development with an objective data source such as the state EHDI database; however, when such avenues of cross-validation are available to assess the reliability of a proxy variable, it is worthwhile to profit from them.

Pilot Data. To examine the performance and utility of a proxy variable, or any variable for that matter, a pilot test of the survey instrument is a valuable tool to detect potential response patterns to the concepts under study. When employed, a pilot test can provide further impetus to revise question items that perform poorly in the target population. Poor performance is typically reflected by a lack of variability in responses or blatant bias in response due to question wording or order. Most question items on the SITS afforded the
respondent a forced choice between two specific values (i.e., yes and no); however, if given more freedom of response with a three to five-item scale (e.g., always, sometimes, never), those parents who experienced a genuine difference in the consistency with which their concerns were met would have had the opportunity to report it. Another concern arises when multiple instrument formats are employed among equal samples. Different configurations of question order can have an observable impact on responses. This effect appears commonly with attitudinal items about the respondent’s dispositions and may have significantly altered the array of SITS responses to inquiries about recommended changes in early intervention services or ratings of the primary provider’s skills. While necessary, expansive pilots that assess the influence of response formats and question order on the data can prove costly to both resources of time and money. Aside from the expense, a pilot test would have endangered the response rate in the targeted population given that those families who received the ‘pilot SITS’ would have been removed from the target population. For the current study, an expert review panel of stakeholders in the hearing health and early intervention provided review of the SITS instrument. To gather parent feedback on the completed questionnaire, another – albeit less ideal – approach might have assessed the SITS instrument in a similar population (e.g., families who have recently transitioned from Part C services).

**Implications for Future Research**

Although the present study detected statistically significant factors that predicted later arrival to diagnostic and intervention services, an insufficient sample size prevented specification of the parameter estimates for each factor. As such, the odds ratios that indicated relative risk for delays in diagnosis and intervention require further precision that
was not possible in an anonymous sample of families. Better precision of the relative risk for
delayed services, including NHS and Part C programs, would benefit from a population-
based approach that examines trends in care for at least two or three years. To this end, a
collaborative effort between state EHDI and Part C programs would allow for cross-
validation of parent reports with NHS follow-up records (i.e., age of diagnosis and date of
early intervention referral) and Part C records including individual IFSPs. Special education
and Part C privacy laws, however, are more stringent than those applied to students in
general education (i.e., Family Educational Rights and Privacy Act or FERPA) and typically
require written consent for release of an infant’s and toddler’s service plan. Privacy sharing
laws, although necessary, commonly inhibit the flow of information between EHDI and Part
C programs, such that many EHDI programs do not know if families ultimately receive
services after referral to Part C or what their service plan might entail (Shulman et al, 2010;
Houston, Behl, White, & Forsman, 2010). Any empirical study of service gaps across the
EHDI and Part C system of care must address privacy issues.

Population data is also vital in examination of factors affecting loss to follow-up. The
SITS did not contact families of infants and toddlers with hearing loss who did not receive
audiologic evaluation or Part C referral and services, and so this investigation could not
address the demographic or child-specific risk factors that predispose them not to receive
suitable follow-up care. Population data can be accessed through the statewide electronic
tracking and data system, Hearing Link, which maintains data regarding the basic
demographic records on the child and mother, the in-hospital and outpatient screening,
diagnosis and early intervention referral for children identified through NHS. Child-specific
records would also afford the opportunity to systematically oversample minority subgroups
so that these groups have higher representation in research samples. In support of this effort, Spanish language materials or interviewers would allow greater inclusion of monolingual Hispanic/Latino families within the state.

Lastly, an ecological approach to future investigation of these issues requires wider inclusion of perspectives other than those of a primary caregiver. Service providers can offer a unique vantage point to barriers in the system of care given their routine involvement with families and history with the Part C system. Future studies might also examine how the coordination of care based on the frequency and type of communication occurring between Part C providers (e.g., teacher of the deaf and hard of hearing, speech-language pathologist) and the audiologist or PCP impact caregiver perceptions on the type of services received by families.

Concluding Remarks

North Carolina’s EHDI and Part C programs offer an extensive cadre of services to families of very young children with hearing loss. Favorable accounts of the early diagnosis and intervention experience by parents highlight the significant role these programs play in their family’s life after their newborn does not pass a hearing screening. Caregivers have reported that they feel adequately involved in the planning and implementation of services for infants and toddlers with hearing loss. Even when delays occur in reaching desired services, parents feel they are acceptable given the constraints placed upon them or the system of care as a whole. Still, it appears that the EHDI and Part C programs do provide many of the individualized supports that parents require to address their child’s developmental issues. When the immediate medical needs of newborn infants prevent timely follow-through after referral from NHS, early intervention services are rendered to many
families in the period between screening and diagnosis which typically lasts longer for
infants with associated conditions and a co-morbid hearing loss. Ongoing coordination of
services is essential to ensure that such families do receive timely follow-up as they and their
child are able.

Nevertheless, access to early intervention services after NHS referral persists as the
most vulnerable point in North Carolina’s system of care. Infants and toddlers with
unilateral hearing loss and those from non-White families are at greater risk for a delayed
start to intervention. These children and families merit focused attention at all stages of
follow-up so that parents will receive the information and guidance required to advocate for
their child’s developmental needs after their initial hearing screening. This endeavor would
call for added professional preparation and development to assist service providers in
addressing the needs of very young children with minimal hearing loss or those from
culturally-diverse backgrounds.

North Carolina’s Part C program has entered its ‘second generation’ of service, and
the EHDI program will soon follow. In the past 15 to 20 years, the birth and maturation of
both programs have prompted a necessary shift in the state agenda from universal
implementation to quality-improvement. Professional stakeholders have diverted their
attention from concerns of ‘whether we can do this… and how’ to questions of ‘how can we
do this better.’ Efforts to meet this need will require ongoing population-based research to
identify segments of the infant and toddler population who receive delayed care or who are
lost to follow-up services entirely.
APPENDIX

Survey of Infant and Toddler Services
This survey is about your child who is 4 years of age or younger and has a hearing loss. If you have more than one child younger than 4 years of age with hearing loss, please answer for your youngest child or request another survey.

Your participation is voluntary and anonymous. For questions about your rights as a participant in this project: Institutional Review Board at (919) 966-3113 or IRB_subjects@unc.edu

For questions or requests about the study:
Aneesha Pretto at (919) 593-3381 or pretto@med.unc.edu or
Melody Harrison at (919) 966-9459 or melody_harrison@med.unc.edu

Sponsored in part by the Division of Speech & Hearing Sciences
February 15, 2010

Dear Parent,

We are conducting a research study to find out more about the services that families of children with hearing loss receive. We understand how busy your lives are. In spite of all the demands on your time, we hope that you will take time to respond to the enclosed survey. It is a survey about your child with hearing loss, your family, and how well your needs are being met by the professionals that work with your family.

Your family was selected because you have a child with hearing loss. We have contacted approximately 417 families from your state to find out more about their experiences with diagnosis and infant and toddler services.

Your participation is voluntary. Returning your completed survey means that you have willingly agreed to participate in the project. There is no cost to you for your participation. We have provided a self-addressed prepaid envelope to return your survey. To encourage your participation, we will send you a reminder postcard approximately 10 days after you receive this letter.

Your answers are anonymous. We cannot identify you or any of the professionals that your family knows. While you do not have to answer any question, we will understand your family’s experiences with infant and toddler services better if you complete the entire survey.

Results from the survey will be at national conferences for professionals who serve families of children with hearing loss. All results will be reported as a group.

We have included a Survey of Infant & Toddler Services ball-point pen as a token of appreciation for your help. This research has been funded in part by the Division of Speech & Hearing Sciences.

If you have questions or comments about the survey, we would be happy to talk to you. You can reach the Principal Investigator for the project at (919) 593-3381 or pretto@med.unc.edu. You may contact the Faculty Advisor, Melody Harrison at (919) 966-9459 or melody_harrison@med.unc.edu.

Research on human volunteers is reviewed by a committee to protect your rights and welfare. If you have concerns about your rights you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or IRB_subjects@unc.edu. The research study name is “Early Intervention for Children who are Deaf or Hard of Hearing” (IRB # 09-0369).

Thank you so much for taking time to participate in this research study.

Sincerely,

Aneesha Pretto, M.S.  Melody Harrison, Ph.D.
Principal Investigator  Professor & Faculty Advisor
SECTION A: ABOUT YOUR CHILD

This survey is about your child who is 4 years of age or younger and has a hearing loss. If you have more than one child younger than 4 years of age with hearing loss, please answer for your youngest child or request another survey.

1. Your child is ....
   A boy.......................... □1
   A girl.......................... □2

2. What is your child's age today?
   Example: If your child is 28 months old, you would then write 2 years and 4 months as:
   Your Child's Age Today 0 2 Years, and 0 4 Months
   Your Child's Age Today □□□ Years, and □□□ Months

3. Does your child have special needs other than hearing loss?
   No................................... □1
   Yes.................................. □2 Please describe ________________________________

4. How would you describe your child's hearing loss over time?
   It has stayed the same................. □1
   It has become worse over time....... □2
   I'm not sure......................... □3

5. What is the cause of your child’s hearing loss or hearing disorder? Check all that apply.
   Unknown .......................... □1
   Genetic/heredity..................... □2
   Meningitis................................... □3
   Prematurity.......................... □4
   Low oxygen................................ □5
   Hyperbilirubinemia.................. □6
   Cytomegalovirus (CMV).......... □7
   Maternal Rubella (Measles)...... □8
   Had treatment with drugs that caused a hearing loss................................. □9
   Other (________________________) □10

6. Does your child have hearing loss in both ears or one ear?
   Both ears........................ □1 Go to Question # 9
   One ear .......................... □2

7. Your child's hearing loss is in the ...
   Right ear.......................... □1
   Left ear .......................... □2
   I'm not sure....................... □3
8. Which category best describes your child’s hearing in this ear? Check one.
   - Mild to Moderate loss □1
   - Moderate to Severe loss □2
   - Severe to Profound loss □3
   - Auditory Neuropathy □4
   - I’m not sure □5

   Go To Question # 10

9. Your child has difficulty hearing in both ears. If your child’s hearing is not the same in both ears, describe the hearing in the better ear. Check one.
   - Mild to Moderate loss □1
   - Moderate to Severe loss □2
   - Severe to Profound loss □3
   - Auditory Neuropathy □4
   - I’m not sure □5

SECTION B: NEWBORN HEARING SCREENING & AUDIOLOGICAL MANAGEMENT

10. Was your child’s hearing screened at birth?
   - Yes □1
   - No □2
   - I’m not sure □3

   Go to Question # 12

11. When your child’s hearing was screened, did he/she pass?
   - No □1
   - Yes □2

   Go to Question # 13

12. Why did you become concerned about your child’s hearing? Check all that apply.
   - Wasn’t developing speech normally □1
   - Wasn’t responding to sounds □2
   - Concerns expressed by friends □3
   - Concerns expressed by other family members □4
   - Concerns expressed by health care provider (e.g., physician or nurse) □5
   - Did not pass a later hearing screening □6
   - Had serious illness requiring a hospital stay □7
   - Other (____________________________________________________________) □8
13. How old was your child when the hearing loss was confirmed by an audiologist?

Example: If your child’s hearing loss was confirmed at 2.5 months (10 weeks old), write 2 months:

Age Hearing Loss was Confirmed  0 0 Years, and  0 2 Months

14. Has your child ever been fitted with hearing aids?

Yes………………………...  □ 1  Go to Question # 16
No…………………………... □ 2

15. If hearing aids were never fitted, why? Check all that apply.

My child’s hearing loss is mild or in only one ear... □ 1
My child has auditory neuropathy……………………... □ 2
I was not ready to get hearing aids for my child.... □ 3
Cost of hearing aids…………………………………… □ 4
Other (__________________________________________) □ 5

Go to Question # 20

16. How old was your child when hearing aids were fitted?

□ □ Years, and □ □ Months

17. How much time passed between identification of the hearing loss and hearing aid fitting?

2 weeks or less............... □ 1
3 to 4 weeks………………... □ 2
5 to 8 weeks ……………….. □ 3
9 to 12 weeks……………… □ 4
More than 12 weeks ……… □ 5
I’m not sure………………… □ 6

18. How did you feel about the amount of time your child waited for hearing aid fitting?

It was reasonable …………... □ 1  Go to Question # 20
It was a little too long………… □ 2
It was much too long ………... □ 3
19. What were the reason(s) for the delay? Check all that apply.

Delay in 3rd party payments like Medicaid or private insurance………………………………… □
Apointments were not available………………………………… □
Ear infections……………………………………………………… □
My child was ill……………………………………………………… □
I was not ready to get hearing aids for my child………………… □
Had trouble getting transportation to appointments ………… □
My child’s paperwork was not yet complete…………………… □
Physician said that hearing aids were not needed……………… □
Other (__________________________________________________) □

20. Which statement best describes your child with regard to the cochlear implant process?

My child has a cochlear implant… □
Go to Question # 21
My child is being evaluated for a cochlear implant…………… □
Go to Question # 23
My child is not a cochlear implant candidate…………………… □
Go to Question # 23

21. Your child wears…

One implant on the right or left ear….. □
One implant with a hearing aid on the other ear…………………………………… □
Two implants, one on each ear…….. □

22. How old was your child when the surgery(s) for each implant occurred?

Example: If the first ear was implanted at 12.5 months, you would write 1 Year as:

Age of surgery on first ear 0 1 Years, and 0 0 Months

Age of surgery on first ear □□ Years, and □□ Months

Age of surgery on second ear □□ Years, and □□ Months

Thank you for sharing about your child and his or her hearing. Now we’d like to find out about your experiences with services to help with your child’s development after diagnosis.
Before a family receives infant and toddler services, a team of professionals will hold a meeting with the family to discuss your concerns, priorities and resources. The team will also test your child to identify his or her skills and areas for growth. Testing may occur once or twice each year as your child grows. This evaluation process is important in developing an early intervention plan, sometimes called the Individualized Family Service Plan (IFSP) that we ask about in Section D.

23. Which statement best describes your child’s experience with testing for services before the age of 3 years?

- My child has been tested at least once. 
- My child is being tested for the first time.
- My child has not been tested.

Go to Question # 25

24. Now we’d like to ask about the last time your child was tested for services. Thinking about the period before, during or just after testing, did the following occur?

<table>
<thead>
<tr>
<th>Did the following occur the last time your child was tested?</th>
<th>Yes</th>
<th>No</th>
<th>I’m not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>I shared my most important concerns with the team of professionals.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I filled out checklists, wrote down observations or gave other parent report.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was invited to be with my child for all testing activities.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The team made sure I understood the purpose of all activities and tests.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was given time to discuss whether my child’s behavior during testing was typical for him or her.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SECTION D: DESIGNING THE INDIVIDUALIZED FAMILY SERVICE PLAN

An Individualized Family Service Plan (IFSP) is a support plan that families and professionals develop together following evaluation. The purpose of the IFSP is to identify the services and people who can help families reach their goals. The IFSP is written and revised at least once each year to show your child and family’s changing needs.

25. Was an IFSP developed with your family?

- Yes
- No

Go to Question # 31
26. How many IFSPs were written before your child’s 3rd birthday?

- One........................................... □ 1
- Two .......................................... □ 2
- Three................................. □ 3
- More than three........... □ 4

27. For the next questions, please think about the last time an IFSP was developed for your child. Check one box for each item.

<table>
<thead>
<tr>
<th>Did the following occur the last time an IFSP was developed?</th>
<th>Yes 1</th>
<th>No 2</th>
<th>I’m not sure 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had time to get to know our provider before we wrote the IFSP.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I helped decide who should participate on the IFSP team.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wanted to be more involved than I was.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was allowed to make decisions at my own pace.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I decided my family’s priorities for the IFSP.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I was an equal partner in planning the goals and services for my child and family.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had enough time to read the IFSP before signing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I didn’t sign the IFSP until I was comfortable with it.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

28. If there is disagreement on what is best for your child, your opinion is given more weight.

- Strongly agree............................. □ 1
- Agree........................................... □ 2
- Undecided..................................... □ 3
- Disagree..................................... □ 4
- Strongly Disagree........................... □ 5

29. If there was disagreement between you and another team member while developing the IFSP, what happened?

_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
_____________________________________________________________________________________
30. We are interested in what the team did AFTER the last IFSP was developed. Check one box for each item.

<table>
<thead>
<tr>
<th>Did the following occur AFTER the last IFSP was developed?</th>
<th>Yes</th>
<th>No</th>
<th>I'm not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Each team member carried out the plan we made.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>The therapy provided by each service provider reflected my family's priorities.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>A team member made changes in the plan as my child progressed.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>A team member helped me schedule therapy and assessments for my child.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

SECTION E: YOUR FAMILY’S INFANT AND TODDLER SERVICES

This section asks about your family’s experience with infant and toddler services. By “infant and toddler services,” we mean any professional services (like speech therapy, sign language instruction, physical therapy, etc.) received by your family before your child’s 3rd birthday. We’d also like to know about the sources of support that have been most helpful to you as a parent.

31. How old was your child when infant and toddler services first began?

[ ] Years, and [ ] Months

☐ Check this box if your child never received services, then Go to Question # 51

32. How did you feel about the amount of time your child waited to receive services?

- It was reasonable ................. [ ] 1
- It was a little too long ............ [ ] 2
- It was much too long .............. [ ] 3

Go to Question # 34

33. What were the reason(s) for the delay? Check all that apply.

- Delay in 3rd party payments like Medicaid or private insurance... [ ] 1
- Difficulty scheduling services........................................... [ ] 2
- Difficulty finding a qualified provider............................... [ ] 3
- My child’s paperwork was not yet complete........................ [ ] 4
- Our family was not ready to start services.......................... [ ] 5
- Had trouble getting transportation to services................... [ ] 6
- My child was ill................................................................. [ ] 7
- Other (______________________________________________________) [ ] 8
34. Does your child currently receive infant and toddler services for his or her hearing loss?

Yes........................................... □1

No........................................... □2 \(\Rightarrow\) Go to Question # 51

35. How long has your child been enrolled in infant and toddler services?

Less than 6 months.............. □1
6 to 12 months...................... □2
13 to 18 months................... □3
19 to 24 months................... □4
25 to 30 months................... □5
More than 30 months........... □6

36. Your child currently receives infant and toddler services at....
Check all that apply.

Our home......................................... □1 \(\Rightarrow\) Go to Question # 39
A daycare center...................... □2
A preschool................................. □3
A school for the deaf................ □4
A clinic or hospital.................... □5
Other (__________________________) □6

37. If your child receives services in a group, how would you describe the other children? Check all that apply.

Children with hearing loss.......................................................... □1
Children with normal hearing (typically developing).......................... □2
Children with other special needs............................................... □3
My child does not receive services in a group.................................. □4

38. Is the location where your child receives services appropriate for your family’s needs?

It is convenient and has most of the resources that we need .................. □1
It is convenient but has few of the resources that we need................... □2
It is not convenient but has most of the resources that we need........... □3
It is not convenient and has few of the resources that we need............. □4

39. Has your family ever moved to another location because of the services available there for your child with hearing loss?

Yes........................................... □1
No ............................................... □2
40. The next questions ask about the choices you were offered the last time you planned infant and toddler services. Mark one box on each row.

<table>
<thead>
<tr>
<th>Did the following occur the last time you planned services?</th>
<th>Yes</th>
<th>No</th>
<th>I’m not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had a choice about the location where my family received services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had a choice about how often my family received services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had a choice about how much I participated in the services with my child</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

41. Was your family’s schedule considered when services were planned?
   - Yes……………………. □1
   - No ………………………. □2

42. Given your family’s daily routine, the number of total visits scheduled with all service providers was …
   - About right…………….. □1
   - Too few…………………. □2  Why? ________________________________________________
   - Too many……………….. □3  Why? ________________________________________________

43. Place a mark beside the service provider you and your child currently see the most often. For the other service providers, please indicate whether your child does see or does not see these professionals now.

<table>
<thead>
<tr>
<th>Service Provider</th>
<th>See the most often (check one)</th>
<th>Also see</th>
<th>Does not see</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early childhood special education teacher</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infant-toddler specialist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teacher of the deaf and hard of hearing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech-Language Pathologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Audiologist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Therapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other provider (______________________)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
44. How often does your child receive services from the Primary Provider? The Primary Provider is the person your child sees the most often to help with communication difficulties due to a hearing loss or disorder.

<table>
<thead>
<tr>
<th>Frequency</th>
<th>□₁</th>
<th>□₂</th>
<th>□₃</th>
<th>□₄</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once a week or more</td>
<td></td>
<td></td>
<td></td>
<td>How often? ________________________________</td>
</tr>
<tr>
<td>Every other week</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once a month</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than once a month</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

45. For the next set of questions, please think about the last 12 months. Then, mark YES or NO to indicate whether your family’s Primary Provider provided the following counseling, services or other assistance. Next, check YES or NO to indicate whether your family wanted this type of help. Remember to mark two boxes in each row.

<table>
<thead>
<tr>
<th>In the last 12 months, did the Primary Provider ...?</th>
<th>Did the Primary Provider ...?</th>
<th>Did your family want this help?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help you fill out forms.</td>
<td>Yes __</td>
<td>No __</td>
</tr>
<tr>
<td>Help you contact parents of other children with hearing loss.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you find funding for services or equipment like hearing aids or a cochlear implant.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demonstrate knowledge of your child’s equipment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you learn to troubleshoot the hearing aids and/or cochlear implant.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encourage you to be the major decision-maker about your child.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Give you time to express your feelings about having a child with hearing loss.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Give helpful suggestions to manage your child’s behavior.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use your suggestions about how to work with your child.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Show you how to use toys, books and play to develop language.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Show you strategies to develop language during your child’s daily activities such as dressing or bathing.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help you learn your child’s communication approach.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
46. What approach best describes how you want to communicate with your child? Check one.

Spoken language................................................................. □ 1
A combination of spoken and signed communication.................... □ 2
Sign language................................................................. □ 3
A communication board or device ............................................. □ 4
Cued Speech................................................................. □ 5
Other (_______________________________________________________) □ 6

47. How skilled is your Primary Provider in using this approach to communicate with your child? Remember: The Primary Provider is the person your child sees the most often to help with communication difficulties due to a hearing loss or disorder.

Very skilled.............. □ 1
Somewhat skilled........... □ 2
Not at all skilled........... □ 3

48. Does the Primary Provider use this approach to communicate with your child?

Yes......................... □ 1
No.......................... □ 2

Go to Question # 50

49. What approach does the Primary Provider use with your child? Check one.

Spoken language ................................................................. □ 1
A combination of spoken and signed communication.................... □ 2
Sign language................................................................. □ 3
A communication board or device ............................................. □ 4
Cued Speech................................................................. □ 5
Other (_______________________________________________________) □ 6
50. Tell us 3 things you would change about your child’s infant and toddler services if you could? Please describe your ideas as fully as possible.

1. __________________________________________________________

2. __________________________________________________________

3. __________________________________________________________

SECTION F: ABOUT YOUR FAMILY

51. How are you related to the child you are responding about?

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>□ 1</td>
</tr>
<tr>
<td>Father</td>
<td>□ 2</td>
</tr>
<tr>
<td>Stepfather</td>
<td>□ 3</td>
</tr>
<tr>
<td>Stepmother</td>
<td>□ 4</td>
</tr>
<tr>
<td>Foster mother</td>
<td>□ 5</td>
</tr>
<tr>
<td>Foster father</td>
<td>□ 6</td>
</tr>
<tr>
<td>Grandmother</td>
<td>□ 7</td>
</tr>
<tr>
<td>Grandfather</td>
<td>□ 8</td>
</tr>
<tr>
<td>Other (_______________________)</td>
<td>□ 9</td>
</tr>
</tbody>
</table>

52. What is your marital status?

<table>
<thead>
<tr>
<th>Status</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never married</td>
<td>□ 1</td>
</tr>
<tr>
<td>Married</td>
<td>□ 2</td>
</tr>
<tr>
<td>Widowed</td>
<td>□ 3</td>
</tr>
<tr>
<td>Separated</td>
<td>□ 4</td>
</tr>
<tr>
<td>Divorced</td>
<td>□ 5</td>
</tr>
</tbody>
</table>

53. How would you describe the area where you live?

<table>
<thead>
<tr>
<th>Area</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>City of 100,000 people or more</td>
<td>□ 1</td>
</tr>
<tr>
<td>City or town less than 100,000 people</td>
<td>□ 2</td>
</tr>
<tr>
<td>Suburb</td>
<td>□ 3</td>
</tr>
<tr>
<td>Rural area</td>
<td>□ 4</td>
</tr>
<tr>
<td>None of these</td>
<td>□ 5</td>
</tr>
<tr>
<td>Please describe</td>
<td></td>
</tr>
</tbody>
</table>

54. What is your racial/ethnic background? Check all that apply.

<table>
<thead>
<tr>
<th>Race</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>White/Caucasian</td>
<td>□ 1</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>□ 4</td>
</tr>
<tr>
<td>Black/African-American</td>
<td>□ 2</td>
</tr>
<tr>
<td>Native American</td>
<td>□ 5</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>□ 3</td>
</tr>
<tr>
<td>Other (_______________________)</td>
<td>□ 6</td>
</tr>
</tbody>
</table>

55. What is your age in years?

<table>
<thead>
<tr>
<th>Age</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your Age</td>
<td>113 years</td>
</tr>
</tbody>
</table>
56. What is the highest level of education you have completed?

- Less than 12th grade
- High school graduate or GED
- Junior college or Technical school
- Some college
- College graduate
- Graduate / Professional school

57. If another parent lives in the home, what is the highest level of education he/she has completed?

- Less than 12th grade
- High school graduate or GED
- Junior college or Technical school
- Some college
- College graduate
- Graduate / Professional school

58. Thinking about your child with a hearing loss, do his or her biological parents have a hearing loss?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>I'm not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

59. How many adults live in the home with your child? An adult is any person over the age of 18 years old.

Total Number of Adults Living in Home: __________________________

60. Please list the other children living in the home, including their ages, sex, and special needs, if any.

<table>
<thead>
<tr>
<th>Age</th>
<th>Boy or Girl</th>
<th>Hearing Loss (Yes or No)</th>
<th>Other Special Needs (Describe)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
61. Is English the only language spoken in your home?

Yes.................................. □₁ Go to Question # 64
No.................................. □₂

62. If no, what other languages are spoken in your home?

Other Languages Spoken in Home: ___________________________________________
................................................................................
................................................................................
................................................................................

63. Is there any other information you would like to share with us about your child, your family, your child’s services, or primary provider?

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

Thank you for completing this survey!
REFERENCES


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