ABSTRACT

Title of Dissertation: FAMILY CHARACTERISTICS, STATE
PROGRAM EFFECTIVENESS, AND REPORT
OF INADEQUATE CARE AMONG
FAMILIES OF YOUNG CHILDREN WITH
HEARING LOSS

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Approximately 1.6 per 1,000 newborns in the U.S. are born with hearing loss.

Congenital hearing loss poses a risk to their speech, language, cognitive, and social-

emotional development. Early detection and intervention can improve outcomes.

Every state has an Early Hearing Detection and Intervention program (EHDI) to

promote and track screening, audiological assessments and linkage to early

intervention. However, a large percentage of children are "lost to system (LTS),"

meaning that they did not receive recommended care or that it was not reported.

This study used data from the 2009-2010 National Survey of Children with

Special Health Care Needs and data from the 2011 EHDI Hearing Screening and

Follow-Up Survey to examine how 1) family characteristics; 2) EHDI program

effectiveness, as determined by LTS percentages; and 3) the family conditions of

education and poverty are related to parental report of inadequate care. The sample comprised 684 children between the ages of 0 and 5 years with hearing loss.

The results indicated that living in states with less effective EHDI programs was associated with an increased likelihood of not receiving early intervention services (EIS) and of reporting poor family-centered communication. Sibling classification was associated with both receipt of EIS and report of unmet need. Single mothers were less likely to report increased difficulties accessing care. Poor and less educated families, assessed separately, who lived in states with less effective EHDI programs, were more likely to report non-receipt of EIS and less likely to report unmet need as compared to similar families living in states with more effective programs. Poor families living in states with less effective programs were more likely to report less coordinated care than were poor families living in states with more effective programs.

This study supports the conclusion that both family characteristics and the effectiveness of state programs affect quality of care outcomes. It appears that less effective state programs affect disadvantaged families' service receipt report more than that of advantaged families. These findings are important because they may provide insights into the development of targeted efforts to improve the system of care for children with hearing loss.

FAMILY CHARACTERISTICS, STATE PROGRAM EFFECTIVENESS, AND
REPORT OF INADEQUATE CARE AMONG FAMILIES OF YOUNG
CHILDREN WITH HEARING LOSS

by

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Dissertation submitted to the Faculty of the Graduate School of the
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Dedication

This dissertation is dedicated, first and foremost, to my husband, Dann, and my children, Cole and Raina. They were my biggest supporters throughout my time as a doctoral student. I am beyond grateful to Dann for his patience, his tackling of many extra duties as a "single father," his help, and his encouragement. My children remained my cheerleaders during this time even though it often meant that I had little free time and often missed important events. Despite this, I was lucky enough to be surrounded by their love notes and motivational messages as I worked on this paper. Raina, who was born with hearing loss, also served as my inspiration for returning to school and focusing my research on matters related to improving the quality of care for children with hearing loss. I am grateful for all of the amazing opportunities that our family has experienced and people that we have met as a result; while I do hope for a future in which all children have the gift of hearing, her hearing loss has been a blessing.

I would also like to dedicate my dissertation to all of the pioneers in the field of early hearing detection and intervention. They are my greatest heroes. As a result of their tireless efforts to implement universal screening and improve the systems of care for identified children, my daughter has thrived socially, academically, and emotionally. I am thrilled that no aspect of her life will be limited by her diagnosis; her future is full of possibilities and she can live up to her full potential. In particular, I want to acknowledge Ms. Irene Forsman, former director of the Newborn Hearing Screening Program, and Dr. Karl White, director of NCHAM, for their efforts and for having provided me with opportunities to be a part of their community.

Acknowledgements

I am exceptionally grateful to Dr. Sandra Hofferth for serving as the Chair of my committee and her incredible guidance over the last two years. She has been instrumental in my finally reaching this milestone by providing me with encouragement, praise, and tough love when I needed it. I am thankful for her time, her commitment to my success, her patience with my questions, and her advice that I pursue a research topic that was so meaningful to me.

I also want to thank my amazing dissertation committee for all of their support. Dr. Elaine Anderson provided constructive feedback in a warm, positive manner; responding to her questions served as learning opportunities for me. With her special education policy background, Dr. Margaret McLaughlin challenged me to think critically about my topic and to express my intent more clearly. Dr. Rada Dagher's inputs were incredibly helpful, particularly her recommendation of a theoretical model that was a better fit to the health systems research focus of my paper. Dr. Xin He possessed a special ability to make complex statistical problems seem easy to understand. His patient, clear, and logical responses to my questions were invaluable. I could not have had a more collegial group of advisors and I am grateful for their time and feedback.

I would also like to thank my friends and family for their support and encouragement as I pursued my doctorate. My parents, Tom and Carmen Henry, raised me to value education and provided me with a strong work ethic by example – and they were always there when needed. My mother-in-law, Sally Determan, has also been incredibly supportive to me and my family in so many ways over the years.

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Chapter 1: Introduction

Expectant parents hope that the birth of their child will be a wondrous occasion of overwhelming happiness, and wish for a positive birth experience that ends with them holding their healthy baby. They may imagine reading to the baby, making funny noises to make the baby laugh, or singing a lullaby as the baby is rocked to sleep. Learning that their newborn is diagnosed with hearing loss can be traumatic for the family and cause them to wonder if these visions with their child are still possible. They may experience a range of feelings such as grief or inadequacy as they process this news (Kurtzer-White & Luterman, 2003). Additionally, families who have children with hearing loss are faced with a steep learning curve regarding medical care, audiological services and devices, early intervention services, educational choices, and communication options; much of which needs to be acted upon quickly in order to create the best outcomes for their children.

More than 90 percent of children born with severe to profound hearing loss are born to normally hearing families who had no reason to believe they would experience this outcome (Meadow-Orlans, 1994). As such, these families may have had little interaction with deaf persons previously; understand little about the implications of the diagnosis, including following a recommended timeline that starts soon after birth; or, most likely, have little to no experience with any visual communication methods, such as American Sign Language. Already dealing with all the new responsibilities and concerns that accompany childbirth, they may become overwhelmed and not feel as though they are capable of handling the added responsibility of managing the child's hearing loss successfully (Kurtzer-White &

Luterman, 2003). The diagnosis may also seem implausible to the new parents, if it appears that the baby does respond to noises, as babies who are not fully deaf can pick up sounds and react to voices (Kurtzer-White & Luterman, 2003).

Fortunately, there are several resources available to families who have children with hearing loss, such as early intervention programs and family support groups. However, although these programs can be immensely helpful, they vary greatly across the U.S. and are impacted by laws and policies that differ among the states. As a result, programs may not be equally successful and may experience a wide range of outcomes across the states. Furthermore, individual family characteristics, such as education level, poverty level, and family structure, may be associated with whether the family understands that these resources exist and accesses them appropriately, as the family may not comprehend the diagnosis, may be confused about the instructions regarding next steps, may not be able to afford recommended care or equipment, may not have the ability to take time off from work for all of the necessary follow-up appointments, or may not understand the materials provided to them. As such, the likelihood that a family will receive recommended health care services, and their family's satisfaction with that care and associated services, could very well depend on their family characteristics, as well as in what state they happen to reside.

Background

Approximately 1.6 per 1,000 newborns in the U.S. are born with hearing loss; of these about one per 1,000 are born with profound hearing loss and approximately

two to three per 1,000 are born with partial hearing loss (Williams, Alam & Gaffney, 2015; D. Marge & M. Marge, 2005). Congenital hearing loss poses a risk to their speech, language, reading, cognitive, and social-emotional development with potential long-term effects on many aspects of their lives, such as attaining lower levels of education or employment as compared to their hearing counterparts (Russ, 2010; Joint Commission on Infant Hearing, 2007). However, it is known that early detection and intervention can greatly improve outcomes for babies with hearing loss. Yoshinaga-Itano, Sedey, Coulter, and Mehl (1998) determined that identification and intervention by six months of age were associated with significantly better language development. Furthermore, in a review of studies investigating outcomes related to age at intervention, Yoshinaga-Itano (2003) reported that "the first 6 months of life represents a particularly sensitive period in early language development, a window of opportunity for initiation of intervention services" (p. 14). In a later study, it was found that children who were identified before three months of age had better expressive and receptive language outcomes when assessed at seven years of age than did those who were identified after three months of age (Yoshinaga-Itano, Baca & Sedey, 2010). This research became the basis for guidelines published by the Joint Commission on Infant Hearing (JCIH) (JCIH, 2007), which recommended screening newborns for hearing loss by one month of age, audiological evaluation by three months of age, and enrollment into early intervention services by six months of age.
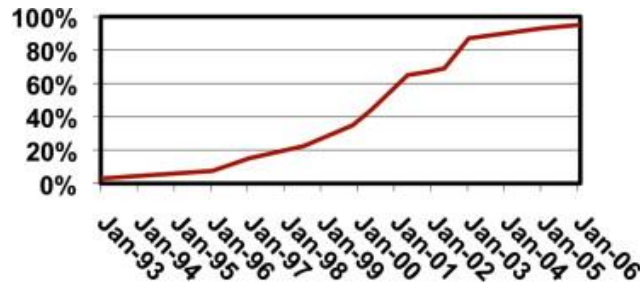
Figure 1. Percentage of newborns screened by year (White, Forsman, Eichwald, & Munoz, 2010)

Through the committed efforts of what began as the Newborn Hearing

Screening Program, and is now referred to as the Early Hearing Detection and

Intervention (EHDI) Program to reflect its larger role, over 97 percent of babies born

in the U.S. are screened by one month of age (Centers for Disease Control and

Prevention (CDC), 2011). Just 20 years ago, fewer than ten percent of U.S. babies

were screened in their first year of life (White, Forsman, Eichwald, & Munoz, 2010;

National Institute on Deafness and Other Communication Disorders (NIDCD), 2012).

However, despite the great gains made in universal screening, a large percentage of

the children who do not pass the screen are "lost to follow-up (LTFU)," meaning that

the baby did not receive or complete the JCIH-recommended diagnostic or

intervention processes, or they may be "lost to documentation (LTD)," meaning that

the baby's diagnostic or intervention status has not been reported to a state EHDI

office (American Speech-Language-Hearing Association, 2008). The American

Speech-Language-Hearing Association (ASHA) suggested that LTFU and LTD be

combined in the term "lost to system (LTS)" to describe both types of losses more

simply (ASHA, 2008; Beauchaine & Hoffman, 2008).

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Over one-third of U.S. children who do not pass the newborn hearing screening are LTS for audiological diagnosis such that it is not known if their families followed recommended guidelines to assess whether the newborn screening failure truly indicated a hearing loss (CDC, 2011a). Furthermore, these numbers vary greatly by state with a range of 8.4 percent LTS in Massachusetts to 82.6 percent LTS in South Dakota (CDC, 2011b). Of the babies who are confirmed as positive for hearing loss through audiological diagnosis, 26 percent are LTS with respect to enrollment in early intervention services (CDC, 2011b). Again, these numbers vary widely by state with six states (Delaware, Idaho, New Mexico, Pennsylvania, Vermont, and Wyoming) reporting no LTS and three states (Maryland, South Dakota, and Washington) reporting 100 percent LTS with regard to early intervention services.

There are several factors behind the large percentages of LTS of audiological diagnosis following failed screens and LTS in the linkage to early intervention services after confirmed hearing loss. These issues may occur at the national or state system-level (e.g., differences in state policies, programs, or reporting systems), at the community level (e.g., access to local providers), and at the family level (e.g., insurance status and access to transportation).

Research studies and history have shown that federal and state policies and legislation may influence screening and follow-up rates. Currently, every state has a mandatory or voluntary newborn screening program, which is reflected in the outcome that more than 97 percent of newborns are screened annually, and 43 states have hearing screening and intervention statutes or rules in place (White, 2014;

Houston, Hoffman, Munoz, & Bradham, 2011). There is great variability in what is

required or covered from state to state, but it is important to note that many of the

states engage in more activities than what is required and that legislation alone is not

"necessary or sufficient" (White, 2014, p. 1-11). Approximately two-thirds of the

states with legislation have a rule requiring that hospitals report screening data to the

EHDI program and 21 percent of them require coverage of screening through

insurance (White, 2014). The effect of legislation can be quite significant. In a study

that examined the effect of legislation on newborn screening rates, states that enacted

a universal newborn hearing screening law had significantly higher screening rates

than those that had not (Green, Gaffney, Devine & Grosse, 2007). In 2003, 76

percent of the states with universal hearing screening legislation screened at least 95

percent of their newborns, whereas this rate was accomplished by only 26 percent of

the states without legislation.

     A 2005 survey of state EHDI programs identified the primary barriers to

linking families to follow-up, including lack of service-system capacity, lack of

provider knowledge, challenges in obtaining services, and information gaps

(Shulman, Besculides, Saltzman, Ireys, White, & Forsman, 2010). Barriers that states

experienced regarding system capacity included insufficient and unreliable screening

equipment, a lack of sufficiently trained pediatric audiologists, inadequate early

intervention services for infants with hearing problems, and a lack of family support

programs. They also found that providers (e.g., pediatricians and hospital staff) had

limited knowledge about infants with hearing loss. Many of the hospitals lacked

screening and reporting protocols; only one-third of the hospital screening programs

had screeners that received training on how to deliver the results to parents, which may be an important factor in family decision-making and follow-up. Furthermore, Shulman et al. (2010) noted that it was difficult for providers to develop expertise in this topic in less-populated regions or in smaller health care practices due to the small number of children with hearing loss. Disturbingly, almost half of the screening programs indicated that there were problems with pediatricians adopting a "wait and see" attitude when infants did not pass the hearing screening. In their study, information gaps referred to poor communication between the hospital screening staff, key providers, and EHDI staff; data systems that are inaccessible to providers to enable them to track and assist families through the process; and privacy-sharing laws that restrict the sharing of health information. Although these issues have most likely improved since the 2005 survey, as a result of the intensive efforts to improve the EHDI programs, it is also quite probable that these barriers remain.

Several family-level risk factors have been associated with lost-to-system (LTS), including socioeconomic status (e.g., insurance status, income, or race/ethnicity), family characteristics (e.g, education and smoking history), and health status of the infant (e.g., birth weight and severity of hearing loss) (Liu, Farrell, MacNeil, Stone, & Barfield, 2008; Spivak, Sokol, Auerbach, & Gershkovich, 2009; Prince, Miyashiro, Weirather, & Heu, 2003; Oghalai, Chen, Brennan, Tonini, & Manolidis, 2002). The study of EHDI programs by Shulman et al. (2010) identified six challenges faced by families in obtaining services: needing to go to an unfamiliar location for diagnostic evaluation, preauthorization requirements for evaluation, lack of transportation, having inadequate insurance for hearing services, being a highly

mobile family challenged continuity of services, and speaking a different language.

Given the complex set of processes in unfamiliar territory that parents need to enact

following a failed newborn screen, it is clear that family characteristics and state

EDHI program indicators may play critical roles in the success of the child meeting

Joint Commission on Infant Hearing care guidelines in a timely manner and of

families reporting receipt of high quality health care and services (JCIH 2007).

Current Study

This study investigated the experiences of families who have children with

hearing loss and report of their experiences regarding non-receipt of early

intervention services, unmet need, poor coordinated care, lack of access, and poor

family-centered communication. These experiences were examined in relation to

family characteristics (i.e., education level, poverty status, and family structure – to

include single mother status and sibling classification examined separately) and the

effectiveness of state EHDI programs, as determined by lost-to-system (LTS)

percentages for audiological diagnosis and linkage to early intervention, separately.

Strength of the state EHDI program was assessed using LTS data from CDC's 2011

EHDI Hearing Screening and Follow-Up Survey (HSFS). Data regarding family

report of experience and satisfaction of care were drawn from the 2009-2010 CDC

National Survey of Children with Special Health Care Needs (NS-CSHCN). Parent

report on the five outcome measures (i.e., non-receipt of early intervention services,

unmet need, lack of coordinated care, lack of access to care, and lack of family-

centered communication) was examined in relation to 1) family direct effects, 2) state

EHDI program direct effects, and 3) the interactions of poverty and education with the state EHDI program indicators.

Research Questions

This study focused on the following research questions:

1) Adjusting for child's age, race, language and insurance status, examine the association between family characteristics and family report of quality of care measures:

   a. Determine the association between education level and family report of quality of care measures.

   b. Determine the association between poverty status and family report of quality of care measures.

   c. Determine the association between single mother status and family report of quality of care measures.

   d. Determine the association between sibling classification and family report of quality of care measures.

2) Adjusting for child's age, race, language and insurance status, examine the association between the quality of state EHDI programs and family report of quality of care measures:

   a. Determine the association between the effectiveness of the state EHDI program quality, as related to lost-to-system percentages for audiological diagnosis, and family report of quality of care measures.

b. Determine the association between the effectiveness of the state EHDI program quality, as related to lost-to-system percentages for linkage to early intervention, and family report of quality of care measures.

3) Adjusting for child's age, race, language and insurance status, examine whether the associations between poverty status and education levels, separately, and family report of quality of care measures are modified by the quality of state EHDI programs.

    a. Adjusting for child's age, race, language and insurance status, examine whether the associations between <u>family poverty status</u> and family report of quality of care measures are modified by the quality of state EHDI programs, as determined by <u>LTS for audiological diagnosis</u>.

    b. Adjusting for child's age, race, language and insurance status, examine whether the associations between <u>family poverty status</u> and family report of quality of care measures are modified by the quality of state EHDI programs, as determined by <u>LTS for linkage to early intervention</u>.

    c. Adjusting for child's age, race, language and insurance status, examine whether the associations between <u>family education level</u> and family report of quality of care measures are modified by the quality of state EHDI programs, as determined by <u>LTS for audiological diagnosis</u>.

    d. Adjusting for child's age, race, language and insurance status, examine whether the associations between <u>family education level</u> and family report of quality of care measures are modified by the quality of state

EHDI programs, as determined by <u>LTS for linkage to early</u>

<u>intervention</u>.

Conceptual Model
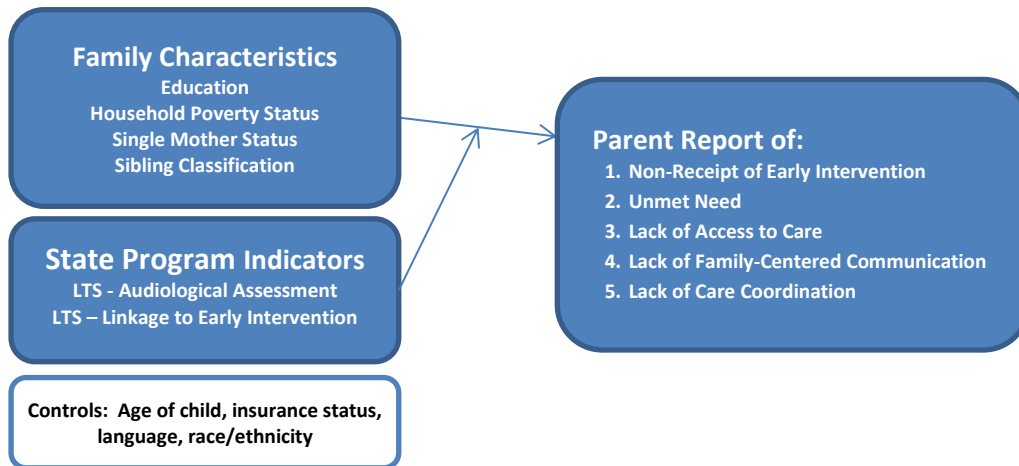
Figure 2. Conceptual Model – The association between 1) family characteristics and 2) state program indicators and parent report of satisfaction with care measures

Theory

This study used the Behavioral Model of Health Services Use, also referred to as Andersen's Behavioral Model of Utilization or the Behavioral Model, as the theoretical model for investigating the effects of family characteristics and the effectiveness of state programs on parent report of non-receipt of Early Intervention Services, unmet need, lack of access to services, lack of family-centered communication, and lack of coordinated care (Andersen, 1995; Babitsch, Gohl, & von Lengerke, 2012). The Andersen Model was applied to describe the relationships between predisposing characteristics, such as family demographics; enabling resources, such as income or health services resources; need characteristics, such as the severity of the condition under examination or the health status of the vulnerable

population; and outcomes, such as receipt of recommended care and various indicators of satisfaction with care.

Purpose

Although the Early Hearing Detection and Intervention Program (EHDI) has made tremendous strides in improving outcomes for children born with hearing loss via the creation of a comprehensive system to track, report, and follow-up identified children, challenges remain related to the large percentage of infants who are "lost-to-system (LTS)." The purpose of this study was to examine family characteristics and the effectiveness of the state EHDI programs in relation to family report of satisfaction with care measures. This study is believed to be unique in combining state-level data from the EHDI Hearing Screening and Follow-Up Survey and the family-level data from the National Survey of Children with Special Health Care Needs. It is hoped that this examination adds to the knowledge base by providing further understanding of the family characteristics that are associated with LTS. By providing additional insights into the associations of certain family characteristics and LTS, policymakers and program coordinators have additional evidence to inform decision-making, guide quality improvement efforts, and provide justification for specific approaches in addressing the system's gaps.

Chapter 2: Literature Review

Introduction

Newborn hearing screening began in Rhode Island, Hawaii, and Colorado in 1989, 1990, and 1993, respectively (Morton & Nance, 2006). It was not until 1993 that the National Institutes of Health (NIH) recommended that all newborns be screened for hearing loss before leaving the hospital, followed by the American Academy of Pediatrics endorsing universal screening and intervention guidelines in 1999 (CDC, 2011d). Congress passed the Newborn and Infant Hearing Screening and Intervention Act of 1999 to coordinate and fund mandatory screening in statewide programs (NIH, 2010). In 1999, fewer than half of U.S. children were screened for hearing loss in their first year of life (National Institute on Deafness and Other Communication Disorders (NIDCD), 2012). However, through the efforts of the Newborn Hearing Screening Program, funded by the Health Resources and Services Administration's (HRSA) Title V program, approximately 73 percent of infants born in the U.S. were screened before age one month by 2005 (NIDCD, 2012) increasing to over 98 percent by 2011 (CDC, 2013).

Despite the monumental public health effort to implement nearly universal screening nationwide, a large number of children who do not pass the screening are lost to follow-up such that it is not known whether they have received further care or early intervention – putting them at risk of potentially preventable adverse outcomes. Although the percentage of children lost to follow-up has improved greatly over the years, dropping to 35.3 percent in 2011 from 64 percent in 2005 (CDC, 2011c), it is critical that improvement efforts continue such that newborns who fail the hearing

screen are tracked appropriately and receive necessary services before the age of six months, when the window of opportunity for improved outcomes starts closing. Having a better understanding of the factors that are linked to early and appropriate receipt of services, as well as the family's perceptions of their experience navigating the health care system, will help policy makers and practitioners better reach and serve this population.

Theoretical Framework

This study used the Behavioral Model of Health Services Use, also referred to as Andersen's Behavioral Model of Utilization or the Behavioral Model, as the theoretical model for investigating the effects of family characteristics and the effectiveness of state programs on parent report of non-receipt of Early Intervention Services, unmet need, lack of access to services, lack of family-centered communication, and lack of coordinated care (Andersen, 1995; Babitsch, Gohl, & von Lengerke, 2012). The Andersen Model was applied to explain the relationships between predisposing characteristics, such as family demographics; enabling resources, such as income or health services resources; need characteristics, such as the severity of the condition under examination or the health status of the vulnerable population; and outcomes, such as receipt of recommended care and various indicators of satisfaction with care.

Andersen's Behavioral Model

The Behavioral Model is widely used to study health care utilization in public health and health services research literature. Although it was originally developed in

the late 1960s to examine the determinants of health care use by families, it has been

refined several times over the years to adapt to new approaches in health services

research, as well as to special populations (Andersen, 1995; Gelberg, Andersen, &

Leake, 2000). The later versions of the model suggest that health services use is

influenced by a combination of three factors: the individual or specific population,

the health care system, the external environment, and the effects that each of these has

on the others (Lo & Fulda, 2008; Andersen, 1995). The latest phase, developed in the

2000s, highlights that health services use and satisfaction with care are best achieved

by focusing on contextual and individual characteristics (Andersen, 2008), see Figure

3. Additionally, the process of medical care, which represents provider behaviors

when interacting with patients such as include quality of communication, test

ordering, and making appropriate referrals, is added to the health behaviors

component (Andersen, 2008). Andersen's model has retained relevancy over the

years through its many adaptations, and is frequently used in health services research

to evaluate access to health care, outcomes, and quality (Phillips, Morrison,

Andersen, & Aday, 1998; Lo & Fulda, 2008; Graves, 2009.)

Figure 3. Phase 5. A behavioral model of health services use including contextual and individual characteristics. (Andersen, 2008)
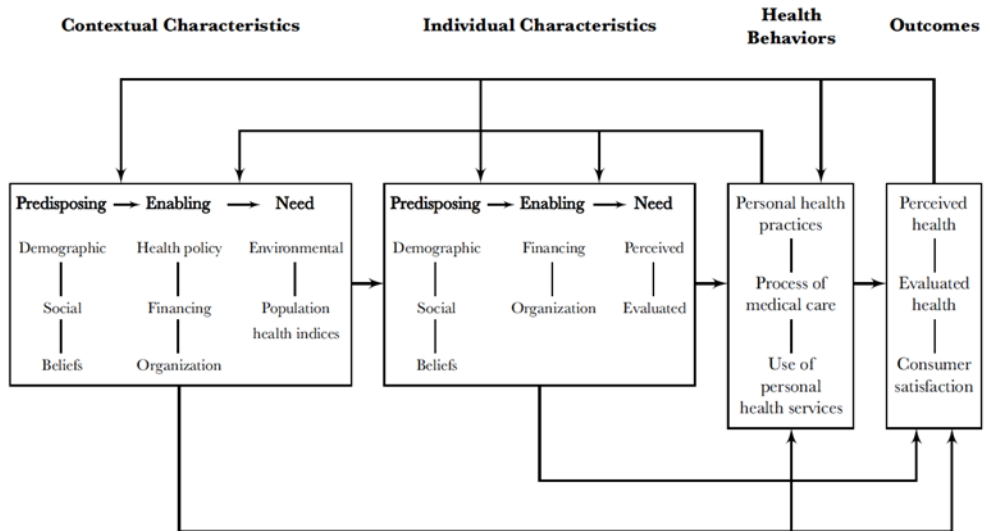
Consistent across all versions of the Behavioral Model is that there are three

determinants of health care use: predisposing factors, enabling factors, and perceived

need within the individual/population characteristics component. Predisposing

factors include biological factors that may determine whether an individual needs a

health service, social structure that may influence how an individual may cope with

health issues, and health beliefs that may influence the perception of need for health

care (Lo & Fulda, 2008). These include sociodemographic characteristics such as

education level, age, race and ethnicity, marital status, and family size. Health beliefs

include constructs such as values concerning health and illness, attitudes towards

health services, and knowledge about the disease or condition.

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Andersen posits that both community and personal enabling factors must be present in order for individuals to access health services (Andersen, 1995). This means that the health services (e.g., personnel and facilities) must be available where people can access them without great difficulty. Furthermore, individuals must have the resources (e.g., money to pay for services) and the knowledge about how to access these services to benefit from them. These enabling factors, or resources, include family characteristics such as income, insurance coverage, access to services (e.g., transportation needs), social support, perceived barriers to care, and community characteristics such as the availability of health services resources (e.g., local infant-family education programs for parents of newborns with hearing loss).

The need domain of the model includes perceived need and objective evaluation (i.e., evaluated need) of health conditions. Perceived needs may include the individual's attitudes, values, and knowledge about a health condition and associated services that affect the perception of whether care is needed (Lo & Fulda, 2008). Evaluated need refers to the professional judgment about an individual's health status and the necessary care. Andersen (1995) suggested that perceived need will explain care-seeking and adherence to a medical regimen, whereas evaluated need may be more related to the kind and amount of treatment that is provided. Some researchers have argued that the need characteristics are most predictive of service use (Andersen, 1995), which could be of interest to policy makers and program planners as it indicates that the population of interest could be influenced by health education programs.

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Later versions of the Behavioral Model acknowledge the influences of the external environment and the health care system on outcomes. Healthcare delivery system characteristics include the policies, resources, and organization of care and services that affect the accessibility, availability, and acceptability of health care services (Phillips et al., 1998). External environmental factors may include items such as the economic climate, crime, politics, the prevailing norms of society, urban versus rural designation, and the physical environment itself. These measures are often reported at the aggregate level (Andersen, 1998). These factors also play an important role in health care utilization.

Theoretical Model

In a paper by Gelberg, Andersen, and Leake (2000), in which a more detailed version of Andersen's model is proposed, the authors discussed the importance of studying the health needs of vulnerable populations because they are at a higher risk for adverse outcomes. They included children and those with disabilities as vulnerable populations, and noted that studying these populations via this model is useful in identifying the specific challenges faced in obtaining necessary care and in determining ways in which the quality of care may be improved. Other researchers agree that the determinants of health service use is an important area for further investigation. According to Eisenberg et al. (2007), research has shifted from describing outcomes in early identified children with hearing loss to investigating what may cause the different outcomes among families. Greater emphasis is now placed on understanding the child and family-related variables that mediate the outcome of intervention (Gascon-Ramos, Campbell, Bamford, & Young, 2010). For

example, satisfaction with and effectiveness of the intervention may be mediated by the family's values, beliefs, perceptions, and prior life experiences (Gascon-Ramos et al., 2010).

For these reasons, Andersen's Behavioral Model is appropriate for this study as it provides a logical mechanism for explaining the multiple associations under investigation (i.e., family characteristics of a child with hearing loss, state program indicators of effectiveness, and the interactions of these state program indicators with education and poverty, separately) and their relationship to the outcomes of parent report of receipt of care and quality of care measures (i.e., unmet need, lack of access to care, lack of family-centered communication, and lack of coordinated care). This study focused on two portions of the Behavioral Model (see Figure 3): the direct relationship between external characteristics (i.e., effectiveness of state programs) and the outcomes, and the direct relationship between family characteristics (i.e., predisposing characteristics, enabling characteristics, and need) and outcomes (i.e., receipt of services and satisfaction with care measures for a specific vulnerable population, families who have young children with hearing loss). It also investigated a few interactions among the external characteristics and two important family characteristics: education and poverty levels. The theoretical model, see Figure 4, highlights only those relationships within the model to clearly illustrate the focus and limits of this investigation. The following sections review the literature in terms of the predisposing, enabling, and need factors that are relevant to this study.

Family Characteristics

Predisposing Characteristics
Parent Education
Single Mother
Sibling Classification
Child age (control)
Race/ethnicity(control)

Enabling Characteristics
Poverty Status
Insurance Status (control)
Primary Language not English
(control)

Need Characteristics
Child with hearing loss
(entire sample)

External Characteristics

State Lost-to-System Percentages
for Audiological Diagnosis

State Lost-to-System Percentages
for Early Intervention

Outcomes

Parent Report of:
Non-Receipt of Early Intervention Services
Unmet Need
Lack of Access to Care
Lack of Family-Centered Communication
Lack of Coordinated Care

Figure 4. Theoretical Model – Based on the Behavioral Model of Health Services Use.
Adapted from Phillips, Morrison, Andersen & Aday, 1998 and Gelberg, Andersen &
Leake, 2000.

Family Characteristics

Predisposing Characteristics

Predisposing factors that are examined here include three of the family

characteristics investigated as main effects (i.e., parent education, single motherhood

status, and sibling classification) and two controls (i.e., child age and race/ethnicity).

Education

In general, studies have shown that a higher maternal education level is

associated with better outcomes regarding the utilization of health care services

(Porterfield & McBride, 2007; Mayer, Skinner & Slifkin, 2004). Porterfield &

McBride (2007) found that parents of lower education levels are less likely than more

educated parents to report that their CSHCN needed specialized health services. In a

survey of caretakers of a CSHCN, where 82.5 percent were parents, only half were

able to provide a description of their child's diagnosis (Carraccio, Dettmer, DuPont,

& Sacchetti, 1998). Applying the Behavioral Model, a parent's lower level of

education, combined with less knowledge about a condition (e.g., hearing loss), could

impact whether or not the parent believes that the child needs additional health

services or early intervention. The parent may perceive that additional services are

unnecessary if she does not understand the benefits that intervention could bring, or

worse, not understand the consequences of not seeking intervention, such as a child

not being able to achieve his expected potential had he been given access to hearing

aids or other communication supports.

Higher levels of maternal education have frequently been associated with increased compliance with recommended treatments, which would include early intervention services. In a recent longitudinal study of 193 children with some degree of hearing loss, Holte et al. (2012) found that, of several family- and child-related factors, only higher levels of maternal education were significantly associated with earlier audiological assessment, confirmation of hearing loss, and intervention (i.e., fitting hearing aids). On average, mothers with graduate degrees confirmed hearing loss through audiological assessment seven months earlier than mothers who attained a high school education or less, even though all of the children in the study were screened by one month of age. To be included in the present study at least one primary caregiver in the family had to speak English, so language issues were not a consideration. As mentioned earlier, delays in treatment can have adverse effects that can persist throughout the child's life. Furthermore, in a study determining predictors of hearing aid use time in children, it was found that higher levels of maternal education were significantly associated with increased hearing aid use (Walker et al., 2013), which is a practice recommended by early intervention programs. Mothers with a college-level education had their children wear hearing aids for 1.9 hours more per day than mothers with a high school education or less. Additionally, there were significant differences in hearing aid use during the weekends based on maternal education, with greater use being associated with higher levels of education. In a study that used a questionnaire to determine parental preferences and satisfaction with the content of early intervention following identification of deafness, it was found that maternal education was significantly associated with the "Supporting Parents"

subscale, which measured issues associated with personal support (Gascon-Ramos et al., 2010). Mothers with lower levels of education rated interventions that support the parents as more important than did mothers with more education. The authors speculate this may be due to the likelihood that less educated mothers may experience economic and other stressors, thus necessitating the need for more parental supports.

In particular, much of the research has shown that maternal education influences follow-up rates in seeking care, audiological diagnosis, and early intervention services. One recent study tested a battery of predictive variables, such as family socioeconomic status (SES), race, ethnicity, service access, and parental education, to determine their associations with successful follow-up (Holte et al., 2012). Only a higher level of maternal education was found to significantly affect the timing of audiological diagnosis and intervention services. Similar studies found that significantly higher follow-up was associated with mothers having completed high school or beyond. A study by Prince et al. (2003) found that 84.1 percent of mothers with at least a high school education followed up on audiological diagnosis versus only 74.5 percent of non-graduates. A study by Liu et al. (2008) reported that 92 percent of high school graduates sought audiological diagnoses as compared to just 79 percent of non-graduates.

Health Literacy as a Function of Education Level

Healthy People 2010 (U.S. Department of Health & Human Services (HHS), 2000) defines health literacy as: *The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to*

make appropriate health decisions (Ratzan & Parker, 2000). Although education alone is not a good measure of health literacy, it is generally agreed that health literacy is linked to education level, and will be discussed here as it relates to the outcomes of interest in this study. In a study of the 2003 National Assessment of Adult Literacy with a sample of 16,000 adults, lower health literacy scores were associated with lower levels of education (Kutner, Greenberg, Jin, & Paulsen, 2006). Average health literacy increased with each high level of educational attainment, and nearly half of the adults who did not complete high school were rated as "below basic" in health literacy (Kutner et al., 2006). There is some research suggesting that a parent's health literacy level will impact their decisions and their perceptions of the medical system and the services received by their family. Low health literacy affects health behaviors, health understanding and health outcomes and has been found to be associated with poor self-management of medical conditions, forgoing medical tests, lower compliance to specific treatments, and higher emergency room utilization (Institute of Medicine (IOM), 2004; HHS, 2010).

Children's health outcomes are greatly affected by their parents' health literacy levels and their understanding of their children's conditions (Otal et al., 2012). In a small study that compared the rate of follow-up of referral to early intervention services by level of health literacy, 75 percent of the participants with less than adequate health literacy did not have their children evaluated by early intervention services, as compared to 39 percent of the parents with adequate health literacy (Jimenez, Barg, Guevara, Gerdes, & Fiks, 2013). The parents with less than adequate health literacy identified four main themes in their experiences that relate to

a lack of access to care and a lack of family-centered communication: 1) most lacked continuity with a primary pediatrician, 2) they found it difficult to contact early intervention services, 3) they experienced much confusion with the referral process and the services offered, and 4) they did not receive helpful information about early intervention (Jimenez et al., 2013). These findings support other research that have found associations between low health literacy and poor health outcomes in children with chronic illnesses (DeWalt & Hink, 2009; Sanders, Federico, Klass, Abrams, & Dreyer, 2009); less likelihood of enrolling in public programs with a complicated application process (Pati et al., 2014); reporting more barriers to care (Yin et al., 2012); and difficulty following provider recommendations (Baker et al., 1996).

Single Mother Status

Having a single mother is associated with outcomes that are typically worse than those for children in a two-parent family. The former are more likely to be poor, experience food insecurity, and be at higher risk for emotional, behavioral, and educational problems (Acs & Nelson, 2001). In an epidemiologic profile conducted by Newacheck et al. (1998) with a sample of over 30,000 children less than 18 years old, children in single-parent families were 40 percent more likely to have existing special health care needs than children with two parents. However, due to the cross-sectional nature of the study, it was not possible to make a causal inference about this finding; it could be that parents separate as a result of the stresses associated with having a special needs child.

Additionally, half of the disparity regarding the well-being of children in two-parent families and those in single-parent families was found to be due to single mothers earning a lower income (McLanahan, 1994). Using the 2003 National Survey of Children's Health with a sample size of nearly 100,000 children, Bramlett and Blumberg (2007) found that children living with both biological parents had a more affluent lifestyle than children in other family structures. They made up the majority of higher-income households, were more likely to live in households where at least one parent attended college, and they were more likely to live in the suburbs. However, even after adjusting for socioeconomic and demographic characteristics, Bramlett and Blumberg (2007) found that children in single-mother households were in poorer physical and mental health than children living with two biological parents. The authors noted that children living with two biological parents were more likely to have private insurance than children in other family structures.

The overall disadvantage of single parent families described above is likely to result in worse access to services and communication with the provider for families with CSHCN. In a study of the 1996-2001 Medical Expenditure Panel Survey, Chen & Escarce (2006) provided unadjusted analyses showing that children living with a single mother averaged fewer total doctor visits than children in two-parent families. As related to a lack of family-centered communication, a study of the 2009-2010 NS-CSHCN, with a sample size of 40,242 CSHCN, found significantly increased odds of living with a single mother and the parent **not** reporting the following: 1) provider discusses a range of options (AOR=1.18, 1.03-1.35), 2) provider encourages asking questions (AOR=1.24, 1.09-1.41), provider makes it easy to ask questions

(AOR=1.27, 1.09-1.47), and provider respects parent's treatment choices (1.27, 1.11-1.47) (Smalley et al., 2014). Kenney, Denboba, Strickland, and Newacheck (2011) had similar results in a study of the 2005-2006 NS-CSHCN (n=40,723) designed to assess MCHB's Core Outcome 1: Family-provider partnerships and satisfaction with services (*see the section on Outcomes for more details*). Single mothers were 23 percent more likely to report that they did not feel like a partner and were dissatisfied with services.

Sibling Classification

Social and behavioral scientists have shown a consistent inverse relationship between family size (i.e., the number of siblings) and children's academic achievement and intellectual development (Downey, 2001; Phillips, 1999), supporting a "resource dilution" model. These scientists theorize that parental resources (e.g., time, energy, and money) are finite and that each child further dilutes these resources, resulting in worse outcomes for each child (Phillips, 1999; Downey, 1995). Although more limited, there are also studies of the effect of family size on health outcomes and utilization of health services. Two studies of immunization rates found that children in larger families were less likely to be vaccinated (Bates & Wolinksy, 1998; Luman, McCauley, Shefer, & Chu, 2003). Chen & Escarce (2006) found that a greater number of children in the household was associated with a reduced likelihood of going to the doctor, visiting the emergency room, and using a prescription medicine, even after adjusting for sociodemographic variables. However, children in families with four or more children had 80 percent fewer

physician office visits; having zero to two siblings did not generate this effect. This finding regarding family size was even more pronounced when examining the interaction between maternal education and family size: reduction of office visits was most evident in children of mothers with lower educational levels. Furthermore, as would be expected, children who were later in the birth order were more likely to have fewer physician office visits than first-born children.

In a study of 4,911 NICU babies and 2,348 well-baby nursery infants at a higher risk of hearing loss, Folsom et al. (2000) found that families were less likely to follow-up on care for their infant if they had more than two other children. However, other research does not support the resource dilution model. Using Alabama data from the 2003 National Survey on Children's Health (including both CSHCN and non-CSHCN), Mulvihill et al. (2007) reported that children living in families with more children under the age of 18 years were more likely to have coordinated care, as evidenced by having a medical home, than children living in families with fewer children under the age of 18 years. A study of the 2000-2002 NS-CSHCN that ran models by socioeconomic levels as defined by poverty level found that the number of children in the household was negatively associated with children receiving necessary specialty care (Lykens, Fulda, Bae, & Singh, 2009); however, this finding was only significant for those whose families had the lowest incomes.

Age of Child

There are differences in the use of health care by child age. The Family's Partner Survey, a 20-state survey of 2,220 families in 1998-1999, revealed that there

were significant differences in reported need of five (of six) core types of services based on child age (Warfield & Gulley, 2006). Younger children were more likely to need specialty services, whereas older children were more likely to need mental health services. Additionally, parents of older children were more likely to report difficulty with finding experienced providers and to mention that their child had an unmet need over the course of the year. Smith, Oswald, & Bodurtha (2015) reported that being an older CSHCN was significantly associated with parent report of unmet need for genetic counseling. The odds of unmet need increased with each yearly increase in age. In a study using 2005-2006 NS-CSHCN data, it was found that CSHCN between the ages of 0 and 4 were more likely to receive coordinated care than older age groups (WA DOH, 2010). In the Alabama study mentioned above in the "Sibling Classification" section, Mulvihill et al. (2007) reported that children under the age of 12 years were significantly more likely to receive coordinated care via a medical home than children 12 and over. In contrast, Lykens et al. (2009) reported that older CSHCN were more likely to receive all necessary specialty care, but this was only significant in families whose incomes were equal to or greater than 300 percent of the federal poverty level.

Race

Research shows an association between minority status and lower rates of health care use (Mayer, Skinner & Slifkin, 2004; Ngui & Flores, 2006). Folsom et al. (2000) studied factors associated with families completing neonatal assessment for hearing loss and returning for follow-up. Their sample included 4,911 high-risk

infants and 2,348 well baby nursery infants who were at higher risk of possible hearing loss. They found significantly higher rates of follow-up for non-Hispanic white infants than for babies of other races. Research by Liu et al. (2008) found similar results in a study of 1,492 infants.

As noted earlier, using data from the 2000-2002 NS-CSHCN, black and Hispanic parents of CSHCN were more than twice as likely as white parents to report dissatisfaction with care and a lack of ease in using health care services, but the effect disappeared for Hispanic parents after controlling for language (Ngui & Flores, 2006). After controlling for adequacy of family-care measures, only black/white disparities in ease of using health care services remained. In a separate study using NS-CSHCN data (n=38,866 children), black and multiracial children were twice as likely to experience unmet need for routine care than white children (Mayer et al., 2004). In an analysis of data from the 2007 National Survey for Children's Health (n=91,642 parents), Toomey, Chien, Elliott, Ratner, & Schuster (2013) reported that black and Hispanic children were more likely to experience unmet needs due to receiving family-centered care less often. Being black was significantly associated with reporting less coordinated care in a study of 2003 NSCH data (Mulvihill et al., 2007). Smalley, Kenney, Denboba, & Strickland (2014) reported in their study of 2009-2010 NS-CSHCN data, that minority racial groups are significantly less likely to report experiencing family-centered communication, as defined in this present study, than non-minority racial groups.

Enabling Characteristics

Enabling factors include: poverty status, lack of insurance, and the primary language of the household not being English.

Poverty

According to the American Academy of Pediatrics' 2003 Report of the Task Force on the Family, poverty is the single strongest predictor of diminished health and well-being for children. Children from poor families are much more likely to have adverse birth outcomes (e.g., prematurity and low birth weight), have higher mortality rates throughout childhood, and have higher chronic health problems and injuries (American Academy of Pediatrics (AAP), 2003). Research shows a strong association between poverty and poor health outcomes and other indicators of care quality. Newacheck et al. (1998) found that children from families who had incomes equal to or less than the federal poverty level were approximately 33 percent more likely to have an existing special health care need than children from families that earned more. In a study of the data from the 1994 National Health Interview Survey Disability Supplement involving 4,452 children 0-17 years old, Silver and Stein (2001) determined that living below or slightly above the federal poverty level was an independent risk factor for unmet need. Using data from the 2001 National Survey of Children with Special Health Care Needs, children of poor families were significantly less likely to use specialist physician services and prescription medicine compared with children of families with incomes above 200 percent of the federal poverty level (Porterfield & McBride, 2007). Porterfield and McBride (2007) also found that lower-income families were more likely to report that their CSHCN had severe

functional limitations, as compared to higher-income parents, but were less likely to report that their child needed specialized health care services. CSHCN who lived in low-income households reported lower rates of satisfaction with care (Kenney et al., 2011) and experienced significantly less family-centered communication (Smalley et al., 2014).

Although poverty is a major risk factor for poor outcomes, it is often difficult to separate the effects of poverty from those of other socioeconomic determinants of health, such as being raised in a single-parent family. Per the 2003 AAP report, the "risk factors interact, and their effects are more than additive." Poor families generally have lower levels of education, fewer social supports, practice riskier health behaviors, and encounter stressful life events more frequently (AAP, 2003). Women and women-headed households are much more likely to live in poverty, and are among the poorest families, making it difficult to disentangle the outcomes of poverty, family structure, and other factors that contribute to the poorer outcomes of their children.

Insurance

Szilagyi (2012) found strong evidence that children with disabilities who have insurance are more likely to have a primary care provider, to be able to access specialty care, to have reduced unmet needs, and to have access to supporting services. Being uninsured was significantly associated with not receiving coordinated care through a medical home (Mulvihill et al., 2007), with not experiencing family-centered communication (Smalley et al., 2014), and with lower rates of satisfaction

with care (Kenney et al, 2011). In a study of the association between state Medicaid and State Children's Health Insurance Program income eligibility and the financial burden reported by low-income families with CSHCN, it was found that there was considerable state-level variability in out-of-pocket expenses for their CSHCN (Parish, Shattuck, & Rose, 2009). Many of the issues that are related to young children with hearing loss not receiving hearing aids and associated professional services - both unmet needs - may be due to external factors, such as public financing limitations (Limb, McManus, Fox, White & Forsman, 2010). For example, there may be variability by state with regard to Medicaid reimbursement for necessary services, restrictions on the definitions of "medically necessary" interventions, and other coverage limitations that may not permit the most appropriate intervention (e.g., a digital hearing aid). Additionally, there may be variability by state with regard to eligibility for early intervention services; some states may only provide services to children with severe hearing loss, despite the guidelines for the care of mild and moderate hearing loss (Limb et al., 2010; Yoshinaga-Itano, 2003).

Language

Health care disparities related to limited English proficiency (LEP) exist despite laws mandating that federally funded programs provide accessible services for persons with limited English (Institute of Medicine (IOM), 2003). According to a Census Bureau report based on the U.S. population in 2011, ten percent of U.S. adults of childbearing age reported having LEP (Ryan, 2013). Studies have shown that children whose parents have LEP are more likely to be uninsured, lack coordinated

care through a medical home, lack specialty referrals, and experience serious medical errors compared to children whose parents are proficient with English (Flores, Bauchner, Feinstein, & Nguyen, 2005; Brousseau, Hoffman, Yauck, Nattinger, & Flores, 2005; DeCamp, Choi, & Davis, 2011). Yu and Singh (2009) also found that CSHCN of non-English-primary-language parents were twice as likely to lack access to a medical home, lack a usual source of care, and lack family-centered communication. They were also significantly more likely to report not receiving coordinated care. In a systematic review of peer-reviewed literature regarding associations between parental LEP and CSHCN outcomes, it was found that CSHCN with LEP parents have significantly worse insurance and medical home access (i.e., coordinated care), family-centered care, and satisfaction with care than CSHCN whose parents are English-proficient (Eneriz-Wiemer , Sanders, Barr, & Mendoza, 2013). These findings existed independent of ethnicity and socioeconomic status. Although parental LEP was independently associated with worse health care access and quality of care for CSHCN, there was not enough evidence to assess relationships between LEP and objective health outcomes. Among Hispanic parents of CSHCN, being interviewed in Spanish was strongly associated with dissatisfaction with care and with problems with ease of using health care services (Ngui & Flores, 2006).

Need Characteristics

Having a child with a hearing loss, as defined for this study, was included as the need factor; this characteristic applies to the entire sample in this study and, following the example of Drummond, Looman, & Phillips (2011), is not a separate analysis variable. In general, the perceived need or severity of the condition would

determine whether a parent will seek care for their child. Unfortunately, our data set does not have information about the severity of hearing loss or the parental perception of need. We know only whether the child has some hearing loss.

External Characteristics

Background

The Health Resources and Services Administration (HRSA) receives appropriated funds, $19,000,000 in 2011, for the "Universal Newborn Hearing Screening and Early Intervention" program (HRSA, 2011). As such, HRSA has responsibility for coordinating actions with CDC's National Center on Birth Defects and Developmental Disabilities, the National Institute on Deafness and Other Communication Disorders, the National Institute on Disability and Rehabilitation Research, and the Office of Special Education and Rehabilitative Services. Through grants or cooperative agreements, HRSA provides funds to the states to develop statewide newborn and infant hearing screening, evaluation, and intervention programs and systems (42 U.S.C. 280g-1, 2010). These funds are used to develop and monitor the efficacy of the state programs and systems, to provide timely evaluation and diagnosis of children who did not pass the screening, to provide appropriate interventions – medical, educational, or audiological – to those identified with hearing loss (Section 399M), and to enable family-to-family support. Furthermore, these funds are used to collect statewide data on these programs and to develop or improve models of care that ensure that identified newborns receive appropriate follow-up. Per this law, CDC is responsible for ensuring quality monitoring of state programs, providing technical assistance to state agencies,

conducting applied research related to these programs, developing standardized procedures for data management, assessing program effectiveness and costs, identifying risk factors for congenital hearing loss, and promoting the sharing of data regarding hearing loss.

Due to the shift of the program from screening to a more comprehensive set of activities, its name was changed from "Universal Newborn Hearing Screening" to "Early Hearing Detection and Intervention (EHDI)." All states and Washington, DC have EHDI programs or voluntarily comply with screening protocols, which are state run and vary quite a bit from state to state. However, CDC set seven national goals (White et al., 2010; CDC National Goals, unspecified year), which specify several program objectives and performance indicators to which the EHDI programs should aspire, including:

1) "All newborns will be screened for hearing loss before 1 month of age, preferably before hospital discharge.

2) All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age.

3) All infants identified with hearing loss will receive appropriate early intervention services before 6 months of age (medical, audiologic, and early intervention).

4) All infants and children with late-onset or progressive hearing loss will be identified at the earliest possible time.

5) All infants with hearing loss will have a medical home as defined by the American Academy of Pediatrics.

6) Every state will have an EHDI Tracking and Surveillance System that minimizes loss to follow-up.

7) Every state will have a system that monitors and evaluates the progress toward the EHDI Goals and Objectives."

Lost-to-System Variables

In order to monitor the outcomes of the EHDI programs across the states, CDC collects data from each EHDI program using the EHDI Hearing Screening and Follow-Up Survey (HSFS). The HSFS measures only documented, non-estimated data for all infants born in a calendar year. It is divided into three parts, which are each broken down into several sections, that include: Part 1-Hearing Screening, Diagnostic, Early Intervention, Part 2-Type and Severity, and Part 3-Demographics. The HSFS collects aggregate data from the state EHDI programs, such that each state reports on items, such as "Total Occurrent Births According to Vital Records." Lost to system (LTS) data for both audiological diagnosis and linkage to early intervention include the following categories: total no diagnosis, parents/family contacted but unresponsive, unable to contact, and unknown. In the proposed research, states' EHDI programs will be categorized as "Low LTS," "Medium LTS," or "High LTS," as based on LTS percentages of audiological diagnosis and linkage to early intervention, in a manner that will be detailed in the Methods section.

LTS numbers are based on a multitude of factors. At the system level, there are primary care barriers, the processes for communicating results, coordination of care, privacy regulations, policies and legislation, reporting mechanisms, and EHDI

program funding (ASHA, 2008). At the family level, LTS may be affected by family

education and awareness of the issues, literacy levels, insurance status, poverty level,

and proximity to resources (ASHA, 2008). In discussing the evolution of the EHDI

program, White et al. (2010) noted that the success of the newborn hearing screening

program, as evidenced by the increased coverage of screenings in the U.S. from 3%

in 1993 to over 97% in 2006, was attributable to 1) policies developed by

government, professional associations, and advocacy groups; 2) federal government

funding; 3) technology improvements; 4) legislative initiatives; and 5) the

demonstrated success of pilot programs.

Interactions

The Behavioral Model, as shown in Figure 3, does not describe interactions

between external characteristics, such as state policies, and family characteristics,

such as poverty level or educational attainment. However, public health researchers

are aware of potential interactions and there is some evidence that this approach may

be warranted. In a journal article published by the University of Wisconsin's Institute

for Research on Poverty (1997), Brooks-Gunn is quoted as saying that early

childhood development programs focused on intervention and prevention efforts

typically target poor children, children who have parents with low educational

attainment, those who are biologically vulnerable, or those who have a combination

of these characteristics. McManus et al. (2009) examined enrollment into early

intervention for children at risk of poor developmental outcomes, using data from the

National Survey of Children With Special Health Care Needs, to determine what

proportion of between-state variability could be explained by individual and family-

level sociodemographic factors and state eligibility policy. The family and child factors that were studied included poverty status, parental education, race/ethnicity, severity of the condition, child gender, and having a usual source of care. The researchers determined that state policy eligibility criteria (i.e., broad, moderate, and narrow policies) interacted with poverty level to influence enrollment into early intervention. Despite non-poor children, defined as > 185% FPL, being more likely overall to receive early intervention services than poor children, non-poor children who lived in states with strict eligibility policies were no more likely than poor children to receive early intervention. The researchers found that factors most significantly associated with lower participation in early intervention included being poor, mild severity of a condition, and not having a diagnosis. They speculate that screening occurs "ineffectively and inconsistently" (p. S372) and that diagnosis due to developmental delay may not occur until school entry. They posit that state policy does not apply to children equally across income groups and that unmet need for early intervention services is a function of state policy and family characteristics operating together. Hallam, Rous, Grove, and LoBianco (2009) studied the association of family-level variables with the level and intensity of services provided by a state's early intervention system and found that service provision varied the interaction of poverty status and living in a rural area. The authors refer to a study using the Early Childhood Longitudinal Survey (Grace et al. (2006)) that found that rural children were more likely to be poor and have less educated parents, which may explain some of the interactions between services provided and family characteristics.

Based on the results of these studies, it seems likely that external characteristics, such as the effectiveness of the state early intervention program, may interact with family-level characteristics, such as poverty and education. Limited state, and less effective state programs may be associated with access, unmet need, and other outcomes differently for families in higher socioeconomic status levels compared with those in more disadvantaged groups. This study uses lost-to-system percentages for the Early Hearing and Detection Intervention state programs as a measure for the effectiveness of the states' policies and programs.

Outcomes

Background

In summarizing the results from a number of studies, Bethell et al. (2014, p. 469) reported that "fewer than 20 percent of CSHCN met the criteria for having access to a high quality system of health services as measured by MCHB." As such, a great percentage of CSHCN experienced significant gaps in their quality of care. The researchers note that it is critical that care for CSHCN be comprehensive, coordinated, and family-centered; gaps in the quality of care are particularly detrimental to CSHCN as they are disproportionately vulnerable. To better serve this vulnerable population, Children with Special Health Care Needs Programs exist in every state (including Washington DC) and territory, and are supported by Title V of the Social Security Act. In recent years, the role of the Title V CSHCN programs has evolved: rather than providing direct services to CSHCN, they have moved to using a public health infrastructure-building approach to provide a system of care for this population (Strickland et al., 2011). MCHB's long-term goal with this systems

approach is that families of CSHCN are able to access affordable and comprehensive health and related services; access to quality health care is made possible through the implementation of appropriate policies and programs; providers are adequately trained; financial matters are considered; and families are included as partners in their children's health care (HHS/HRSA/MCHB, 2013). To track performance of these programs, and measure quality of the overall system of care per the National Agenda for Children with Special Health Care Needs (endorsed by over 70 professional and voluntary organizations) (HHS/HRSA, n.d.), the Maternal and Child Health Bureau developed six core quality indicators (Strickland et al., 2011):

1) family partnership in decision-making and satisfaction with care;
2) receipt of care through a medical home, which includes the measures of <u>coordinated care</u> and <u>family-centered communication</u>;
3) adequate health insurance;
4) early and continuous screening and surveillance;
5) services that are organized for ease of use, which includes the measures of <u>access to care</u> and <u>unmet need</u>; and
6) effective transition planning for adult health care.

Four components of these measures, or, rather, the lack of them, were selected as relevant outcomes for this study of families of young children with hearing loss: unmet need, lack of access to care, lack of coordinated care, and lack of family-centered communication. These measures were chosen as some of the most important regarding the quality of health care and associated services for these families. They are also in line with the report of the 2004 National Consensus on Effective Educational and Health Care Interventions for Infants and Young Children with Hearing Loss (Marge & Marge, 2005), which recommended that hearing health

care and early intervention services be accessible, family-centered, comprehensive, coordinated, compassionate, and culturally sensitive. The fifth outcome is related to NS-CSHCN results regarding non-receipt of early intervention services, a measure of whether children identified with hearing loss received early care and support services critical to their optimal growth and development.

Non-Receipt of Early Intervention

Before the fairly recent implementation of newborn hearing screening programs across the U.S., late diagnosis was the norm with the average age of identification typically between 2 ½ to 3 years or later (Russ, White, Dougherty, & Forsman, 2010), particularly for children with mild-to-severe hearing losses (Moeller, McCleary, Putman, Tyler-Krings, However, & Stelamachowicz, 2010), long into a critical period for speech and language development (NIH, 2010). This "window of opportunity" hypothesis is based upon research supporting the assertion that most language development occurs before 18 months of age and a "lack of typical auditory and/or supplemental visual language input during this critical period will irreversibly interfere with the healthy development of language and literacy skills" (Marge & Marge, 2005, p.1). Additionally, a study of the influence of early cochlear hearing loss on the development of the auditory pathway demonstrated that the human brain is particularly sensitive to auditory deprivation indicating the importance of acoustic inputs during sensitive periods in early childhood to ensure normal hearing and speech development (Tibussek, Meister, Walger, Foerst, & Von Wedel, 2002).

Before universal newborn hearing screening and linkage to early intervention, children who were deaf or hard of hearing (DHOH) left schools with language skills that were "grossly undeveloped," and, for many, were not even at functional literacy levels (Stewart & Clarke, 2003). It was widely believed and cited that most deaf adults read at a fourth-grade level, however the truer statistic for that time was that 50 percent of deaf students graduated from high school with a fourth grade reading level or less (Mayer, 2007). A 2003 study found that access to language before six months enables DHOH children to develop language skills that are only slightly lower than that of their hearing peers, but that are still within the normal developmental continuum (Yoshinaga-Itano, 2003). Given the improvements to hearing screening and intervention programs since 2003, it is likely that outcomes for identified children are even better than what was found in Yosinaga-Itano's study. Early identification has resulted in significantly higher scores on measures of vocabulary, articulation, intelligibility, social adjustment, and behavior, all of which are critical for optimizing communication, psychosocial, academic, and vocational outcomes for DHOH children (JCIH, 2007).

Early intervention is comprised of specialized health, educational, and therapeutic services designed to meet the developmental needs of children ages 0 to 3 years and their families (Nelson, Bradham & Houston, 2011). It is a critical component of the CDC/HRSA Early Hearing Detection and Intervention (EHDI) program, and must include the provision of services that address the linguistic, communication, social, and cognitive needs of children who are deaf or hard-of-hearing (DHOH) (Nelson, Bradham & Houston, 2011). White (2007) describes a

strong state EHDI program as one that has the following components: 1) well-defined eligibility criteria to participate in IDEA Part C early intervention programs, 2) a comprehensive child-find and referral system with written policies and procedures, 3) a comprehensive plan for personnel training, 4) early intervention services that use only optimal hearing technology, and 5) public awareness efforts to inform stakeholders (e.g., parents, providers, teachers) about current policies, recommendations, and technology.

Unmet Need

Children with special health care needs typically require more health care and associated services than the general pediatric population (Newacheck et al., 1998); estimates of use for the general population range from 13 to 22 percent (Kuhlthau, Nyman, Ferris, Beal, & Perrin, 2004). Approximately nine percent of CSHCN reported having unmet specialty care needs (Boudreau et al., 2014). More than ten percent of CSHCN reported having an unmet need for medical, dental, prescription medications, or mental health in the previous year; a finding that was significantly greater than children without special health care needs – in fact, the percentage of CSHCN reporting unmet needs was double that of non-CSHCN (Newacheck et al., 1998). In a study of the data from the 1994 National Health Interview Survey Disability Supplement involving 4,452 children 0-17 years old, it was found that children with chronic conditions were more likely to have a usual source of care for both sick and preventive care after adjusting for socioeconomic variables. However, even with a usual source of care, they were more likely to have experienced an unmet

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need, to be unable to get necessary medical care, and to have delayed seeking care for financial reasons (Silver & Stein, 2001). With relation to the population of CSHCN that have hearing loss, there is much evidence showing that they are not receiving appropriate and timely early intervention services (CDC, 2010b; White, 2007). The U.S. Department of Education referred to this gap as a "growing national crisis in the provision of essential early intervention and health care services…that will enable them to enter preschool and school ready to succeed" in a 2006 letter disseminated to the state EHDI programs (NCHAM/Hager & Giannini, personal communication, 2006). Additionally, in a study involving 1,982 CSHCN with hearing difficulties, Kenney and Kogan (2011) demonstrated that an unmet need for hearing aids did exist for this group.

Lack of Access to Care

Lack of access to care, as measured in this study, was based on parent report of difficulty or delays due to ineligibility, unavailability of services, appointment backlogs, costs, trouble receiving needed information, and family frustration with care. These complaints are found throughout literature regarding families' experiences after being notified of their child's potential hearing loss. A recent study of parents' perspectives regarding diagnostic hearing assessment found that parents of children born between 2006 and 2009 were more comfortable regarding follow-up procedures than were parents of children born between 1999 and 2005, showing that quality improvement efforts have been working (Larsen, Munoz, DesGeorges, Nelson, & Kennedy, 2012). Even so, 20 percent of the parents of the children born

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between 2006 and 2009 reported not knowing the screening results or where to take their child for further testing. Due to the greater demand for diagnostic services created by universal newborn screening, more than one-third of these parents reported delays in scheduling follow-up appointments. Although this may appear to be a small matter of inconvenience, this issue could affect both timely compliance to the recommended guidelines, as well as potentially impact the likelihood of follow-up. Another potential barrier is that the diagnostic process may require multiple appointments at a variety of facilities: nearly one-third of the parents in this study had to go to two or three locations to complete the battery of tests needed, and reported that three or more appointments were needed. Despite the system improvements to newborn hearing screening and follow-up, a large percentage of the parents with children born between 2006 and 2009 reported that they did not receive information regarding early intervention (36 percent), hearing aids (45 percent), resources (48 percent), medical referrals (55 percent), or parent support (62 percent) (Larsen et al., 2012). Holte et al. (2012) interviewed parents to determine reasons behind the delays in the EHDI process. The most common reason for the delay in first audiological assessment was the need for multiple rescreens, which ranged from two to nine rescreens, and delayed diagnostic testing up to nine months. Some families were told they did not need further assessment, and others experienced delays due to a backlog of appointments with audiological services. Fitzpatrick, Angus, Derieux-Smith, Graham, & Coyle (2008) also reported that parents had strong feelings about several components of service related to their child with hearing loss

including dissatisfaction with the lack of timely access to pediatric audiologists

during the identification stage.

There are also issues with access to appropriately trained health care and other

support providers. Dorros, Kurtzer-White, Ahlgren, Simon, & Vohr (2007) found

that only 43-45 percent of pediatricians who had patients with hearing loss considered

themselves knowledgeable about services or recommended follow-up care. Due to a

lack of service providers (e.g., pediatric audiologists and teachers of the deaf) with

the necessary competencies to serve the deaf and hard-of-hearing, there are

insufficient early intervention services available to infants and toddlers with hearing

loss (Johnson, 2004; Houston & Caraway, 2010). Given that most early intervention

services were initially designed to serve children identified later in life, usually

between two to three years of age (White, Forsman, Eichwald & Munoz, 2010), many

state EHDI programs do not have the staff resources to accommodate the increased

number of children in their system who are now identified through the Newborn

Hearing Screening Program (Shulman et al., 2010; White, 2007).

Lack of Family-Centered Communication

Family-centered care is a concept embraced by many involved in the

improvement of health care (see Figure 5Figure 5). It was championed by Surgeon

General Koop in 1987 and endorsed by the American Academy of Pediatrics, the

American Academy of Family Physicians, and agencies within both the Department

of Health and Human Services (with the Maternal and Child Health Bureau leading

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the development of the concept) and the Department of Education (Arango, 2011). In 2006, the following definition was advanced by leaders in the field:

> Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services. (Arango, 2011)

A number of studies show that family-centered care is associated with improved access and satisfaction, more appropriate use of services, and improved health and functional status (Arango, 2011). In order to achieve family-centered care, family-centered communication must be practiced by health care providers and the other professionals that work with families of CSHCN. Family-centered communication involves providers and families working in partnership, respect for the skills and expertise that each offer, trust and open communications, and a willingness to negotiate.

Figure 5. Context, process, and outcomes of family-centered care (Arango, 2011)
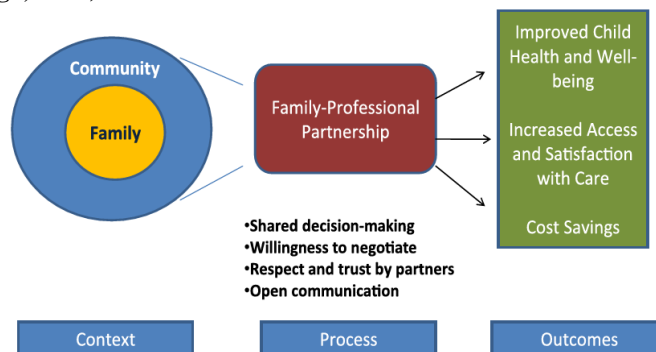
The Joint Commission (2010) describes effective communication in family-centered care as a two-way process that is both expressive and receptive in which ideas are shared until the information is understood by both parties. It takes place

only when providers understand and integrate the information shared by patients, and when patients receive messages that are comprehensible, accurate, timely, complete, and unambiguous.

For this study, family-centered communication was defined by the following measures regarding whether doctors: spend enough time with family, listen, are sensitive, provide needed information, provide a range of options, encourage questions, and make it easy to ask questions. This outcome was aligned with the important constructs associated with the literature on family-centered communication with families of children with hearing loss. Prior research has shown that the parents' reactions, acceptance, and advocacy for their child with hearing loss are critical to the success of their child's development (Moeller, 2000). However, these beliefs may be impacted by misguided professionals, outdated information, other families who have children with hearing loss, and others in their social network. For example, pediatricians may have a "wait and see" attitude regarding a screening failure, which is contrary to Joint Commission on Infant Hearing (JCIH) guidelines (JCIH, 2007), or parents may receive inaccurate information from other families regarding recommended practices and procedures.

In a Canadian study, Kelly and Bibby (2008) interviewed a small group of parents about their experiences regarding newborn hearing screening after their children were diagnosed with hearing loss. All of the parents reported being "confused" by the notification that their infant had not passed the screen, and some stated that they were not provided with adequate information about the process. When the children did not pass the screen, some technicians suggested rescheduling

the screen as it may have been due to equipment malfunction or that the current state

of the child may have affected the result (e.g., the infant was "too mucousy"). The

parents reported not receiving enough information, or that they received too much but

not delivered in a manner that was helpful. The provider interaction influenced the

responses: parents left feeling uninformed when providers seemed too busy to

answer questions, but others shared positive experiences when providers took steps

such as calling the parents to follow-up on the information provided. All of the

parents shared that they would have preferred "less ambiguity and more sensitivity"

regarding the health information shared with them. In semi-structured interviews

with 21 parents, Fitzpatrick et al. (2008) also reported that parents were dissatisfied

with communication of the diagnosis.

Using a questionnaire to determine parents' perceptions of the various health

care providers that are involved in the care of a child with hearing loss, Day & Brice

(2012) reported that audiologists and speech/language pathologists were the most

consistently rated as supportive, most knowledgeable about hearing loss, and most

important to the family's decision-making processes. Pediatricians, geneticists, and

psychologists were rated the lowest on these three items. Additionally, parents with

low health literacy perceived that pediatricians do not have the time to explain early

intervention offerings or the referral process (Jimenez et al., 2013). In contrast, in

research regarding U.S. Hispanic families and hearing loss, it was found that the

majority of the sample reported that one of the most important factors in making

decisions was professional recommendation (Steinberg, Bain, Li, Delgado, &

Ruperto, 2003).

In a manuscript geared toward professionals working with families of children with hearing loss, DesGeorges (2003) shared recommendations made by parents regarding the medical community; parents want: freedom from misinformation, medical information about hearing loss, timely referrals to specialists, knowledge of the resources available to them, sensitivity to the complexity of the decisions they make, meaningful partnerships with health care providers, understanding that there may be a positive aspect to their situation, and respect for their own acquired expertise. Furthermore, in discussing effective collaborative relationships between providers and parents, DesGeorges identified several elements for success: mutual respect for skills and knowledge, honest communication, empathy, shared planning and decision making, accessibility, and responsiveness.

<u>Lack of Coordinated Care</u>

Coordination of care is an important concept for the care of CSHCN as this population is often served by multiple medical providers, other health-related services, and programs that may provide education or other supports. The health care system is poorly organized (IOM, 2001), can be difficult for parents to navigate, and, worse, could be problematic if the various components of this system are not on the same page, communicating, or sharing records about the diagnoses, symptoms, treatments, outcomes, or experiences of the child with special health care needs. According to the IOM's 2001 report, "Crossing the Quality Chasm," the delivery of care is overly complex and uncoordinated, which leads to patient "handoffs" that decrease patient safety.

In an effort to provide improve the coordination of care for CSHCN, the medical home concept was developed to make care more family-centered. The National Center for Medical Home Implementation, an initiative sponsored by the American Academy of Pediatrics (AAP) and the Maternal and Child Health Bureau, describes the medical home as an "approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families" that includes specialty care, educational services, family support and other necessary services (AAP, n.d.). Coordinated care is considered to be such a critical part of providing quality health care that the major primary care professional organizations in the U.S. proposed using the patient-centered medical home as a necessary component of health reform in 2007 (Rittenhouse & Shortell, 2009). Coordination of care is associated with parent report of decreased unmet specialty care needs among CSHCN across all income levels (Boudrou et al., 2014).

The coordination of care outcome for this study comprises the following elements: problems getting referrals, satisfaction with doctor-to-doctor communication, satisfaction with doctor-to-program (e.g., early intervention), and whether the family needed help coordinating care. These are all common themes in the literature regarding families' experiences navigating the system of care for their child with hearing loss. The process beginning with newborn screening and ending with linkage to early intervention is not an easy, direct route for most families. When the infant fails the newborn hearing screen, the family may be asked to schedule one to several rescreens to rule out other causes for the "failed" result. The family must then follow-up with a pediatric audiologist for diagnostic assessment to determine the

level of hearing loss. The diagnostic assessment may also take several appointments to complete, as the infant must be asleep and still during the entire evaluation procedure, which can be quite lengthy. The child's pediatrician may be involved, should the pediatrician be aware of the screening and/or diagnostic results. Often, the family is referred to an otolaryngologist, or an Ear Nose and Throat (ENT) doctor, for additional medical evaluations, who may also request genetic testing and additional procedures, such as CT scans, to rule out other issues. If the hearing loss is confirmed by audiological diagnosis, the family is also referred to early intervention, which should provide the family with educational and medical resources to mitigate outcomes (e.g., language, communication, and social) related to hearing loss. Families may experience problems navigating this process as it is complex, fragmented, and often not understood by all of the professionals involved. Although congenital hearing loss is the most prevalent birth defect (Hilgert, 2009), it is considered a low-incidence disability, such that the rate of occurrence is relatively small and may not be encountered often by many health care providers. As a result, there are many points at which families could fall through the cracks, experience a lack of coordinated care and unmet need, or receive an abundance of informational materials, some of which may be contradictory.

In an exploratory qualitative study of five parents whose children were diagnosed with hearing loss, parents reported feeling overwhelmed by the number of professionals that had become engaged in the care of their newborn (Kelly & Bibby, 2008). They also felt unsupported as they transitioned through stages of the process (e.g., moving from diagnostics to intervention). Adding to the confusion, some

parents spoke of receiving contradictory information from the different professionals

with whom they worked noting that health care providers may not always be up on

the latest guidelines. Fitzpatrick et al. (2008) interviewed 21 parents and reported that

parents had strong feelings about several components of service related to their child

with hearing loss. Parents reported dissatisfaction with the fragmented health care

system (which may involve an ENT, a pediatrician, an audiologist, and a social

worker), and the lack of adequate support in locating helpful information resources.

Furthermore, a lack of integrated data management and tracking systems among

providers and between states adds to a lack of coordinated care (JCIH, 2007), as do

health privacy regulations, which may make it more difficult to share information

easily (ASHA, 2008).

Chapter 3: Methods

Description of the data

Data for this study will be drawn from two sources. The cohort of mothers with children with hearing loss will be drawn from CDC's 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN).   Data regarding the outcomes of the Early Hearing Detection and Intervention (EHDI) Program, referring to the two state program indicators, will be pulled from CDC's 2011 EHDI Hearing Screening and Follow-Up Survey (HSFS).

Survey descriptions

National Survey of Children with Special Health Care Needs (NS-CSHCN)

The NS-CSHCN is a module of the State and Local Area Integrated Telephone Survey (SLAIT) (Blumberg et al., 2008). The NS-CSHCN was designed to provide national and state-specific prevalence estimates of children with special health care needs (CSHCN), describe the services that are required and used by them, and assess the system of care for CSHCN (Blumberg et al., 2008). The design and administration of the 2009-2010 survey was enhanced and differs a bit from previous versions, which took place twice previously in 2001 and 2005-2006 (Blumberg et al., 2008). The primary funder of the NS-CSHCN is HRSA's Maternal and Child Health Bureau; however, it is conducted by CDC's National Center for Health Statistics (Blumberg et al., 2008). This is a cross-sectional survey based on telephone interviews of U.S. households with at least one resident aged 0 to 17 years at the time of the interview (Blumberg et al., 2008). It uses the same sampling frame as CDC's National Immunization Survey (NIS), and immediately follows the NIS interview in

selected households (CDC, 2011e). The survey has a complex design which is stratified by state and sample type (i.e., landline or cell-phone) and with clustering of children within the households (CDC, 2011e). Households are selected through list-assisted random-digit-dial for both landline telephone numbers and cell-phone numbers independently (CDC, 2011e).

To be eligible for participation, both residential status and the presence of children aged 0 to 17 years were confirmed at the time of the call (CDC, 2011e). If contacted by cell phone, the household was eligible only if they did not have a landline or were unlikely to be reached via the landline (CDC, 2011e). All children within the households are screened for special health care needs, and if none exist, the call is ended after a few demographics-related questions are asked (CDC, 2011e). If the screen indicated that a child with special health care needs lived in the household, a detailed interview is performed regarding that child (CDC, 2011e). If more than one child with special health care needs lives in a particular household, one child is chosen at random to be the subject of a detailed interview (CDC, 2011e). The screening tool, the CSHCN Screener (Bethell et al, 2002), has five stem questions on general health care needs, which are followed up by questions to ascertain if those needs are the result of a chronic health condition. The CSHCN Screener is based on a definition for special health care needs put forth by the Maternal & Child Health Bureau (McPherson et al., 1998): "Children with special health care needs are those who have…a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

EHDI Hearing Screening and Follow-Up Survey (HSFS)

Beginning in 2005, the EHDI Hearing Screening and Follow-Up Survey (HSFS) is a web-based survey that is administered annually (Cahill, Gaffney, & Richardson, 2014; CDC website, n.d.). The HSFS is a voluntary survey that collects calendar year data in the aggregate for each state and territory. The goal of the survey is to provide accurate and detailed data about the EHDI systems in the states, to determine progress related to the National EHDI Goals, as described earlier, and to provide information for Healthy People 2020. There are three components to the survey: Part 1 covers screening, diagnostics, and intervention data; Part 2 covers hearing loss type and severity; and Part 3 covers demographics. Only documented, non-estimated data are to be reported.

The data of most interest to this study are those related to "lost to follow-up" or "lost to documentation," which will be called "lost to system" (LTS) here. The HSFS tracks LTS for audiological diagnosis following a failed newborn hearing screen and LTS for linkage to early intervention services, separately, via the following categories: parents/family contacted but unresponsive, unable to contact, and unknown. Forty-six states (excluding AL, DC, GA, NH and NY) reported on audiological diagnosis in the 2011 survey, as reported in August 2013. These data revealed that of 3,416,209 newborns screened in the U.S. (not including the four states mentioned and DC), 59,161 babies did not pass the screen (CDC, 2011b). Of the nearly 60,000 who did not pass, 5,088 were diagnosed with hearing loss; 28,575 did not have hearing loss; and 25,498 had no diagnosis. Of those without a diagnosis, 20,857 newborns, or 35.3 percent of those who did not pass the screen, were deemed

LTS. A November 2013 report indicates that forty-seven states (excluding DC, GA, NH, and NY) reported on linkage to early intervention following confirmed hearing loss. The November report shows that a slightly higher number of newborns were identified as having hearing loss (n=5,170 in November versus n=5,088 in August). Of these 5,170 newborns, nearly 63 percent were enrolled in early intervention services and 1,346 newborns, or 26 percent, were considered LTS.

Weighting and complex survey design

The NS-CSHCN has a complex survey design, with stratification by state and sample type (i.e., landline or cell phone), as well as clustering of children within households (CDC FAQs). There are three associated data files:

- The Interview file included data specific to CSHCN (n=40,242), with one record per CSHCN randomly selected from the household as the interview target.
- The Household file included data for 196,150 households (with one record per household) and may or may not have CSHCN. The Household file provided information about the primary language in the household, the number of children, highest education level of the household, and poverty level.
- The Screener file included data for 371,617 children (one record for every child eligible by age). The Screener file provided information about race and ethnicity.

The sampling weights provided in the data files were used to generate estimates that are "representative of CSHCN or households with CSHCN at the state and national levels" (CDC FAQs). The weights adjust the responses to characteristics of the child population as based on U.S. Census counts. Per the NS-CSHCN codebook, it is recommended that the Interview Weight be used if the "unit of

analysis is the child with special health care needs and the data analyzed include variables that are on the CSHCN Interview File" (CDC, p. 35, 2014).

Analytic Sample

Data for the 2009-2010 survey were collected between July 7, 2009 and March 2, 2011 (CDC, 2011e). According to the CDC, 372,698 children from 196,519 households were screened for special health needs in the 50 states and Washington, DC, and ranged from 5,911 (KY) to 10,290 (CA). Based on the results of the CSHCN Screener, detailed interviews were conducted for 40,242 children, ranging from 751 (DC) to 878 (TX). As such, the target number of 750 CSHCN was reached in every state and DC. Three data files were released for the 2009-2010 survey: 1) the CSHCN Interview File has data for the 40,242 CSHCN, 2) the Household File has data for 196,159 households (one for every household regardless of whether there is a CSHCN present), and 3) the Screener File has data for 371,617 children. The files are linkable through a unique household identifier and a unique child identification number. Three sampling weights were created (i.e., a household weight, a child screener weight, and a child interview weight). Of the 40,242 CSHCN in this sample, 7,294 were between the ages of 0 and 5 years.

From the 7,294 CSHCN between the ages of 0 and 5 years, there were 868 children with hearing loss. As there was no distinct variable to determine this condition in the 2009-2010 NS-CSHCN, the families that were included were those who had a special health care needs child between the ages of 0 and 5 years, *and*:

1) Responded that they have a child who experiences "a lot of difficulty" or "a little difficulty" hearing even when using a hearing aid or other device (n=503).

or

2) Responded "yes" to "During the past 12 months/Since (his/her) birth, was there any time when [child] needed hearing aids or hearing care?" (n=638).

The sample was further reduced when any of the six independent or four control variables were missing for an observation. The final sample comprised 684 CSHCN between the ages of 0 and 5 years with hearing loss, as defined here.

Handling missing data

This study used a few approaches to handle the problem of missing data. First, when a follow-up question to a lead-in screener question had missing responses due to legitimate skips, the variable of interest was developed to include both the lead-in question and the follow-up question. The legitimate skips were included in the non-problematic response categories as it was assumed that the respondent did not experience the issue indicated in the leading question. For example, a lead-in question may ask whether the child had seen a specialist that year. If the respondent indicated that the child had not seen a specialist that year, a follow-up question asking about dissatisfaction with the specialist's treatment options would not be applicable to this respondent. It is assumed that the respondent did not experience a problem. There were a number of questions for which only a small percentage of the sample

experienced a particular issue indicated in a leading question. If the respondent

indicated that the issue was not applicable to them, the response to the follow-up

question would appear as missing data. To remedy this, those who did not experience

the issue indicated in the leading question were included in the data for the follow-up

question, but indicated as not experiencing dissatisfaction.

To account for missing data in one or more of the variables comprising the

composite dependent variables, lack of coordinated care and lack of family-centered

communication, average index measures were used. The process for doing so is

described in detail in the section on each of these dependent variables.

As a result of the 2011 EHDI Hearing Screening and Follow-Up Survey not

reporting data on a few states (i.e., AL, GA, NH, NY, and DC), and therefore lacking

lost-to-system information for these states, there were 91 additional cases missing key

data, reducing the sample from 868 to 777. The missing data from the non-reporting

states decreased the sample size by just over ten percent. Prior to running the

multivariate analyses, a final data set was created with the condition that only the

observations not missing data for any of the independent variables and controls would

be included. As a result of this step, the final sample size of this study decreased

from 777 to 684.

Tests for Correlation

Tests using PROC CORR were run for two purposes. The first was to assess

the internal validity of the three composite dependent variables; the Cronbach's

alphas for these are reported in this chapter under each variable. The second was to

assess correlations between: 1) the independent variables and the dependent variables

(reported in the Results Section), 2) the independent variables and controls against themselves (results in the Appendix), and 3) the dependent variables against themselves.

Measures

This section defines the variables and indicates how each was used in performing the analyses. When possible, individual and composite variables followed the format of the 2009-10 NS-CSHCN SAS Codebook as developed by the National Data Resource Center for Child and Adolescent Health (DRC) for the Maternal and Child Health Bureau. The SAS Codebook includes formats for 15 key child health indicators used for the National Chartbook, which reports on outcomes of the National Survey on Children's Health, and for the 6 MCHB Core Outcomes to measure the performance of Title V CSHCN programs. A primary difference is that the variables used in this study were coded to make the negative outcomes the higher score, so the variables reflect the problematic measure of care (e.g., "lack of coordinated care" rather than "coordinated care"). A second important difference is that these surveys are meant to be comprehensive in scope, in order to ascertain the health and well-being of the whole child. As this study focuses on young children with hearing loss and the issues that their families face, it was prudent to drop variables from composite measures that were not relevant to this study (e.g., number of dental visits).

Dependent Variables

This study has five dependent variables to assess parent perspectives regarding their experiences in obtaining care for children with hearing loss: non-receipt of early intervention services, unmet need, lack of access to care, lack of family-centered communication, and lack of coordinated care.

Non-Receipt of Early Intervention

Non-receipt of early intervention was created using the responses on two variables. If the CSHCN was less than 36 months of age, parents were asked, "Does [child] receive services from a program called Early Intervention Services? Children receiving these services often have an Individualized Family Service Plan." If the CSHCN was 36 months of age or greater, parents were asked, "At any time before [child] was 3 years old, did [he/she] receive services from a program called Early Intervention Services? Children receiving these services often have an Individualized Family Service Plan." The responses options for these questions were: 'no,' 'yes,' 'don't know,' and 'refused.' As such, there were two variables indicating non-receipt of services for this sample; one for the lower age group of 0 to < 36 months and one for the upper age group of 36 to 60 months. The original variables were each transformed into dichotomous dummy variables coded as '1' for 'no' and '0' for 'yes.' Responses that were legitimately skipped because the CSHCN was in the other age category were coded as '0' for 'yes.' Therefore, responses that were coded '0' for 'yes' indicated that the child had received early intervention services or did not need them. A dichotomous variable to indicate non-receipt of early intervention

services was created by combining the responses of the two age-based dummy variables: if non-receipt of services was indicated for either age group (i.e., those coded as '1's), they were coded as non-receipt for the combined variable.

Unmet Need

Unmet need was ascertained from the responses to two questions – a lead-in question and a follow-up question - from the NS-CSHCN to capture legitimate skips due to not needing the care being measured. The unmet need variable was created from the responses to the following questions from the NS-CSHCN; response options are in italics following the questions:

1) [During the past 12 months/Since [his/her] birth], was there any time when [child] needed hearing aids or hearing care?
   Yes, No, Don't Know, Refused

   a. Did [child] receive *all* of the hearing aids or hearing care that [he/she] needed?
   Yes, No, Don't Know, Refused

Although Question 1 was one of the two questions used to determine eligibility, it held true for about 74 percent (n=505) of the sample. Only those that answered yes would have been asked Question 1a. Therefore, Question 1a would have indicated 179 legitimate skips without accounting for the lead-in question. This study coded the responses to Question 1a as a dichotomous variable: 'yes' and legitimate skips were coded as '0,' there was no unmet need. 'No' responses to Question 1a were coded as '1,' meaning that there was unmet need. Although there were response options of "don't know" and 'refused,' those responses were not given by any of the respondents in this sample.

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This variable for unmet need was based on the National Chartbook indicator for "unmet needs for care" presented in the SAS Codebook. However, their indicator inquired about the need for 14 different health services or equipment, including items such as substance abuse care or mobility items that were not relevant to this study. This study used only the question recommended to assess unmet need for hearing aids/care, but designed it to be a dichotomous variable. The Chartbook indicator used a different methodology to develop a three-category variable. Chartbook coded the responses in the following manner: if the response to Question 1 was 'no' then unmet need was coded as '0,' 'did not need hearing care;' if the response to Question 1a was 'yes' then unmet need was coded as '1,' 'got all needed hearing care;' and if the response to Question 1a was 'no,' then unmet need was coded as '2,' 'unmet hearing care needs.'

Lack of Access to Care

Lack of access to care was measured using an composite variable created from the responses of the parents or guardians to the following questions from the NS-CSHCN:

1) [During the past 12 months/Since (his/her) birth], did you have any difficulties or delays getting services for [child] because [he/she] was not eligible for the service?

2) [During the past 12 months/Since (his/her) birth], did you have any difficulties or delays because the services [child] needed were not available in your area?

3) [During the past 12 months/Since (his/her) birth], did you have any difficulties or delays because there were waiting lists, backlogs, or other problems getting appointments?

4) [During the past 12 months/Since (his/her) birth], did you have any difficulties or delays because of issues related to cost?

5) [During the past 12 months/Since (his/her) birth], did you have any difficulties or delays because you had trouble getting the information you needed?

6) [During the past 12 months/Since (his/her) birth], how often have you been frustrated in your efforts to get services for [S.C.]?

Responses fell into the following categories for Questions 1-5: 'no,' 'yes,' 'don't know,' and 'refused.' Each item was coded '1' for 'no,' '0' for 'yes' and 'don't know,' and '[missing]' for 'refused.' Each item was analyzed separately as a dichotomous variable. Question 6 had the following responses: 'never,' 'sometimes,' 'usually,' 'always,' 'don't know,' and 'refused.' A dichotomous variable was created with "experienced frustration" indicated by the responses 'sometimes,' 'usually,' and 'always;' which was coded as '1.' It was interpreted that the respondent did not experience frustration when the responses were 'never' or 'don't know;' which were coded as '0.'

The six individual dichotomous variables were summed and analyzed as an ordinal variable with a range of zero to six, with higher scores indicating increased difficulties obtaining care. The Cronbach's alpha for this composite measure was 0.78 indicating that the composite measure was internally consistent.

This variable was modeled after the MCHB Core Outcome #5, "Community-based services for CSHCN are organized so that families can use them easily." The variables included in the composite measure were an exact match to those used in MCHB's indicator, however this study dropped a variable inquiring about

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'difficulties or delays due to other reasons' because too many were missing in this sample.

<u>Lack of Care Coordination</u>

Lack of care coordination was measured using a composite variable based on four concepts: 1) problems getting referrals, 2) needing extra help coordinating care among providers/services, 3) satisfaction with provider-to-provider communication, and 4) satisfaction with provider-to-program (e.g., early intervention) communication. In order to capture legitimate skips due to not needing the services mentioned, it was necessary to define three of the final variables via a two-step process to capture the responses of lead-in questions. For example, for the variable concerning problems getting a referral, one-third of the responses were missing when the variable was analyzed alone. However, the lead-in question asking whether a referral had been needed during the past year had no missing responses. It was necessary to combine the responses of the 'problem' question with the responses of its lead-in 'need' question to capture those who did not need a referral and legitimately skipped the 'problem' question. If the question were legitimately skipped, the skip was counted as not having a problem, rather than a missing, for the 'problem getting a referral' question. The variables were created from the responses to the following questions from the NS-CSHCN; response options are in italics following the questions:

2) [During the past 12 months/Since [his/her] birth], did [child] need a referral to see any doctors or receive any services?
   Yes, No, Don't Know, Refused
   a. Was getting referrals a big problem, a small problem, or not a problem?
      Big Problem, Small Problem, Not a Problem, Don't Know, Refused

The process to define the variable indicating 'problems getting referrals' is described in Table 1. The scores ranged from zero to two with higher scores indicating more difficulty obtaining the care that was needed.

Table 1. Algorithm for coding the variable: Problems getting referrals

Lead-in Question Response: Needed a referral?	Operator	Follow-Up Question Response: How big of a problem was it to get a referral?	Code
Yes	AND	Big problem	2: Big problem
Yes	AND	Small problem	1: Small problem
No or Don't Know	OR	No problem, Don't Know, Legitimate Skip	0: No problem
Refused or Missing	OR	Refused or Missing	Missing

3) [During the past 12 months/Since (his/her) birth], have you felt that you could have used extra help arranging or coordinating [child's] care among these different health care providers or services?
Yes, No, Don't Know, Refused
   a. [During the past 12 months/Since (his/her) birth], how often did you get as much help as you wanted with arranging or coordinating [child's] care?
   Never, Sometimes, Usually, Don't Know, Refused

The process to define the variable indicating 'needed extra help coordinating care is described in Table 2. The scores ranged from zero to two with higher scores indicating more difficulty obtaining the care that was needed.

Table 2. Algorithm for coding the variable: Needed extra help coordinating care

Lead-in Question Response: Needed help with coordinating care?	Operator	Follow-Up Question Response: How often received the help needed?	Code
Yes	AND	Never	2
Yes	AND	Sometimes	1
No or Don't Know	OR	Usually, Don't Know, Legitimate Skip	0
Refused or Missing	OR	Refused or Missing	Missing

4) Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [child's] doctors and other health care providers?
Very Satisfied, Somewhat Satisfied, Somewhat Dissatisfied, Very Dissatisfied, No Communication Needed or Wanted, Don't Know, Refused

This paragraph describes the code algorithm used to create the variable focused on provider-to-provider communication. If the response was 'very satisfied,' 'no communication needed or wanted,' or 'don't know,' the item was coded as '0.' 'somewhat satisfied' was coded as a '1,' 'somewhat dissatisfied' was coded as a '2,' and 'very dissatisfied' was coded as a '3.' The scores ranged from zero to three with higher scores indicating more difficulty obtaining the care that was needed.

5) Do [child's] doctors or other health care providers need to communicate with [his/her] school, early intervention program, child care providers, vocational education or rehabilitation program?
   a. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?
   Very Satisfied, Somewhat Satisfied, Somewhat Dissatisfied, Very Dissatisfied, Don't Know, Refused

The process to define the variable indicating 'satisfaction with provider-to-program communication' is described in **Table 3**. The scores ranged from zero to three with higher scores indicating greater dissatisfaction with the communication.

Table 3. Algorithm for coding the variable: Satisfaction with provider-to-program communication

Lead-in Question Response: Do doctors need to communicate with other programs?	Operator	Follow-Up Question Response: How satisfied are you with that communication?	Code
Yes	AND	Very Dissatisfied	3
Yes	AND	Somewhat Dissatisfied	2
Yes	AND	Somewhat Satisfied	1
No or Don't Know	OR	Very Satisfied, Don't Know, Legitimate Skip	0
Refused or Missing	OR	Refused or Missing	Missing

Lack of Care Coordination Composite Variable

In order to correct for missing data and zero-values, an average index measure was used to sum the four individual variables. To correct for missing and zero values, an average index measure was created by doing the following:

1) Creating a variable, A, that was equal to the sum of the four variables for each observation.

2) Creating a variable, B, that was equal to the count of non-missing and non-null values. This was done via the SAS "N" function.

3) Creating the final variable, C, that was equal to A/B to produce an average index measure. Prior to this step, if B was equal to '0' or to missing, C was set to missing.

As a result of the average index measure, the range of possible scores changed from 0 to 24 to the imputed range of 0 to 1. The Cronbach's alpha for this composite measure was 0.62. Although most research institutions use a Cronbach's alpha of 0.7 or higher as acceptable, a reliability of 0.6 or 0.5 "will suffice" in the early stages of research (Nunnally, 1967, p. 226; Hassad, 2011). Additionally, a reliability of 0.6 may be considered acceptable for scales with less than ten items (Lowenthal, 1996;

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Hassad, 2011). As such, the Cronbach's alpha of 0.62 will be considered adequate

for this measure in this exploratory study.

This variable was modeled after two subcomponents of MCHB Core

Outcomes #2, "CSHCN receiving ongoing, coordinated and comprehensive care

within a medical home":   Subcomponent 4, "No problems getting needed referrals,"

and Subcomponent 5, "Effective care coordination." The variables that were chosen

from the MCHB Core Outcomes were deemed most relevant to the concerns of

parents of children with hearing loss, as described in the Literature Review.

Lack of Family-Centered Communication

Lack of family-centered communication was measured using a composite

variable created from the responses to the following questions from the NS-CSHCN:

1) [During the past 12 months/Since (his/her) birth], how often did [child's] doctors and other health care providers spend enough time with [him/her]?
2) [During the past 12 months/Since (his/her) birth], how often did [child's] doctors and other health care providers listen carefully to you?
3) When [child] is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?
4) [During the past 12 months/Since (his/her) birth], how often did you get the specific information you needed from [child's] doctors and other health care providers?
5) [During the past 12 months/Since (his/her) birth], how often did [child's] doctors and other health care providers help you feel like a partner in [his/her] care?
6) [During the past 12 months/Since (his/her) birth], how often did [child's] doctors or other health care providers discuss with you the range of options to consider for [his/her] health care or treatment?
7) [During the past 12 months/Since (his/her) birth], how often did [child's] doctors or other health care providers encourage you to ask questions or raise concerns?

8) [During the past 12 months/Since (his/her) birth], how often did [child's] doctors or other health care providers <u>make it easy for you to ask questions</u> or raise concerns?

For all eight questions, the response options were as follows: 'never,' 'sometimes,' 'usually,' 'always,' 'don't know,' and 'refused.' Question 6 had an additional response option, 'there were no options to consider.' Each item was coded '3' for 'never;' '2' for 'sometimes;' '1 for 'usually,' 'don't know,' and (Question 6) 'there were no options to consider;' and '0' for 'always.' To correct for missing and zero values, an average index measure was created by doing the following:

1) Creating a variable, A, that was equal to the sum of the eight variables for each observation.
2) Creating a variable, B, that was equal to the count of non-missing and non-null values. This was done via the SAS "N" function.
3) Creating the final variable, C, that was equal to A/B to produce an average index measure. Prior to this step, if B was equal to '0' or to missing, C was set to missing.

As a result of the average index measure, the range of possible scores changed from 0 to 24 to the imputed range of 0 to 2.875. The Cronbach's alpha for this composite measure was 0.90.

This variable was modeled after two components of MCHB Core Outcomes #1, "CSHCN whose families are partners in decision-making for child's optimal health" and #2, "CSHCN receiving ongoing, coordinated and comprehensive care within a medical home"/Subcomponent 3: "Family-Centered Care." In order to create a variable that focused on the communication aspects of decision-making and family-centered care, this study selected only the variables that seemed most relevant.

All of the Family-Centered Care variables were used; one variable was not included from MCHB Core Outcome #1.

Independent variables

This study examined six independent variables to predict maternal perspectives regarding CSHCN quality of care indicators. The independent variables studied were parent education, poverty, two family structure variables: single mother status and sibling classification, the state EHDI program indicator regarding lost-to-system (LTS) for audiological diagnosis, and the state EHDI program indicator regarding LTS for linkage to early intervention.

Parent Education

The NS-CSHCN reports on the "highest education level of parents in household" using three categories: 'less than high school,' 'high school graduate,' and 'more than high school.' An dummy variable for education was developed by creating two categories: 'high school graduate or less' and 'more than high school;' the latter served as the reference group for analysis.

Poverty Level

The NS-CSHCN's Household File reports on the poverty level of the household, using a derived categorical variable that has nine categories and is based on Department of Health and Human Services guidelines, as follows :

'At or below 50 percent poverty level'
'Above 50% to at or below 100% poverty level'
'Above 100% to at or below 133% poverty level'
'Above 133% to at or below 150% poverty level'
'Above 150% to at or below 185% poverty level'
'Above 185% to at or below 200% poverty level'

'Above 200% to at or below 300% poverty level'
'Above 300% to at or below 400% poverty level'
'Above 400 percent poverty level' [verbatim]

For this study, a dummy variable was created to indicate the poverty status of the household. Using the eligibility criteria for the Women, Infants, and Children's Program, on the basis of income, poverty status was defined as an income at or less than 185 percent of the Federal Poverty Level (FPL)/U.S. Poverty Income Guidelines. Households with incomes greater than 185 percent of FPL served as the reference group for analyses (USDA, 2015).

Single Mother Status

The NS-CSHCN's Interview File reports on family structure type using a categorical variable that has four categories, as follows :

'Two parent biological/adopted'
'Two parent stepfamily'
'Single mother, no father present'
'Other' [verbatim]

For this study, a dummy variable was created to indicate whether the child with special health care needs lived in a household led by a single mother. As such, 'single mother, no father present' was coded as '1' and the other three categories were combined and coded as '0.' The non-single mother category was the reference category for analysis.

Sibling Classification

The NS-CSHCN's Household File contains derived variables describing the number of children in the household. First, a three-level categorical variable was created based on responses to two variables: one that represented the total number of

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children in the household without a special health care need and one that represented the total number of children in the household with a special health care need. The three-levels were created in relation to the child with hearing loss such that the they created the following categories: the child with hearing loss was an only child; the child with hearing loss had one or more siblings, but none with special needs; and the child with hearing loss had one or more siblings, at least one of whom had a special health care need. Each of the categories was then put into dummy variable format so that '1' indicated 'yes' for that category and '0' indicated 'no.' The category for the child with hearing loss being an only child served as the reference for analysis.

State EHDI Program Indicator Regarding Audiological Diagnosis

Nearly all states participate in the CDC Early Hearing Detection and Intervention Program (EHDI) and submit their state's aggregate data. The EHDI Hearing Screening and Follow-Up Survey determines the percentage of children who are "lost to system (LTS)" for audiological diagnosis after failing the newborn hearing screening. The 2011 survey has audiological diagnosis data for 46 states (not including AL, GA, NH, NY or DC).

Based on the percentage of LTS for audiological diagnosis, the states were grouped into three categories: 'Low LTS' (best), 'Medium LTS,' and 'High LTS' (worst). 'Low LTS' was defined as the lowest quartile (i.e., less than or equal to 17.2 percent), 'Medium LTS' was defined as the middle two quartiles (i.e., greater than 17.2 percent and less than 52.9 percent) , and 'High LTS' was defined as the highest quartile (i.e., greater than or equal to 52.9 percent). The three variables were coded as

dummy variables with '1' indicating that the defining criteria was met. They were analyzed together as a categorical variable to indicate LTS for audiological diagnosis. 'Low LTS' served as the reference for analysis.

State EHDI Program Indicator Regarding Linkage to Early Intervention

The 2011 survey has early intervention linkage data following confirmed hearing loss for 47 states (not including GA, NH, NY or DC). Based on the percentage of LTS for linkage to early intervention, the states were grouped into three categories: 'Low LTS' (best), 'Medium LTS,' and 'High LTS' (worst). 'Low LTS' was defined as the lowest quartile (i.e., less than or equal to 9.1 percent), 'Medium LTS' was defined as the middle two quartiles (i.e., greater than 9.1 percent and less than 40.9 percent) , and 'High LTS' was defined as the highest quartile (i.e., greater than or equal to 40.9 percent). The three variables were coded as dummy variables with '1' indicating that the defining criteria was met. They were analyzed together as an categorical variable to indicate LTS for linkage to early intervention. 'Low LTS' served as the reference for analysis.

Controls

This study controlled for four variables: age of the child, race, primary language of the household, and insurance status.

Age of Child with Hearing Loss

Child's age is a derived variable that was captured (in completed years) at the time of the interview. For this study, a categorical variable was created with two levels: one for the younger age range (i.e., 0, 1, 2 year olds) and one for the older age

range (i.e., 3, 4, 5 year olds). Each age range was coded as a dichotomous dummy variable with '1' indicating that the criteria was met. The younger age range served as the reference.

Race/Ethnicity

Race and ethnicity were combined into a four-level categorical variable. Each individual race was coded as a dummy variable with '1' indicating that the criteria defining that level was met. The following categories were used: Hispanic ethnicity (any race), White (non-Hispanic), Black (non-Hispanic), and Other (non-Hispanic). 'White' served as the reference for analysis.

Primary Language not English

Primary language was a derived variable in the Household Data File. To protect confidentiality, languages other than English were not identified in the data set. A dummy variable was created with '1' indicating a 'language other than English' and '0' indicating a category made up of 'English,' 'Don't Know,' and 'Refused.'

Insurance Status

This study developed an insurance variable based on two derived variables from the NS-CSHCN. The first variable indicated whether the child was ever uninsured over the past 12 months and the second variable indicated current insurance status. By combining the two, the adverse event was defined as the child being uninsured at the time of the interview or having been uninsured at any point during the past year. The study's insurance variable was coded as a dichotomous variable

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with the adverse event coded as '1;' a child who did not experience being without

insurance during that time frame was coded as '0.'

Analytic Design

The empirical strategy used a variety of analyses to investigate associations

between the independent and dependent variables. The first step was to conduct

descriptive statistics (including means and frequencies) on all study variables.

Bivariate correlations of all of the study variables were examined using the SAS

PROC CORR function; the matrices are presented in the Appendices. Additionally,

Cronbach's alpha was computed for each composite dependent variable (i.e., lack of

family-centered communication, lack of access to care, and lack of coordinated care)

to determine whether each was internally consistent. Each research question was then

be analyzed separately. Data was weighted in all of the multivariate analyses; per the

NS-CSHCN codebook, it is recommended that the Interview Weight be use the "unit

of analysis is the child with special health care needs and the data analyzed include

variables that are on the CSHCN Interview File" (CDC, p. 35, 2014). SAS 9.3

software was used to conduct all analyses using SAS survey procedures. For all of

the multivariate analyses, SAS PROC SURVEYLOGISTIC or SURVEYREG were

used as these procedures allow for analyses in a clustered sampling design. As this

study investigated the effect of state programs on outcomes, it was necessary to

analyze the data defining 'state' as the cluster variable. Odds ratios (OR) and 95%

confidence intervals were reported for each association generated through PROC

SURVEYLOGISTIC. Regression coefficient estimates and standard errors were reported for associations generated through PROC SURVEYREG.

Identical statistical modeling was used for all of the analyses. The associations between the independent variables and unmet need (a dichotomous variable) and non-receipt of early intervention services (a dichotomous variable) were each tested using logistic regression. Lack access to care (a ordinal variable with six values) was tested using ordinal logistic regression. Again, PROC SURVEYLOGISTIC was used for the analyses that included the statements, CLUSTER=STATE and WEIGHT=WEIGHT_I (i.e., the weight of the Interview file). For both unmet need and non-receipt of early intervention services, the model included the option, EVENT="1," to generate associations based on the adverse event occurring (e.g., a family experiencing unmet need.) To test the associations for lack of access to care, a composite variable comprised of six dichotomous variables, PROC SURVEYLOGISTIC was used to create the proportional odds model by including the option "(descending)" to generate results predicting the adverse event (i.e., higher scores indicating more problems). The associations between the independent variables and lack of family-centered communication (a continuous variable) and lack of coordinated care (a continuous variable) were each tested using OLS regression. The statement, 'CLUSTER=STATE,' was used in SURVEYREG, as well. All of the associations were tested alone and with controls, however controls were used in all of the reported results of this study except for the model testing the effectiveness of state programs alone.

Following the modeling procedures described above, the first part of the analysis examined the associations between family characteristics and the dependent variables, separately, after adjusting for controls. The second part of the analysis examined the associations between the two state policies and the dependent variables, first without any other variables, then including the family characteristics and control variables. The third part of the analysis tested for evidence of interaction of poverty and strength of the state EHDI program, as related to LTS for audiological diagnosis, on each dependent variable to determine whether there were different experiences for poor families living in states with strong EHDI programs versus poor families living in states with weak EHDI programs. The fourth part of the analysis was similar to the third part, but it tested for the strength of the state EHDI program as related to LTS for early intervention. The fifth part of the analysis tested for evidence of interaction of education and strength of the state EHDI program, as related to LTS for audiological diagnosis, on each dependent variable. This analysis was designed to determine whether there were different experiences for families where the parents were less educated and living in states with strong EHDI programs versus families with less educated parents living in states with weak EHDI programs. The sixth part of the analysis was similar to the fifth, but it examined differences due to strength of the state EHDI program as related to LTS for linkage to early intervention.

Table 4. Summary of research questions, hypotheses, and analytical strategy

Research Question	Hypothesis	Analytic Strategy
1. **Family Direct Effects** After controlling for child's age, race, language, and insurance status, examine whether and how **family characteristics** (i.e., education; poverty status; and family structure, including mother's marital status and sibling classification) are associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.	After controlling for child's age, race, language, and insurance status, parents of children with hearing loss, with family characteristics typically defined as more disadvantaged, will report that they have less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services.	*Logistic regression (SAS Surveylogistic)*: DV-Unmet need DV-Received Early Intervention DV-Access to Care *OLS regression (SAS Surveyreg)*: DV-Communication DV-Coordinated Care
2. **Program Direct Effects – Lost to System: Audiological Diagnosis & Linkage to Early Intervention** After controlling for family characteristics, child's age, race, language, and insurance status, examine whether and how the **quality of state EHDI programs, as related to audiological diagnosis and linkage to early intervention separately**, is associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss who reside in states with less developed Early Hearing Detection and Intervention (EHDI) programs, as determined by their loss to follow-up results for audiological diagnosis and linkage to early intervention separately, will report that they have less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services.	*Logistic regression (SAS Surveylogistic)*: DV-Unmet need DV-Received Early Intervention DV-Access to Care *OLS regression (SAS Surveyreg)*: DV-Communication DV-Coordinated Care
3. **Interaction: Poverty and Strength of EHDI program (related to Audiological Diagnosis)** After controlling for family characteristics, child's age, race, language, and insurance status, determine whether the effect of poverty on the parental reports of care (as described above) is modified by the strength of the EHDI programs (related to audiological diagnosis).	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss living in higher levels of poverty and who reside in states with weaker EHDI programs (based on lost-to-system percentages for audiological diagnosis), will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than those living in higher levels of poverty in states with stronger EHDI programs.	*Logistic regression (SAS Surveylogistic)*: DV-Unmet need DV-Received Early Intervention DV-Access to Care *OLS regression (SAS Surveyreg)*: DV-Communication DV-Coordinated Care
4. **Interaction: Poverty and Strength of EHDI program (related to Early Intervention)** After controlling for family characteristics, child's age, race,	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss living in higher levels of poverty and	*Logistic regression (SAS Surveylogistic)*: DV-Unmet need DV-Received Early Intervention

language, and insurance status, determine whether the effect of poverty on the parental reports of care (as described above) is modified by the strength of the EHDI programs (related to linkage to early intervention).	who reside in states with weaker EHDI programs (based on lost-to-system percentages for linkage to early intervention), will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than those living in higher levels of poverty in states with stronger EHDI programs.	DV-Access to Care *OLS regression (SAS Surveyreg)*: DV-Communication DV-Coordinated Care
5. **Interaction**: **Education and Strength of EHDI program (related to Audiological Diagnosis)** After controlling for family characteristics, child's age, race, language, and insurance status, determine whether the effect of education on the parental reports of care (as described above) is modified by the strength of the EHDI programs (related to audiological diagnosis).	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss, and who have lower levels of education and reside in states with weaker EHDI programs (related to audiological diagnosis), will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents with lower education levels in states with stronger EHDI programs.	*Logistic regression (SAS Surveylogistic)*: DV-Unmet need DV-Received Early Intervention DV-Access to Care *OLS regression (SAS Surveyreg)*: DV-Communication DV-Coordinated Care
6. **Interaction**: **Education and Strength of EHDI program (related to Early Intervention)** After controlling for family characteristics, child's age, race, language, and insurance status, determine whether the effect of education on the parental reports of care (as described above) is modified by the strength of the EHDI programs (related to linkage to early intervention).	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss, and who have lower levels of education and reside in states with weaker EHDI programs (based on lost-to-system percentages for linkage to early intervention), will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents with lower education levels in states with stronger EHDI programs.	*Logistic regression (SAS Surveylogistic)*: DV-Unmet need DV-Received Early Intervention DV-Access to Care *OLS regression (SAS Surveyreg)*: DV-Communication DV-Coordinated Care

Chapter 4: Results

This chapter first describes the characteristics of the sample used in the analysis. The results of the multivariate analyses are then presented. The reported sample sizes and frequencies are unweighted. All of the analyses were calculated using weights. Six research questions were examined for each of five dependent variables related to satisfaction and receipt of health care.

Descriptive Analyses

A total of 684 children ages 0 to 5 with indicators of hearing loss were included in the sample; characteristics of this sample are summarized in Table 5. The following family characteristics were examined: education; poverty status; presence of siblings, including whether there were other children with special needs; and family structure, meaning whether the child in question was living with a single mom. Education, as recorded on the National Survey of Children with Special Health Care Needs (NS-CSHCN), is that of the highest level attained by a parent in the household. Furthermore, poverty status was defined as living at or below 185 percent of Federal Poverty Level (FPL), which is the level that qualifies families for participation in the Supplemental Nutrition Program for Women, Infants and Children (USDA, 2015).

In this sample, using weighted data, 43.8 percent of the children had parents whose level of education was a high school graduate or less, and 56.2 percent had at least one parent with education higher than high school graduate. Nearly two-thirds of the households were identified as living in poverty per the definition used in this study: 35.7 percent of the households had incomes that were greater than 185 percent

Table 5. Select descriptive statistics of sample of children with hearing loss (N = 684)

Variable	%	Frequency	Weighted %	Definition
Family Education				Based on highest education level in household
HS graduate or less	27.92	191	43.79	
More than HS	72.08	493	56.21	
Poverty				Poverty is defined as living <= 185% of FPL; This is the level at which families are eligible for WIC benefits
<= 185% of FPL	51.61	353	64.30	
> 185% of FPL	48.39	331	35.70	
Family Structure				
Single Mother	32.31	221	35.34	
Other	67.69	463	64.66	
Types of Siblings				Based on whether the child with special needs (i.e., hearing loss) has no other siblings, other siblings without special needs, or other siblings including those with special needs)
No Siblings	26.9	184	20.96	
Has siblings (none with special needs)	52.34	358	45.29	
Has siblings (has 1 or more w/special needs)	20.76	142	33.75	
Age of Child with Hearing Loss				
0 to 2 years old	31.73%	217	37.79%	
3 to 5 years old	68.27%	467	62.21%	
Race				
Non-Hispanic White	62.28	426	53.07	
Hispanic	17.11	117	27.09	
Non-Hispanic Black	7.16	49	10.41	
Other (Non-Hispanic)	13.45	92	9.43	
Insurance				Uninsured is defined as the child being currently uninsured or was uninsured any time during the year
Uninsured	8.63	59	13.05	
Insured	91.37	625	86.95	
Primary Language				
English	90.35	616	79.04	
Not English	9.65	66	20.96	
Lost to System – Audiological Assessment				Based on "Aud LTS percentage" quartiles (low is <= 25th percentile, med is greater than 25th & less than 75th, high is >= 75th percentile)
Low LTS	29.97	205	34.22	
Medium LTS	44.59	305	34.99	
High LTS	25.44	174	30.79	
Lost to System – Linkage to Early Intervention				Based on "EI LTS percentage" quartiles (low is <= 25th percentile, med is greater than 25th & less than 75th, high is >= 75th percentile)
Low LTS	25.44	174	22.61	
Medium LTS	48.98	335	53.42	
High LTS	25.58	175	23.97	

of FPL, whereas 64.3 percent had incomes at or below 185 percent of FPL. For each reference child, the presence of siblings was categorized in the following manner: there were no other siblings (21.0 percent); there were other siblings, but none with special health care needs (45.3 percent); or there were other siblings including at least one with special health care needs (33.8 percent). Additionally, 35.3 percent of the children had single mothers and 64.7 had family structures of another type.

Sociodemographic variables were also examined as controls for this sample. The mean age of the children with hearing loss in this sample was 3.17 years. Nearly two-thirds of the sample were children with hearing loss between the ages of 3 and 5 years (62.2 percent); the remainder were between the ages of 0 and 2 years (37.8 percent). In terms of race, 53.1 percent of the children were non-Hispanic white, 27.1 percent were Hispanic, 10.4 percent were non-Hispanic black, and 9.4 percent were of another race. In 21.0 percent of the households, English was not reported as the primary language spoken at home. Despite the fact that a slight majority of the sample lived at or below 185 percent of FPL, only 13.1 percent were uninsured. The remaining 87.0 percent had insurance of some type be it private, public, a mix of both, or other.

The analyses also included CDC data regarding each state's lost to system information, which are shown in Table 6. Lost to system data regarding audiological follow-up (Aud-LTS) were analyzed for 46 states. States that did not report this information were AL, DC, GA, NH, and NY. The Aud-LTS mean was 36.6 percent, and ranged from a low of 3 percent in MA to a high of 82.6 percent in South Dakota. As described in the Methods section, the states were categorized by high, medium,

and low LTS percentages. The weighted percentages for Aud-LTS were as follows: high was 30.8 percent, medium was 35.0 percent, and low was 34.2 percent. Lost to system data regarding linkage to Early Intervention following audiological diagnosis (EI-LTS) were analyzed for 47 states. States that did not report this information were DC, GA, NH, and NY. The EI-LTS mean was 28.3 percent, and ranged from a low of 0 percent in six states (i.e., DE, ID, NM, PA, VT and WY) to 100 percent in three states (i.e., MD, SD, and WA). The weighted percentages for EI-LTS were as follows: high was 24.0 percent, medium was 53.4 percent, and low was 22.6 percent.

Tests for correlation were run between the independent and dependent variables (see Table 7). Correlations, defined as point biserial coefficients for the dichotomous versus continuous variable analyses and as phi coefficients for the dichotomous versus dichotomous variable analyses, were calculated for all of the variables with the exception of correlations with the variable, lack of access to care. For this ordinal variable, Spearman's correlation coefficients were calculated. Independent variables that were positively correlated with non-receipt of early intervention include age of child (0 to 2 years old) ($r=0.35$, $p< .0001$) and states with high LTS for early intervention ($r=0.08$, $p=0.04$). Three independent variables were positively correlated with unmet need: Hispanic race ($r=0.08$, $p=0.04$), household primary language was not English ($r=0.14$, $p=0.0002$), and not having insurance ($r=0.13$, $p=0.0005$). Four independent variables were correlated with lack of communication: poverty ($r=0.09$, $p=0.02$), age of child (3 to 5 years old) ($r=0.08$, $p=0.04$), "Other" race ($r=0.11$, $p=0.0034$), and not having insurance ($r=0.09$, $p=0.02$). Lack of access to care was correlated with not having insurance ($r=0.18$, $p=<.0001$).

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Lack of coordinated care was correlated with age of child (3 to 5 years old) (r=0.08, p=0.03).

Table 6. Lost to system (LTS) percentages by state (Source: CDC, 2011b)

State	LTS Audiology (%)	LTS Early Intervention (%)
Alabama	.	72.7
Alaska	44.7	72.0
Arizona	47.2	4.0
Arkansas	63.2	43.6
California	8.4	1.9
Colorado	64.7	31.3
Connecticut	31.2	13.2
DC	.	.
Delaware	17.2	0.0
Florida	56.5	20.1
Georgia	.	.
Hawaii	24.6	11.5
Idaho	30.0	0.0
Illinois	64.0	24.7
Indiana	9.9	30.0
Iowa	36.9	14.0
Kansas	21.7	9.4
Kentucky	15.8	51.4
Louisiana	33.0	20.3
Maine	23.9	40.9
Maryland	16.4	100.0
Massachusetts	3.0	6.1
Michigan	52.8	59.0
Minnesota	41.4	18.3
Mississippi	9.2	16.2
Missouri	34.9	22.3
Montana	81.1	60.7
Nebraska	20.0	6.9
Nevada	73.4	9.1
New Hampshire	.	.
New Jersey	43.1	20.3
New Mexico	7.1	0.0
New York	.	.
North Carolina	34.3	11.8
North Dakota	66.2	54.5
Ohio	34.1	20.6
Oklahoma	16.5	38.0
Oregon	52.2	15.7
Pennsylvania	10.0	0.0
Rhode Island	20.4	6.3
South Carolina	52.9	29.7
South Dakota	82.6	100.0
Tennessee	32.6	17.7
Texas	74.4	72.1
Utah	55.2	12.5
Vermont	39.9	0.0
Virginia	13.3	39.4
Washington	53.0	100.0
West Virginia	33.6	14.3
Wisconsin	20.8	19.8
Wyoming	14.0	0.0

Table 7. Correlations (p-values) between the independent and dependent variables

	Non-Receipt of Early Intervention (Phi Coefficient)	Unmet Need (Phi Coefficient)	Lack of Communication (Point Biserial Coefficient)	Lack of Access to Care (Spearman's Rank)	Lack of Coordinated Care (Point Biserial Coefficient)
	Correlation Coefficients				
	Prob > |r| under H0: Rho=0				
Education	0.02	0.00	0.05	-0.06	0.00
	0.58	0.91	0.16	0.11	0.93
Poverty	0.06	0.04	0.09	0.06	0.05
	0.14	0.32	0.02	0.11	0.21
Single Mom	0.01	0.04	0.05	-0.05	-0.02
	0.87	0.27	0.16	0.17	0.54
No Siblings	0.04	0.03	0.02	0.01	0.01
	0.26	0.44	0.64	0.76	0.86
Has Siblings (none with special needs)	-0.04	-0.03	-0.01	0.00	-0.01
	0.32	0.43	0.87	0.94	0.83
Has Siblings (1 or more with special needs)	0.00	0.00	-0.01	-0.02	0.00
	1.00	0.90	0.76	0.66	0.95
Age of Child (0 to 2 yrs old)	0.35	0.07	-0.08	-0.03	-0.08
	<.0001	0.06	0.04	0.43	0.03
Age of Child (3 to 5 yrs old)	-0.35	-0.07	0.08	0.03	0.08
	<.0001	0.06	0.04	0.43	0.03
Race: White	0.01	-0.07	-0.07	0.00	0.00
	0.72	0.08	0.05	0.94	0.93
Race: Black	0.02	0.01	0.03	-0.04	-0.01
	0.53	0.82	0.39	0.36	0.79
Race: Hispanic	-0.01	0.08	-0.03	-0.03	-0.03
	0.77	0.04	0.47	0.42	0.37
Race: Other	-0.03	0.00	0.11	0.06	0.04
	0.51	0.97	0.00	0.13	0.28
Primary Language not English	0.02	0.14	0.04	-0.05	0.02
	0.70	0.00	0.29	0.17	0.61
No Insurance	-0.04	0.13	0.09	0.18	0.06
	0.24	0.00	0.02	<.0001	0.09
High LTS Audiology	0.01	0.02	-0.01	0.01	0.01
	0.77	0.54	0.72	0.73	0.72
Medium LTS Audiology	0.03	0.01	0.03	0.04	0.04
	0.45	0.86	0.37	0.27	0.33
Low LTS Audiology	-0.04	-0.03	-0.02	-0.06	-0.05
	0.27	0.44	0.52	0.13	0.16
High LTS Early Intervention	0.08	0.02	-0.03	0.03	0.04
	0.04	0.56	0.49	0.37	0.33
Medium LTS Early Intervention	-0.03	-0.04	0.07	-0.03	-0.05
	0.42	0.30	0.07	0.49	0.23
Low LTS Early Intervention	-0.04	0.02	-0.05	-0.004	0.02
	0.27	0.54	0.17	0.92	0.68

Multivariate Results

The multivariate results portion of this paper are organized in sections by dependent variable. The results of the analyses are grouped by research question within each dependent variable section. In all of the following analyses, regression models were used. Model 1 examined the associations between family characteristics, the controls, and the dependent variable. Specifically, the variables analyzed in Model 1 included: the main constructs of education, poverty status, family structure (i.e., whether headed by a single mother or not), and sibling classification (i.e., whether the child had siblings with and/or without special health care needs), and the control variables of child age, race, language (i.e., whether English was the primary language of the household), and insurance status. The strength of the state EHDI programs, as measured by LTS in audiological follow-up and early intervention diagnosis, was analyzed as a main effect without controls in Model 1b. Model 2 examined the combined effects of the state policies variables, the family characteristics variables, and the controls. When the outcomes were significant, Model 3 (and any following models) tested Model 2 plus the interactions for poverty and education separately. Specifically, Model 3 tested the interaction of poverty and Aud-LTS, Model 4 tested the interaction of poverty and EI-LTS, Model 5 tested the interaction of education and Aud-LTS, and Model 6 tested the interaction of education and EI-LTS. Results are only considered significant at the p-value of less than .05.

Dependent Variable 1: Did Not Receive Early Intervention Services

Research Question 1: Family Characteristics

After controlling for sociodemographic variables, the first part of this analysis

examined associations between family characteristics and not having received Early

Intervention Services. Table 8 shows the results from a series of logistic regression

models. Only one family characteristic was found to be significant in Model 1.

Having one or more siblings, none of which had special needs, had a protective

effect, making it 45 percent as likely that the child with hearing loss would not have

received Early Intervention Services (OR=0.55, 95% CI 0.32, 0.95, p<.05). The age

of the child with hearing loss, a control variable, was significant for children between

the ages of 3 to 5 years. Being in the upper age range was associated with a 79

percent reduction in the likelihood of not having received Early Intervention Services

(OR=0.21, 95% CI 0.09, 0.48, p<.001) as compared to children who were between

the ages of 0 and 2 years.

Research Question 2: Strength of EHDI program, per lost-to-system
percentages for audiological diagnosis (Aud-LTS) and linkage to Early
Intervention (EI-LTS)

Model 1b examined the direct association of the strength of the EHDI

program, as indicated by lost to system rankings for audiological diagnosis and

linkage to Early Intervention, separately, reported in the 2011 CDC EHDI Hearing

Screening & Follow-up Survey (HSFS), on the receipt of early intervention by the

child with hearing loss per the National Survey on Children with Special Health Care

Needs (NS-CSHCN). No findings were significant for lost-to-system percentages for

audiological diagnosis (Aud-LTS). However, compared with living in a state with

Table 8. Family characteristics and strength of state programs predicting non-receipt of early intervention services

Name	Model 1 OR	Model 1 95% CI	Model 1b OR	Model 1b 95% CI	Model 2 OR	Model 2 95% CI	Model 4 OR	Model 4 95% CI	Model 6 OR	Model 6 95% CI
Education										
High School Degree or Less	1.10	(0.57, 2.11)			1.17	(0.64, 2.14)	1.24	(0.66, 2.31)	0.36	(0.14, 0.90) *
More than High School		omitted				omitted		omitted		omitted
Poverty (<=185% of FPL; 1=Yes)	1.66	(0.90, 3.04)			1.65	(0.92, 2.95)	0.32	(0.15, 0.72) **	1.74	(0.96, 3.14)
Single Mom (1=Yes)	0.82	(0.37, 1.83)			0.74	(0.33, 1.65)	0.75	(0.33, 1.68)	0.75	(0.34, 1.65)
Sibling Status										
None (reference)		omitted				omitted		omitted		omitted
1+ (none with special needs)	0.55	(0.32, 0.95) *			0.56	(0.33, 0.95) *	0.55	(0.32, 0.94) *	0.57	(0.33, 0.98) *
1 or more w/special needs	0.49	(0.21, 1.15)			0.46	(0.20, 1.07)	0.46	(0.20, 1.09)	0.47	(0.20, 1.09)
Age of Child with Hearing Loss										
0 to 2 years old		omitted				omitted		omitted		omitted
3 to 5 years old	0.21	(0.09, 0.48) ***			0.22	(0.10, 0.49) ***	0.22	(0.09, 0.51) ***	0.22	(0.09, 0.49) ***
Race										
White (reference)		omitted				omitted		omitted		omitted
Hispanic	1.96	(0.75, 5.09)			2.06	(0.70, 6.04)	2.13	(0.69, 6.63)	2.13	(0.73, 6.21)
Black	1.07	(0.39, 2.97)			1.00	(0.35, 2.82)	0.99	(0.34, 2.83)	1.01	(0.36, 2.84)
Other Race	1.86	(0.79, 4.39)			1.83	(0.77, 4.33)	1.81	(0.75, 4.36)	1.88	(.82, 4.29)
Primary Language Not English (1=Yes)	0.45	(0.17, 1.18)			0.53	(0.21, 1.29)	0.58	(0.24, 1.42)	0.57	(0.23, 1.43)
No Insurance (1=Yes)	0.50	(0.11, 2.31)			0.51	(0.12, 2.21)	0.58	(0.14, 2.43)	0.55	(0.13, 2.36)
Lost to System - Audiology										
High			1.02	(0.59, 1.77)	0.92	(0.46, 1.84)	0.87	(0.43, 1.74)	0.84	(0.41, 1.70)
Medium			1.33	(0.78, 2.29)	1.56	(0.83, 2.92)	1.58	(0.82, 3.05)	1.50	(0.79, 2.88)
Low (reference)				omitted		omitted		omitted		
Lost to System - Link to Early Intervention										
High			2.77	(1.45, 5.28) **	2.94	(1.49, 5.77) ***	1.02	(0.51, 2.05)	1.77	(0.91, 3.42)
Medium			2.42	(1.26, 4.63) *	2.05	(0.90, 4.67)	0.70	(0.30, 1.67)	1.09	(0.57, 2.12)
Low (reference)				omitted		omitted		omitted		omitted
Interaction 3							6.42	(2.83, 14.59) ***		
Interaction 4							6.49	(2.59, 16.28) ***		
Interaction 7									3.16	(1.12, 8.94) *
Interaction 8									4.06	(1.65, 9.97) ***

***p<.001, **p<.01, *p<.05; 2-tailed test

Models:
Model 1: Family Characteristics
Model 1b: LTS Audiological Diagnosis (LTS Aud) & LTS Early Intervention (LTS EI)
Model 2: Family Chararacteristics, LTS Aud & LTS EI
Model 3: Model 2 + interaction of poverty & LTS Aud
Model 4: Model 2 + interaction of poverty & LTS EI
Model 5: Model 2 + interaction of education & LTS Aud
Model 6: Model 2 + interaction of education & LTS EI

Interactions:
Interaction 1 = Poverty x High LTS Aud
Interaction 2 = Poverty x Medium LTS Aud
Interaction 3 = Poverty x High LTS EI
Interaction 4 = Poverty x Medium LTS EI
Interaction 5 = Education x High LTS Aud
Interaction 6 = Education x Medium LTS Aud
Interaction 7 = Education x High LTS EI
Interaction 8 = Education x Medium LTS EI

Note: The ORs for the interactions are the ratios of odds ratios. For example, the odds of not receiving services in Interaction 3 is the ratio of: ORpoverty in a High LTS EI state divided by the ORpoverty in a Low LTS EI state. The Low LTS EI state serves as the reference for all of the interactions.

low lost-to-system percentages, living in a state with medium (25th to 75th percentile

or high (75th and higher percentile) lost-to-system percentages for early intervention

(EI-LTS) was associated with a likelihood of two and a half times that a child with

hearing loss had not received Early Intervention Services (OR=2.42, 95% CI 1.26,

4.63, p<.05; OR =2.77, 95% CI 1.45, 5.28, p<.01).   Model 2 added family

characteristics and controls to Model 1b. The presence of one or more siblings

without special needs continued as a protective factor in Model 2 (OR=0.56, 95% CI

0.33,0.95, p<.05). The control variable for age remained significant for children

between the ages of 3 to 5 years (OR=0.22, 95% CI 0.10, 0.49, p<.001). In Model 2,

living in a state with medium EI-LTS percentages was no longer significantly

associated with not receiving Early Intervention Services. However, living in a state

with high EI-LTS was associated with almost three times the likelihood that children

with hearing loss indicators had not received Early Intervention Services (OR=2.94,

95% CI 1.49, 5.77, p<.001).

Research Question 3: Interaction of poverty and the strength of the EHDI program, per Aud-LTS percentages

The effect of the interaction of poverty and the strength of the EHDI program,

as related to Aud-LTS, was tested in Model 3. No additional findings were

significant, and thus the results of Model 3 are not reported here.

Research Question 4: Interaction of poverty and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of poverty and the strength of the EHDI program,

as related to EI-LTS, was tested in Model 4. Having one or more siblings without

special needs remained a protective factor of similar magnitude as in the previous

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models (OR=0.55, 95% CI 0.32, 0.94, p<.05). Also, having an income that was less than or equal to 185 percent of the U.S. Federal Poverty Level (FPL) was found to be significant and protective as a main effect (OR=0.32, 95% CI 0.15, 0.72, p<.05). The control variable for child age remained significant for children between the ages of 3 to 5 years (OR=0.22, 95% CI 0.09, 0.51, p<.001). The interaction of poverty with EI-LTS was found to be very significant for both medium and high EI-LTS percentage states. Poor children with hearing loss who lived in a medium EI-LTS percentage state had 6.49 times the odds of not having received Early Intervention Services (ratio of ORs=6.49, 95% CI 2.59, 16.28, p<.001) as compared to poor children living in low EI-LTS percentage states. Poor children with hearing loss who lived in high EI-LTS percentage states were also highly likely to not have received Early Intervention Services (ratio of ORs=6.42, 95% CI 2.83, 14.59, p<.001) as compared to poor children living in low EI-LTS states.

Research Question 5: Interaction of education and the strength of the EHDI program, per Aud-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to Aud-LTS, was tested in Model 5. No additional findings were significant; the results of Model 5 are not reported here.

Research Question 6: Interaction of education and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to state EI-LTS percentages, was tested in Model 6. Having parents with the educational level of "High school degree or less" was determined to be a protective factor (OR=0.36, 95% CI 0.14, 0.90, p<.05). The protective effect for

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the presence of one or more siblings without special needs was found to be significant in Model 6 (OR=0.57, 95% CI 0.33,0.98, p<.05). The control variable for child age remained significant for children between the ages of 3 to 5 years (OR=0.22, 95% CI 0.09, 0.49, p<.001).

The interaction of education and EI-LTS percentages was significant for both states with high EI-LTS percentages and medium EI-LTS percentages. Children with hearing loss who had parents with less than a high school education and who lived in a medium EI-LTS percentage state had over four times the odds of not having received Early Intervention Services (ratio of ORs=4.06, 95% CI 1.65, 9.97, p<.001) as compared to similar children with less educated parents living in low EI-LTS percentage states. Children with hearing loss who lived in high EI-LTS percentage states and who had less educated parents were also highly likely to not have received Early Intervention Services (ratio of ORs=3.16, 95% CI 1.12, 8.94, p<.05) as compared to children with less educated parents living in low EI-LTS states.

Dependent Variable 2: Parent Report of Unmet Need

Research Question 1: Family Characteristics

The first part of this analysis examined associations between family characteristics and parent report of unmet need, after controlling for sociodemographic variables. Table 9 shows the results from a series of logistic regression models. Having a sibling with a special health care need was determined to be a protective factor (OR=0.12, 95% CI 0.02, 0.68, p<.05). Two control variables were found to be significant for unmet need: living in a household where the primary language is not English and having no insurance. Living in a household whose

Table 9. Family characteristics and strength of state programs predicting parent report of unmet need

Name	Model 1 OR	Model 1 95% CI		Model 1b OR	Model 1b 95% CI		Model 2 OR	Model 2 95% CI		Model 3 OR	Model 3 95% CI		Model 5 OR	Model 5 95% CI	
Education															
High School Degree or Less	0.90	(0.30, 2.67)					1.13	(0.36, 3.59)		1.07	(0.35, 3.21)		7.32	(1.09, 48.91)	*
More than High School		omitted						omitted			omitted			omitted	
Poverty (<=185% of FPL; 1=Yes)	1.26	(0.45, 3.51)					1.07	(0.36, 3.20)		6.69	(1.20, 37.34)	*	1.02	(0.34, 3.10)	
Single Mom (1=Yes)	1.53	(0.39, 6.09)					1.38	(0.36, 5.25)		1.39	(0.39, 4.95)		1.26	(0.32, 5.07)	
Sibling Status															
None (reference)		omitted						omitted			omitted			omitted	
1+ (none with special needs)	0.42	(0.15, 1.21)					0.45	(0.15, 1.34)		0.40	(0.14, 1.15)		0.42	(0.15, 1.16)	
1 or more w/special needs	0.12	(0.02, 0.68)	*				0.11	(0.02, 0.74)	*	0.09	(0.01, 0.70)	*	0.08	(0.01, 0.57)	*
Age of Child with Hearing Loss															
0 to 2 years old		omitted						omitted			omitted			omitted	
3 to 5 years old	0.55	(0.17, 1.81)					0.52	(0.14, 1.95)		0.50	(0.13, 1.93)		0.56	(0.16, 1.92)	
Race															
White (reference)		omitted						omitted			omitted			omitted	
Hispanic	0.77	(0.17, 3.45)					1.14	(0.26, 5.09)		1.18	(0.26, 5.37)		0.95	(0.19, 4.73)	
Black	2.80	(0.62, 12.68)					3.28	(0.60, 17.88)		3.53	(0.66, 18.97)		3.58	(0.64, 20.00)	
Other Race	0.38	(0.08, 1.92)					0.47	(0.10, 2.28)		0.40	(0.09, 1.75)		0.34	(0.08, 1.52)	
Primary Language Not English (1=Yes)	6.12	(1.80, 20.80)	**				3.55	(0.97, 13.07)		3.28	(0.92, 11.63)		3.62	(0.87, 15.04)	
No Insurance (1=Yes)	9.91	(3.93, 25.00)	***				9.93	(4.61, 21.38)	***	9.26	(4.39, 19.52)	***	8.76	(4.22, 18.20)	***
Lost to System - Audiology															
High				1.01	(0.23, 4.50)		0.67	(0.06, 8.22)		5.21	(0.13, 214.86)		3.78	(0.15, 96.54)	
Medium				1.53	(0.48, 4.84)		1.50	(0.52, 4.31)		11.59	(0.93, 144.03)	†	7.03	(0.95, 51.94)	†
Low (reference)					omitted			omitted			omitted			omitted	
Lost to System - Link to Early Intervention															
High				0.20	(0.04, 1.00)	†	0.24	(0.01, 3.91)		0.24	(0.02, 3.33)		0.27	(0.02, 3.77)	
Medium				0.21	(0.07, 0.69)	*	0.40	(0.10, 1.70)		0.37	(0.09, 1.60)		0.41	(0.09, 1.84)	
Low (reference)					omitted			omitted			omitted			omitted	
Interaction 1										0.09	(0.00, 1.93)				
Interaction 2										0.08	(0.01, 0.80)	*			
Interaction 5													0.07	(0.01, 0.74)	*
Interaction 6													0.06	(0.01, 0.39)	**

***p<.001, **p<.01, *p<.05, †p=.05; 2-tailed test

Models:
Model 1: Family Characteristics
Model 1b: LTS Audiological Diagnosis (LTS Aud)
        & LTS Early Intervention (LTS EI)
Model 2: Family Chararacteristics, LTS Aud & LTS EI
Model 3: Model 2 + interaction of poverty & LTS Aud
Model 4: Model 2 + interaction of poverty & LTS EI
Model 5: Model 2 + interaction of education & LTS Aud
Model 6: Model 2 + interaction of education & LTS EI

Interactions:
Interaction 1 = Poverty x High LTS Aud
Interaction 2 = Poverty x Medium LTS Aud
Interaction 3 = Poverty x High LTS EI
Interaction 4 = Poverty x Medium LTS EI
Interaction 5 = Education x High LTS Aud
Interaction 6 = Education x Medium LTS Aud
Interaction 7 = Education x High LTS EI
Interaction 8 = Education x Medium LTS EI

Note: The ORs for the interactions are the ratios of odds ratios. For example, the odds of reporting unmet need in Interaction 2 is the ratio of: ORpoverty in a Medium LTS EI state divided by the ORpoverty in a Low LTS EI state. The Low LTS EI state serves as the reference for all of the interactions.

primary language was not English increased the odds of reporting unmet need by over

six times (OR=6.12, CI 1.80, 20.90, p<.01). Having no insurance was also a big risk

for unmet need, increasing its likelihood by a multiple of almost ten (OR=9.91, 95%

CI 3.93, 25.00, p<.001).

Research Question 2: Strength of EHDI program, per lost-to-system percentages for audiological diagnosis (Aud-LTS) and linkage to Early Intervention (EI-LTS)

Model 1b examined the direct association of the strength of the EHDI

program, as indicated by lost to system rankings for audiological diagnosis and

linkage to Early Intervention separately on the 2011 CDC EHDI Hearing Screening &

Follow-up Survey (HSFS), and parent report of unmet need. No findings were

significant for lost-to-system percentages for audiological diagnosis (Aud-LTS).

However, living in a state with medium (25th to 75th percentile) lost-to-system

percentages for early intervention (EI-LTS) made it 79 percent less likely that a

parent would report unmet need as compared to those living a state with a low EI-

LTS percentage (OR=0.21, 95% CI 0.07, 0.69, p<.05). Living in a state with high

(75th and higher percentile) EI-LTS percentages approached significance (OR=0.22,

95% CI 0.04, 1.00, p=.05).

Model 2 examined family characteristics and strength of the EHDI program as

associated with parent report of unmet need after controlling for sociodemographic

variables. The presence of one or more siblings with special needs continued as a

protective factor in Model 2 (OR=0.11, 95% CI 0.02, 0.74, p<.05). The likelihood of

reporting unmet was nearly ten times higher for the uninsured (OR=9.93, 95% CI

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4.61, 21.38, p<.001). Neither of the EHDI program variables, Aud-LTS nor EI-LTS, was found to be significant in this model.

Research Question 3: Interaction of poverty and the strength of the EHDI program, per Aud-LTS percentages

The association of the interaction of poverty and the strength of the EHDI program, as related to state lost-to-system percentages for audiological diagnosis (Aud-LTS), was tested with regard to report of unmet need in Model 3. Having an income of less than or equal to 185 percent of FPL was associated with a nearly seven-fold increased risk of reporting unmet need (OR=6.69, 95% CI 1.20, 37.34, p<,05). As in the previous models, having a sibling with one or more special health care needs was protective (OR=0.09, 95% CI 0.01, 0.70, p<.05), whereas being uninsured increased the odds of reporting unmet need (OR=9.26, 95% CI 4.39, 19.52, p<.001). Although not quite significant, Model 3 also found living in a state with a medium Aud-LTS percentage to be associated with a greater likelihood that a parent would report unmet need as a main effect (OR=11.59, 95% CI 0.93, 144.03, p=.05). Only the interactive effect of poverty and living in a medium Aud-LTS percentage state was significant for unmet need. Poor families with children with hearing loss who lived in a medium Aud-LTS percentage reported significantly lower odds of unmet need (ratio of ORs=0.08, 95% CI 0.01, 0.80, p<.05) as compared to poor families with children with hearing loss living in low Aud-LTS percentage states.

Research Question 4: Interaction of poverty and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of poverty and the strength of the EHDI program, as related to EI-LTS, was tested in Model 4. No additional findings were significant for unmet need; the results of Model 4 are not reported here.

Research Question 5: Interaction of education and the strength of the EHDI program, per Aud-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to Aud-LTS, on parent report of unmet need was tested in Model 5. Having parents with a high school degree or less significantly increased the likelihood of reporting unmet need (OR=7.32, 95% CI 1.09, 48.91, p<.05). Having one or more siblings with special needs remained a protective factor of similar magnitude as in the previous models (OR=0.08, 95% CI 0.01, 0.57, p<.05). However, not having insurance greatly increased the chance that a parent would report unmet need (OR=8.76, 95% CI 4.22, 18.20, p<.001). As with Model 3, the likelihood of experiencing unmet need in a medium Aud-LTS percentage state was not quite significant (OR=7.03, 95% CI 0.95, 51.94, p=.05). Poor families of children with hearing loss who lived in medium EI-LTS percentage states had 0.06 times the odds of reporting unmet need as poor families of children with hearing loss in low EI-LTS states (ratio of ORs= 0.06, 95% CI 0.01, 0.39, p<.01). A similar association was generated for poor families in high EI-LTS states, as compared to poor families in low EI-LTS states (ratio of ORs=0.07, 95% CI 0.01, 0.74, p<.05).

Research Question 6: Interaction of education and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to EI-LTS, was tested in Model 6. No additional findings were significant for unmet need; the results of Model 6 are not reported here.

Dependent Variable 3: Lack of Access to Care

Research Question 1: Family Characteristics

The first part of this analysis examined associations between family characteristics and parent report of lack of access to care, after controlling for sociodemographic variables. Table 10 shows the results from a series of ordinal logistic regression models. For children with hearing loss, having a single mother decreased the level of difficulty in obtaining care; the odds of single mothers being in a higher category (i.e., reporting increased difficulty) was approximately one-third the odds for non-single mothers (OR=0.37, 95% CI 0.20, 0.70, p<.01). Two controls were found to be significantly associated with parent report of lack of access to care: living in a household where the primary language was not English and having no insurance. Living in a household whose primary language was not English was associated with a 47 percent lower odds of reporting the highest levels of lack of access as compared to households where the primary language was English (OR=0.53, CI 0.30, 0.93, p<.05). Having no insurance was a significant risk factor for the reporting of lack of access; the odds that uninsured persons reported the greatest lack of access was nearly seven times that of insured persons (OR=6.91, 95% CI 2.24, 21.29, p<.001).

***Research Question 2: Strength of EHDI program, per lost-to-system
percentages for audiological diagnosis (Aud-LTS) and linkage to Early
Intervention (EI-LTS)***

Model 1b examined the direct association of the strength of the EHDI

program, as indicated by lost to system rankings for audiological diagnosis and report

of lack of access to care on the 2011 CDC EHDI Hearing Screening & Follow-up

Survey (HSFS). No findings were significant for lost-to-system percentages for

audiological diagnosis (Aud-LTS) on parent report of lack of access. However, living

in a state with medium lost-to-system percentages for early intervention (EI-LTS),

meaning that the LTS percentage was within the 25th and 75th percentiles, was

associated with almost twice the odds that a parent would report the most difficulty

with a lack of access to care (OR=1.93, 95% CI 1.06, 3.52, p<.05).

Model 2 added family characteristics and controls. Having a single mom

continued to be a protective factor in Model 2 (OR=0.42, 95% CI 0.23, 0.77, p<.01),

Not having insurance was associated with a slightly increased risk of reporting the

greatest problems with the lack of access to care in this model (OR=7.01, 95% CI

2.34, 21.00, p<.001), but living in a household where the primary language was not

English lost significance. Neither of the EHDI program variables, Aud-LTS nor EI-

LTS, was found to be significant in this model.

***Research Question 3: Interaction of poverty and the strength of the EHDI
program, per Aud-LTS percentages***

The effect of the interaction of poverty and the strength of the EHDI program,

as related to Aud-LTS, on the report of a lack of access to care was tested in Model 3.

No additional findings were significant, and thus the results of Model 3 are not reported here.

Table 10. Family characteristics and strength of state programs predicting parent report of a lack of access to care

Name	Model 1 OR	95% CI	Model 1b OR	95% CI	Model 2 OR	95% CI	Model 4 OR	95% CI	Model 6 OR	95% CI
Education										
High School Degree or Less	1.02	(0.68, 1.54)			0.98	(0.67, 1.43)	0.99	(0.67, 1.45)	1.31	(0.52, 3.29)
More than High School		omitted				omitted		omitted		omitted
Poverty (<=185% of FPL; 1=Yes)	1.12	(0.53, 2.38)			1.07	(0.50, 2.31)	1.38	(0.48, 3.97)	1.04	(0.48, 2.25)
Single Mom (1=Yes)	0.37	(0.20, 0.70) **			0.42	(0.23, 0.77) **	0.40	(0.21, 0.77) **	0.43	(0.23, 0.81) **
Sibling Status										
None (reference)		omitted				omitted		omitted		omitted
1+ (none with special needs)	0.88	(0.65, 1.20)			0.90	(0.66, 1.23)	0.96	(0.71, 1.29)	0.93	(0.68, 1.27)
1 or more w/special needs	1.14	(0.61, 2.12)			1.20	(0.66, 2.18)	1.26	(0.69, 2.32)	1.18	(0.64, 2.17)
Age of Child with Hearing Loss										
0 to 2 years old		omitted				omitted		omitted		omitted
3 to 5 years old	1.34	(0.81, 2.24)			1.40	(0.86, 2.29)	1.43	(0.85, 2.42)	1.41	(0.87, 2.30)
Race										
White (reference)		omitted				omitted		omitted		omitted
Hispanic	0.81	(0.37, 1.77)			0.74	(0.34, 1.60)	0.80	(0.46, 1.40)	0.75	(0.36, 1.56)
Black	2.02	(0.79, 5.14)			1.93	(0.76, 4.90)	2.11	(0.76, 5.86)	1.93	(0.74, 5.02)
Other Race	0.91	(0.43, 1.95)			0.90	(0.44, 1.86)	0.95	(0.45, 2.02)	0.96	(0.42, 2.15)
Primary Language Not English (1=Yes)	0.53	(0.30, 0.93) *			0.65	(0.36, 1.17)	0.62	(0.33, 1.15)	0.69	(0.36, 1.31)
No Insurance (1=Yes)	6.91	(2.24, 21.29) ***			7.01	(2.34, 21.00) ***	7.22	(2.46, 21.21) ***	8.03	(2.62, 24.59) ***
Lost to System - Audiology										
High			1.24	(0.55, 2.80)	1.33	(0.55, 3.18)	1.26	(0.52, 3.08)	1.28	(0.54, 3.05)
Medium			0.83	(0.48, 1.43)	0.89	(0.54, 1.46)	0.86	(0.52, 1.43)	0.84	(0.52, 1.38)
Low (reference)				omitted		omitted		omitted		omitted
Lost to System - Link to Early Intervention										
High			2.12	(0.91, 4.94)	1.65	(0.63, 4.31)	3.19	(0.96, 10.59)	2.66	(1.20,5.93) *
Medium			1.93	(1.06, 3.52) *	1.72	(0.88, 3.38)	1.84	(1.01, 3.35) *	1.93	(1.04, 3.60) *
Low (reference)				omitted		omitted		omitted		omitted
Interaction 3							0.38	(0.03, 4.44)		
Interaction 4							0.96	(0.34, 2.72)		
Interaction 7									0.34	(0.07, 1.77)
Interaction 8									0.95	(0.43, 2.12)

***p<.001, **p<.01, *p<.05; 2-tailed test

Models:
Model 1: Family Characteristics
Model 1b: LTS Audiological Diagnosis (LTS Aud)
           & LTS Early Intervention (LTS EI)
Model 2: Family Chararacteristics, LTS Aud & LTS EI
Model 3: Model 2 + interaction of poverty & LTS Aud
Model 4: Model 2 + interaction of poverty & LTS EI
Model 5: Model 2 + interaction of education & LTS Aud
Model 6: Model 2 + interaction of education & LTS EI

Interactions:
Interaction 1 = Poverty x High LTS Aud
Interaction 2 = Poverty x Medium LTS Aud
Interaction 3 = Poverty x High LTS EI
Interaction 4 = Poverty x Medium LTS EI
Interaction 5 = Education x High LTS Aud
Interaction 6 = Education x Medium LTS Aud
Interaction 7 = Education x High LTS EI
Interaction 8 = Education x Medium LTS EI

Note: The ORs for the interactions are the ratios of odds ratios. For example, the odds of reporting difficulty accessing care in Interaction is the ratio of: ORpoverty in a High LTS EI state divided by the ORpoverty in a Low LTS EI state. The Low LTS EI state serves as the reference for all of the interactions.

Research Question 4: Interaction of poverty and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of poverty and the strength of the EHDI program, as related to EI-LTS, was tested in Model 4. Having a single mom was associated with a 60 percent lower likelihood of reporting the greatest difficulties with the lack of access to care (OR=0.40, 95% CI 0.21, 0.77, p<.01) as compared to reporting the least difficulty in accessing care. For children with hearing loss, being uninsured was a strong and very significant risk factor for a parent report of a lack of access to care at the highest levels (OR=7.22, 95% CI 2.46, 21.21, p<.001). None of the interactions was found to be significant, but the main effects of EI-LTS did produce significant results. Living in a state with a medium EI-LTS percentage greatly increased the chance that a parent would report the most difficulties with a lack of access to care on the NS-CSHCN (OR=1.84, 95% CI 1.01, 3.35, p<.05).

Research Question 5: Interaction of education and the strength of the EHDI program, per Aud-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to Aud-LTS, was tested in Model 5. No additional findings were significant for parent report on the lack of access to care; the results of Model 5 are not reported here.

Research Question 6: Interaction of education and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to EI-LTS, was tested in Model 6. Being in a household led by a single mother lowered the odds of reporting the most difficulties with the lack of

access to care (OR=0.43, 95% CI 0.23, 0.81, p<.01). Not having insurance remained

a strong and very significant risk factor for parent report of a lack of access to care at

the highest levels in this model (OR=8.03, 95% CI 2.62, 24.59, p<.001). None of the

interactions was found to be significant, but the main effects of EI-LTS did produce

significant results. Living in a state with a medium EI-LTS percentage nearly

doubled the likelihood that a parent would report the greatest difficulties with thelack

of access to care (OR=1.93, 95% CI 1.04, 3.60, p<.05). The risk was greater in states

with a high EI-LTS percentage (OR=2.66, 95% CI 1.20, 5.93, p<.05). However,

given that these are components involved in the interactions, these main effects do not

provide much additional information.

Dependent Variable 4: Poor Family-Centered Communication

Research Question 1: Family Characteristics

Model 1 examined associations between family characteristics, with

sociodemographic variables as controls, and parent report of poor family-centered

communication with health care providers. Table 11 shows the results from a series

of OLS regression models. Only age of the child with hearing loss resulted in a

significant association with poor communication. Having children between the ages

of 3 and 5 years was associated with a poorer report of family-centered

communication with providers (B= 0.23, t(45) = 3.30, p<.01).

Research Question 2: Strength of EHDI program, per lost-to-system percentages for audiological diagnosis (Aud-LTS) and linkage to Early Intervention (EI-LTS)

Model 1b examined the direct association of the strength of the EHDI

program, as indicated by lost-to-system rankings for audiological diagnosis and

linkage to Early Intervention separately reported in the 2011 CDC EHDI Hearing Screening & Follow-up Survey (HSFS). No findings were significant for lost-to-system percentages for audiological diagnosis (Aud-LTS). However, living in a state with medium lost-to-system percentages for early intervention (EI-LTS) was associated with a poorer report of family-centered communication by providers (B= 0.21, t(45) = 3.09, p<.01), as did living in a state with high EI-LTS (B= 0.15, t(45) = 2.02, p<.05).

Model 2 added family characteristics and sociodemographic controls to Model 1b. Again, the only family characteristic found to be significant was that of the age of the child with hearing loss; having a child in the upper age group was associated with poorer report of family-centered communication (B= 0.24, t(45) = 3.32, p<.01). Both variables measuring strength of the state EHDI program, as related to lost-to-system percentages for early intervention, were found to be significant when compared to states with low EI-LTS percentages. Living in a state with a medium EI-LTS percentage was associated with a poorer report of family-centered communication (B= 0.22, t(45) =3.34, p<.01). Living in a state with a high EI-LTS percentage was also associated with a poorer report of family-centered communication (B= 0.15, t(45) = 2.30, p<.05).

Table 11. Family characteristics and strength of state programs predicting parent report of poor family-centered communication

Name	Model 1 Estimate	Std Error		Model 1b Estimate	Std Error		Model 2 Estimate	Std Error	
Education									
High School Degree or Less	0.0633	0.1127					0.0511	0.1105	
More than High School		omitted						omitted	
Poverty (<=185% of FPL; 1=Yes)	0.1588	0.0825					0.1338	0.0879	
Single Mom (1=Yes)	-0.1233	0.0705					-0.0713	0.0612	
Sibling Status									
None (reference)		omitted						omitted	
1+ (none with special needs)	0.0180	0.1056					0.0225	0.1054	
1 or more w/special needs	-0.1431	0.1141					-0.1405	0.1093	
Age of Child with Hearing Loss									
0 to 2 years old		omitted						omitted	
3 to 5 years old	0.2296	0.0697	**				0.2395	0.0722	**
Race									
White (reference)		omitted						omitted	
Hispanic	-0.1458	0.1389					-0.1716	0.1285	
Black	0.0382	0.1187					0.0097	0.1140	
Other Race	0.2221	0.1135					0.2114	0.1088	
Primary Language Not English (1=Yes)	0.1069	0.1248					0.1868	0.1279	
No Insurance (1=Yes)	0.0657	0.1738					0.0842	0.1559	
Lost to System - Audiology									
High				0.0820	0.0788		0.0980	0.0761	
Medium				-0.1037	0.0711		-0.0516	0.0600	
Low (reference)					omitted			omitted	
Lost to System - Link to Early Intervention									
High				0.1523	0.0755	*	0.1529	0.0664	*
Medium				0.2089	0.0676	**	0.2227	0.0667	**
Low (reference)					omitted			omitted	

***p<.001, **p<.01, *p<.05; 2-tailed test

Models:

Model 1: Family Characteristics
Model 1b: LTS Audiological Diagnosis (LTS Aud)
              & LTS Early Intervention (LTS EI)
Model 2: Family Chararacteristics, LTS Aud & LTS EI
Model 3: Model 2 + interaction of poverty & LTS Aud
Model 4: Model 2 + interaction of poverty & LTS EI
Model 5: Model 2 + interaction of education & LTS Aud
Model 6: Model 2 + interaction of education & LTS EI

Interactions:

Interaction 1 = Poverty x High LTS Aud
Interaction 2 = Poverty x Medium LTS Aud
Interaction 3 = Poverty x High LTS EI
Interaction 4 = Poverty x Medium LTS EI
Interaction 5 = Education x High LTS Aud
Interaction 6 = Education x Medium LTS Aud
Interaction 7 = Education x High LTS EI
Interaction 8 = Education x Medium LTS EI

Research Questions 3: Interaction of poverty and the strength of the EHDI program, per Aud-LTS percentages

The effect of the interaction of poverty and the strength of the EHDI program, as related to Aud-LTS, on the parent report of poor family-centered communication with health care providers was tested in Model 3. No findings were significant; the results of Model 3 are not reported here.

Research Question 4: Interaction of poverty and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of poverty and the strength of the EHDI program, as related to EI-LTS, on the parent report of poor family-centered communication with health care providers was tested in Model 4. No findings were significant; the results of Model 4 are not reported here.

Research Question 5: Interaction of education and the strength of the EHDI program, per Aud-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to Aud-LTS, on report of provider communication was tested in Model 5. No additional findings were significant; the results of Model 5 are not reported here.

Research Question 6: Interaction of education and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to EI-LTS, on report of provider communication was tested in Model 6. No additional findings were significant; the results of Model 6 are not reported here.

Dependent Variable 5: Lack of Coordinated Care

Research Question 1: Family Characteristics

The first part of this analysis examined associations between family

characteristics and parent report on the lack of coordinated care, after controlling for

sociodemographic variables. Table 12 shows the results from a series of OLS

regression models. The only variable found to be significantly associated with the

lack of coordinated care was age of the child with hearing loss; having a child with

hearing loss between the ages of 3 and 5 years was associated with a slight increase in

the likelihood of experiencing a lack of coordinated care, as compared to having a

child with hearing loss between the ages of 0 and 2 years (B= 0.10, t(45) = 2.93,

p<.01).

Research Question 2: Strength of EHDI program, per lost-to-system
percentages for audiological diagnosis (Aud-LTS) and linkage to Early
Intervention (EI-LTS)

Model 1b examined the direct association of the strength of the EHDI

program, as indicated by lost-to-system rankings for audiological diagnosis and

linkage to Early Intervention separately reported in the 2011 CDC EHDI Hearing

Screening & Follow-up Survey (HSFS), and parent report of the lack of coordinated

care. No findings were significant for lost-to-system percentages for audiological

diagnosis (Aud-LTS). However, without adjusting for controls, living in a state with

medium lost-to-system percentages for early intervention (EI-LTS) was associated

with a higher report of poor coordination of care (B= 0.05, t(45) = 2.23, p<.05).

Table 12. Family characteristics and strength of state programs predicting parent report of less coordinated care

Name	Model 1 Estimate	Std Error		Model 1b Estimate	Std Error		Model 2 Estimate	Std Error		Model 4 Estimate	Std Error	
Education												
High School Degree or Less	0.0471	0.0416					0.0428	0.0403		0.0464	0.0411	
More than High School		omitted						omitted			omitted	
Poverty (<=185% of FPL; 1=Yes)	0.0441	0.0309					0.0375	0.0316		-0.0352	0.0443	
Single Mom (1=Yes)	-0.0391	0.0282					-0.0234	0.0287		-0.0219	0.0290	
Sibling Status												
None (reference)		omitted						omitted			omitted	
1+ (none with special needs)	-0.0102	0.0369					-0.0105	0.0372		-0.0112	0.0375	
1 or more w/special needs	-0.0270	0.0330					-0.0268	0.0319		-0.0253	0.0306	
Age of Child with Hearing Loss												
0 to 2 years old		omitted						omitted			omitted	
3 to 5 years old	0.1014	0.0346	**				0.1032	0.0335	**	0.1059	0.0335	**
Race												
White (reference)		omitted						omitted			omitted	
Hispanic	-0.0603	0.0394					-0.0680	0.0367		-0.0631	0.0344	
Black	0.0114	0.0491					0.0062	0.0457		0.0076	0.0455	
Other Race	0.0017	0.0395					0.0017	0.0406		0.0020	0.0390	
Primary Language Not English (1=Yes)	0.0189	0.0455					0.0348	0.0494		0.0436	0.0480	
No Insurance (1=Yes)	0.0009	0.0429					0.0077	0.0405		0.0168	0.0374	
Lost to System - Audiology												
High				0.0320	0.0220		0.0404	0.0213		0.0363	0.0206	
Medium				-0.0271	0.0189		-0.0162	0.0156		-0.0148	0.0158	
Low (reference)					omitted			omitted			omitted	
Lost to System - Link to Early Intervention												
High				0.0114	0.0250		0.0084	0.0258		-0.0209	0.0476	
Medium				0.0513	0.0231	*	0.0461	0.0261		-0.0209	0.0476	
Low (reference)					omitted			omitted			omitted	
Interaction 3										0.0555	0.0479	
Interaction 4										0.1010	0.0479	*

***p<.001, **p<.01, *p<.05; 2-tailed test

Models:
Model 1: Family Characteristics
Model 1b: LTS Audiological Diagnosis (LTS Aud) & LTS Early Intervention (LTS EI)
Model 2: Family Chararacteristics, LTS Aud & LTS EI
Model 3: Model 2 + interaction of poverty & LTS Aud
Model 4: Model 2 + interaction of poverty & LTS EI
Model 5: Model 2 + interaction of education & LTS Aud
Model 6: Model 2 + interaction of education & LTS EI

Interactions:
Interaction 1 = Poverty x High LTS Aud
Interaction 2 = Poverty x Medium LTS Aud
Interaction 3 = Poverty x High LTS EI
Interaction 4 = Poverty x Medium LTS EI
Interaction 5 = Education x High LTS Aud
Interaction 6 = Education x Medium LTS Aud
Interaction 7 = Education x High LTS EI
Interaction 8 = Education x Medium LTS EI

Model 2 examined the variables above in combination with those for family characteristics and sociodemographic controls. None of the family characteristics was determined to be significant. However, having a child with hearing loss in the upper age range slightly increased parental report of experiencing poor coordination of care (B= 0.10, t(45) = 3.08, p<.01). Neither of the state EHDI program indicators was found to be significant.

Research Questions 3: Interaction of poverty and the strength of the EHDI program, per Aud-LTS percentages

The effect of the interaction of poverty and the strength of the EHDI program, as related to Aud-LTS, on the parent report of the lack of coordinated care was tested in Model 3. No findings were significant; the results of Model 3 are not reported here.

Research Question 4: Interaction of poverty and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of poverty and the strength of the EHDI program, as related to EI-LTS, on the parent report of the lack of coordinated care was tested in Model 4. As with the previous models, only the control variable for child age was significant; having a child with hearing loss between the ages of 3 to 5 years was associated with a parent reporting a lower level of coordinated care (B= 0.11, t(45) = 3.16, p<.01). Additionally, as compared to low-income families in states with low EI-LTS percentages, families whose incomes were less than or equal to 185 percent of FPL experienced less coordinated care in medium EI-LTS percentage states (B= 0.10, t(45) = 2.11, p<.05).

Research Question 5: Interaction of education and the strength of the EHDI program, per Aud-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to Aud-LTS, on report of the lack of coordinated care was tested in Model 5. No additional findings were significant; the results of Model 5 are not reported here.

Research Question 6: Interaction of education and the strength of the EHDI program, per EI-LTS percentages

The effect of the interaction of education and the strength of the EHDI program, as related to EI-LTS, on report of the lack of coordinated care was tested in Model 6. No additional findings were significant; the results of Model 6 are not reported here.

Summary of Findings

After controlling for sociodemographic variables, the associations between family characteristics and strength of the state EHDI program were assessed via six models in relation to five dependent variables measuring receipt and/or satisfaction of patient care: non-receipt of Early Intervention Services, unmet need, lack of access to care, poor family-centered communication, and lack of coordinated care. There were consistent trends across the models for many of the dependent variables.

For the children with hearing loss, having one or more siblings without special needs and being between 3 to 5 years of age were associated with decreased likelihoods of not having received Early Intervention Services. For some of the models, being in a state with a medium or high EI-LTS percentage was associated

with significantly greater risks that the child with hearing loss would not have received Early Intervention Services. This risk was even greater when being in a state with a medium or high EI-LTS percentage was analyzed for interactionswith poverty and education, separately.

Having one or more siblings with a special need was consistently associated with a decreased likelihood of reporting unmet need across all of the models. However, being uninsured dramatically increased the odds of reporting unmet need with odds ratios ranging from 8.76 to 9.93 across the models. When examining family characteristics and the sociodemographic controls only, living in a household whose primary language was not English made it six times more likely that a parent would report unmet need. Protective associations were found in the analyses of the interactive effects of education and poverty, individually, with higher state Aud-LTS percentages making it less likely that a more disadvantaged parent would report unmet need.

In examining associations with reporting the greatest difficulty in accessing care, having a single mother was associated with less risk across all of the models, whereas not having insurance greatly increased the risk and level of significance with odds ratios ranging between 6.91 to 8.03. When examining only family characteristics and sociodemographic controls, living in a household where English was not the primary language decreased the likelihood of reporting the most difficulties in accessing care by almost half, as compared to reporting the least difficulty. In most of the models, living in a state with medium EI-LTS percentages

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was associated with nearly double the risk of reporting great difficulty in accessing care compared to the risk or reporting the least difficulty.

The analyses related to report of poor family-centered communication had minimal findings, and none of the models involving interactions were discussed as they did not produce many significant associations. In both models that included family characteristics and sociodemographic controls, having a child with hearing loss between the ages of 3 and 5 years was associated with poorer family-centered communication. Additionally, living in a state with medium EI-LTS percentages was associated poorer family-centered communication. Families living in a state with a high EI-LTS percentage also reported poor family-centered communication.

The analyses with regard to the lack of coordinated care revealed even fewer associations with the variables of interest. Being in the upper age group (i.e., 3 to 5 years) was associated with a lower level of coordinated care across the models that included family characteristic variables and sociodemographic controls. In the model that examined only the strength of the EHDI program, living in a state with a medium EI-LTS percentage was significantly associated with a poorer level of coordinated care. In addition, in a medium EI-LTS state, families whose incomes were less than or equal to 185 percent of FPL reported of experiencing less coordinated care than poor families living in low EI-LTS states.

Chapter 5: Discussion

This chapter provides an interpretation of the results presented in the previous chapter. The findings are discussed in relation to each hypothesis (see Table 13 for a summary of findings). This chapter also covers study limitations and then discusses the potential implications for future policy and program decisions.

Interpretation of Findings

> ***Hypothesis 1a. After controlling for child's age, race, language, and insurance status, <u>parents with lower levels of education</u> will report less access to care, greater unmet need, less coordinated care, poor family-centered communication, and lower levels of participation in Early Intervention Services programs than parents with higher levels of education.***

This hypothesis was not supported; the education level of the parents on its own was not associated with any of the outcome variables. Associations between education and the outcome variables were only found to be significant when examined in combination with the strength of the states' Early Hearing and Detection Intervention (EHDI) programs, which is described in the sections for Hypotheses 5 and 6. In general, studies have shown that a higher maternal education level is associated with *better outcomes* regarding the utilization of health care services (Porterfield & McBride, 2007; Mayer, Skinner & Slifkin, 2004). Although parent education level may have a direct effect on choices that parents may make regarding their children's medical care, it may be less precise as related to *perception* of care. Porterfield & McBride (2007) emphasized the importance of targeted outreach to less-educated parents of CSHCN as they found that these children were less likely to access health services because their parents did not recognize the need for those

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services or did not know what services were available. Given that the NS-CSHCN is

based on parent report of various satisfaction measures, it would be affected by the

lack of awareness regarding quality of care standards and current guidelines. It may

be that parents with a lower education level are less likely to be aware of the care that

their children should have received, and, therefore, less likely to report dissatisfaction

with care. Also, as mentioned earlier, these results may be explained via the

Behavioral Model in that a parent's lower level of education, combined with less

knowledge about a condition (e.g., hearing loss), could impact whether or not the

parent believes that the child needs additional health services or early intervention.

The parent may perceive that additional services are unnecessary if she does not

understand the benefits that intervention could bring, or worse, not understand the

consequences of failing to seek intervention, such as a child being unable to achieve

his expected potential had he been given access to hearing aids or other

communication supports. If this were the case, the parent would be unlikely to report

negatively on any of the outcome measures assessed in this study.

Table 13. Summary of research questions, hypotheses, and findings

Research Question	Hypothesis	Findings
1. Family Direct Effects After controlling for child's age, race, language, and insurance status, examine whether and how **family characteristics** (i.e., education; poverty status; and family structure, including mother's marital status and sibling classification) are associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.		
1a. **Education** After controlling for child's age, race, language, and insurance status, examine whether and how **parent level of education** is associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.	After controlling for child's age, race, language, and insurance status, parents of children with hearing loss, who have a **high school education or less**, will report that they have less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parent with more than a high school education.	This hypothesis was not supported; there were no significant findings.
1b. **Poverty** After controlling for child's age, race, language, and insurance status, examine whether and how **poverty status** is associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.	After controlling for child's age, race, language, and insurance status, parents of children with hearing loss, who have a **earn less than or equal to 185 percent of the Federal Poverty Level**, will report that they have less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents who are higher earners.	This hypothesis was not supported; there were no significant findings.
1c. **Family Structure: Single Mother** After controlling for child's age, race, language, and insurance status, examine whether and how **poverty status** is associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.	After controlling for child's age, race, language, and insurance status, **single mothers** of children with hearing loss will report less access to care, greater unmet need, less coordinated care, poor family-centered communication, and lower levels of participation in Early Intervention Services programs than other types of family structures.	This hypothesis was not supported. Households led by single mothers were 60% less likely to report the most difficulty in accessing care as compared to those reporting the least difficulty.
1d. **Family Structure: Sibling Classification** After controlling for child's age, race, language, and insurance status, examine whether and how **sibling classification** is associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.	After controlling for child's age, race, language, and insurance status, **families with larger numbers of children, particularly those with more than one child with special health care needs**, will report less access to care, greater unmet need, less coordinated care, poor family-centered communication, and lower levels of participation in Early Intervention Services programs than families with less children.	This hypothesis was not supported. Households with more than one child (but none with special needs) were nearly half as likely to report non-receipt of Early Intervention Services than those where the child with hearing loss was an only child. Households with more than one child with special needs were 80% less likely to report unmet need than households where the child with hearing loss was an only child.
2. Program Direct Effects – Lost to System: Audiological Diagnosis & Linkage to Early Intervention After controlling for family characteristics, child's age, race, language, and insurance status, examine whether and how the **quality of state EHDI programs**, **as related to audiological diagnosis and linkage to early**		

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intervention separately, is associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.		
2a. **Program Direct Effects – Lost to System: Audiological Diagnosis** After controlling for family characteristics, child's age, race, language, and insurance status, examine whether and how the **quality of state EHDI programs, as related to audiological diagnosis**, is associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss who **reside in states with less developed Early Hearing Detection and Intervention (EHDI) programs, as determined by their loss to follow-up results for audiological diagnosis**, will report that they have less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents who reside in states with more effective EHDI programs.	This hypothesis was not supported.
2b. **Program Direct Effects – Lost to System: Linkage to Early Intervention** After controlling for family characteristics, child's age, race, language, and insurance status, examine whether and how the **quality of state EHDI programs, as related to linkage to early intervention**, is associated with parental reports of access to care, unmet need, coordinated care, family-centered communication, and receipt of Early Intervention Services.	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss who **reside in states with less developed Early Hearing Detection and Intervention (EHDI) programs, as determined by their loss to follow-up results for linkage to early intervention**, will report that they have less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents who reside in states with more effective EHDI programs.	This hypothesis was supported in part. Families living in states with less developed EHDI programs, as determined by their lost-to-follow up results for linkage to early intervention, were almost 3 times as likely to report non-receipt of early intervention services. However, in contrast, they were 25% as likely to report poor family-centered communication.
Interactions of Poverty and Strength of EHDI Program		
3. **Interaction: Poverty and Strength of EHDI program (related to Audiological Diagnosis)** After controlling for family characteristics, child's age, race, language, and insurance status, determine whether the effect of poverty on the parental reports of care (as described above) is modified by the strength of the EHDI programs (related to audiological diagnosis).	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss living in **higher levels of poverty and who reside in states with weaker EHDI programs (based on lost-to-system percentages for audiological diagnosis)**, will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than higher income families in similar states.	The hypothesis was not supported. Families with incomes less than or equal to 185% of FPL and who lived in states with weaker EHDI programs, based on audiological follow-up, were 92% less likely to report unmet need than poor families living in states with stronger EHDI programs.
4. **Interaction: Poverty and Strength of EHDI program (related to Early Intervention)** After controlling for family characteristics, child's age, race, language, and insurance status, determine whether the effect of poverty on the parental reports of care (as described above) is modified by the	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss living in **higher levels of poverty and who reside in states with weaker EHDI programs (based on lost-to-system percentages for linkage to early intervention)**, will report less	This hypothesis was supported in part. Families with incomes at or below 185% of the FPL and who lived in states with weaker EHDI programs, based on early intervention follow-up, were almost 6.5 times as likely to report non-

strength of the EHDI programs (related to linkage to early intervention).	access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than higher income families in similar states.	receipt of Early Intervention Services than low-income families in states with stronger EHDI programs. They were 11% more likely to report a lack of coordinated care, as well.
Interactions of Education and Strength of EHDI Program		
5. **Interaction**: **Education and Strength of EHDI program (related to Audiological Diagnosis)** After controlling for family characteristics, child's age, race, language, and insurance status, determine whether the effect of education on the parental reports of care (as described above) is modified by the strength of the EHDI programs (related to audiological diagnosis).	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss, and who have **lower levels of education and reside in states with weaker EHDI programs (related to audiological diagnosis)**, will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents with more education in similar states.	This hypothesis was not supported. Households whose parents had a high school degree or less, and who lived in a state with a weak EHDI program based on audiological follow-up, were 93% less likely to report unmet need than households with similarly educated parents living in states with strong EHDI programs.
6. **Interaction**: **Education and Strength of EHDI program (related to Early Intervention)** After controlling for family characteristics, child's age, race, language, and insurance status, determine whether the effect of education on the parental reports of care (as described above) is modified by the strength of the EHDI programs (related to linkage to early intervention).	After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss, and who have **lower levels of education and reside in states with weaker EHDI programs (based on lost-to-system percentages for linkage to early intervention)**, will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents with more education in similar states.	This hypothesis was supported in part. Households whose parents had a high school degree or less, and who lived in a state with a weak EHDI program based on linkage to early intervention, were 3-4 times as likely to report non-receipt of Early Intervention Services than households with less educated parents living in states with strong EHDI programs.

Hypothesis 1b. After controlling for child's age, race, language, and insurance status, <u>families who have incomes at or below 185 percent of the Federal Poverty Level</u> will report less access to care, greater unmet need, less coordinated care, poor family-centered communication, and lower levels of participation in Early Intervention Services programs than parents with higher incomes.

This hypothesis was not supported; the household's income level on its own was not associated with any of the outcome variables. As with education, however, associations between having an income at or below 185 percent of the Federal Poverty Level (FPL) and the outcome variables were found to be significant when examined in combination with the strength of the states' Early Hearing and Detection Intervention (EHDI) programs, as described in the sections covering Hypotheses 3 and 4.

In a study that used the 2009-2010 NS-CSHCN to provide a population-based assessment of the quality of the health care system (using MCHB's six quality indicators), attainment rates of the quality indicators were lower for those in lower income households (Strickland et al., 2015). Although our study did not use all of the MCHB quality indicators, it was expected that the outcomes would be similar: families with lower incomes would report experiencing more problems in obtaining care for their children. Furthermore, a recent study of 2009-2010 data found that over one-third of CSHCN families reported increased difficulties, delays, and frustrations in receiving health care and related services; however, families in poverty were significantly more likely to report negative experience than those above the poverty line (Rosen-Reynoso et al., 2016). Given that education and poverty are highly correlated, this outcome may also be the result of a lack of awareness among poor

families. If they did indeed receive lower quality of care, they may not realize that they should have expected more from the health care system. This finding is supported by the outcomes of a study using 2001 NS-CSHCN data, in which Porterfield and McBride (2007) surmised that lower-income parents have a lower perceived need for specialized health care services.

Alternatively, another possible explanation for this finding may be that potential disparities due to poverty status were lessened because over 91 percent of the families in the sample were covered by some type of insurance. Szilagyi (2012) found strong evidence that children with disabilities who have insurance are more likely to have a primary care provider, to be able to access specialty care, to have reduced unmet needs, and to have access to supporting services. Also, in the study described above, Rosen-Reynoso et al. (2016) found that being uninsured, as compared to having private insurance, was associated with significantly decreased odds of reporting positively on access measures regarding ease of use. Although nearly half of the sample in this study were found to be living in poverty, using the definition of having an income <185% of the FPL, less than ten percent of the entire sample reported a lack of insurance. Although insurance status was included in the statistical models as a control variable, it may be that the number of uninsured families was too small to generate the power needed to determine significant differences between the insured poor and uninsured poor.

Additionally, McManus et al. (2009) found that disparities in quality of care and unmet need resulted from the interaction of poverty and state policies. Both poverty and insurance status were defined as variables within the individual enabling

characteristics. Per the Behavioral Model, individual/family-level characteristics are

impacted by external variables that reach the family, such as state program policies;

therefore, it is possible that associations between poverty and the outcomes of

inadequate care, after controlling for insurance, were not found because they were not

examined within the context of the external environment in this model.

> **Hypothesis 1c. After controlling for child's age, race, language, and insurance status, <u>single mothers</u> will report less access to care, greater unmet need, less coordinated care, poor family-centered communication, and lower levels of participation in Early Intervention Services programs than other types of family structures.**

This hypothesis was not supported. In fact, the findings contradicted what

was predicted with respect to reporting a lack of access to care. The effect was nearly

the same across all of the models reported here for a lack of access to care:

households headed by a single mother were approximately sixty percent less likely to

report a lack of access to care as compared to other family structures. Living in a

household headed by a single mother was not significant for any of the other outcome

variables in this study. These findings are in contrast to those reported by Kenney,

Denboba, Strickland, and Newacheck (2011) who found that single mothers were 23

percent more likely to report that they did not feel like a partner in the family-

provider relationship and were dissatisfied with services. Furthermore, in a study of

enrollment into early intervention following discharge from a neonatal intensive care

unit, it was found that single-parent household status was significantly associated

with delayed service initiation, waiting an average of 24 days longer, although having

health insurance reduced this time (Litt & Perrin, 2014). They also found that single

parents were 1.5 times more likely to report expending greater effort to find services for their children. In a study of over 2,500 parents who had children in early intervention, it was found that single parents had significantly lower scores on an index created to measure family outcomes (Bailey et al., 2005).

Turchi et al. (2009) found that households led by two-parent family structures were more likely to report not receiving coordinated care, but also not needing it. Upon reflection, it may make sense that family structure is not associated with care coordination, as defined in this study. Care coordination is defined by four variables: problem getting a referral in the past year, satisfaction with the communication between doctors and other programs (e.g., school), satisfaction with the communication between usual doctors and other health care providers, and needing extra help to coordinate care among different providers. The first three variables that make up the access index measure are less likely to have different outcomes based on marital status/family structure alone. Only the latter (i.e., needing extra help to coordinate care among different providers) would seem likely to be associated with marital status/family structure. As compared to mothers in other family structures, a single mother may have a more difficult time arranging appointments with multiple providers or getting the time off to take her child to health care visits. However, this variable did not take into account possible living arrangements or other social support, such as cohabitation with a partner or other adult relative, that could provide help to the single mother. With regard to the outcomes, in general, an alternative hypothesis may be that single mothers are more likely to receive adequate care

because they may already be in the system for other safety net services, such as the

WIC program or welfare assistance.

> ***Hypothesis 1d. After controlling for child's age, race, language, and insurance status, <u>families with larger numbers of children, particularly those with more than one child with special health care needs</u>, will report less access to care, greater unmet need, less coordinated care, poor family-centered communication, and lower levels of participation in Early Intervention Services programs than families with less children.***

This hypothesis was not supported. Family structure, as related to sibling

classification, was significant for only two of the outcome variables: non-receipt of

Early Intervention Services and unmet need. For both of these variables, the

outcomes were contrary to what was predicted, but in different ways. As described in

the Methods section, sibling classification had three categories: the child with

hearing loss was an only child, which served as the reference category; the child with

hearing loss had one or more siblings, but no other siblings with special health care

needs; or the child with hearing loss had one or more siblings, including at least one

with special health care needs. Families that had more than one child, but no

additional siblings with special needs, were almost half as likely to report non-receipt

of Early Intervention Services than families whose child with hearing loss was an

only child.

As noted earlier, social scientists theorized that parental resources (e.g., time,

energy, and money) are finite and that each child further dilutes these resources,

resulting in worse outcomes for each child (Phillips, 1999; Downey, 1995). Having

one or more siblings was expected to increase overall risk among all of the studied

outcomes given that larger families would be more apt to face additional constraints

on time, money, and other resources than a family with an only child; rather, having a larger family served to protect against non-receipt of Early Intervention Services. Although the results differ from what was expected, they are not completely counterintuitive. Yes, larger families may have to stretch resources across more children, but there may be other factors that make them more advantageous.

The results of this research are in line with some of the studies mentioned in the literature review. Mulvihill et al. (2007) reported that children living in families with more children under the age of 18 years were more likely to have coordinated care, as evidenced by having a medical home, than children living in families with fewer children under the age of 18 years. A study of the 2000-2002 NS-CSHCN that ran models by socioeconomic levels as defined by poverty level found that the number of children in the household was negatively associated with children receiving necessary specialty care (Lykens, Fulda, Bae, & Singh, 2009); however, this finding was only significant for those whose families had the lowest incomes.

In this study, birth order was not controlled, so it is unknown if the child with hearing loss is first-born or one of the younger siblings. The child with hearing loss had to be under age 6 in this study, therefore, would likely be one of the younger siblings. It is likely that the family has had prior experience raising children, which may enable them to adapt more quickly to the special needs without having to learn everything about child rearing from scratch. For example, a "seasoned" parent may already have established routines and relationships with pediatricians and child care providers. Adding a special needs issue may complicate matters, but their baseline

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level of knowledge and competency would be higher than that of brand new parents facing a special health care need in addition to learning how to be new parents.

Similarly, the presence of additional siblings also produced unexpected results for parent report of unmet need. However, in this case, families who had more than one child with special health care needs were almost 90 percent less likely to report unmet need than families for whom the child with hearing loss was an only child. Again, this finding, although initially surprising, does make sense when given more thought. As mentioned above, families that had more than one child with special health care needs were predicted to report worse experiences in their interactions with the health care system that could result from the potentially increased stressors on the family. Children with special health care needs require more visits to health care providers, including more visits with specialists than typical children, which may negatively impact the family by increasing stress and anxiety, tapping financial resources, and adding to demands on limited time. Having more than one child with a special health care need was predicted to strain these issues further such that parents may not have been able to follow through on recommendations for care, and, as a result, experience unmet needs. However, it is also not difficult to imagine that parents who have multiple children with special health care needs would actually be more equipped to handle the additional issues. If the child with hearing loss has an older sibling with special needs, it is quite likely that the parents would already be aware of programs and resources that provide services to families who have children with special health care needs, would be educated on their children's conditions, would be in their states' data tracking systems, and would have connected with other

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families that have children with special needs. Therefore, while having more than one child with a special health care need would seem to have an adverse effect on the family, it may be beneficial as the parents may be better able to adapt to the new challenges presented by additional children with special health care needs than parents who are facing them for the first time.

> ***Hypothesis 2a. After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss who reside in states with less developed Early Hearing Detection and Intervention (EHDI) programs, <u>as determined by their lost to follow-up results for audiological diagnosis</u>, will report that they have less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services.***

This hypothesis was not supported, as results were only significant for unmet need, but in the opposite direction than predicted, at a p-value equal to 0.05 (which is not considered significant in this study), and only when poverty status was assessed in combination with state lost-to-system percentages for audiological diagnosis.

The results may not be significant for the strength of the EHDI program, based on lost-to-system for audiological diagnosis alone, because there is a vast difference between the cases included in the lost-to-system for audiological diagnosis pool versus those in those in the lost-to-system for early intervention pool. As described in detail in the Literature Review, over 95 percent of newborns are screened for hearing loss in the U.S. The states track the cases that do not pass the newborn screen (e.g., over 59,000 babies in 2011), which is a quick assessment that can be applied on a universal level, and could possibly include a number of false-positives that do not need further audiological assessment or other follow-up. In contrast, the

states track a much smaller pool of newborns (e.g., over 5,000 babies in 2011) for

linkage to early intervention after audiological diagnosis has been performed. As

such, the cases that make up the pool of lost-to-system for linkage to early

intervention (i.e., confirmed cases of hearing loss that most likely require early

intervention follow-up) is quite different from the pool of lost-to-system for

audiological diagnosis (i.e., newborns who fail a preliminary screen, some of whom

may not need additional follow-up). Associations between the lost-to-system for

early intervention data, which tracks confirmed cases of hearing loss, and the

outcomes generated by the National Survey of Children with Special Health Care

Needs are more likely to be stronger than associations between the lost-to-system for

audiological diagnosis data and the outcomes of the survey.

> ***Hypothesis 2b. After controlling for family characteristics, child's age, race,
> language, and insurance status, parents of children with hearing loss who
> reside in states with less developed Early Hearing Detection and
> Intervention (EHDI) programs, as determined by their lost to follow-up
> results for linkage to early intervention, will report that they have less access
> to services, greater unmet need, less coordinated care, worse family-centered
> communication, and less use of Early Intervention Services.***

This hypothesis was strongly supported, as results were in line with the

expectations across most of the outcome variables, although some were more strongly

associated than others. Families who lived in states with weaker EHDI systems, as

indicated by high lost-to-system percentages, were nearly three times more likely to

report non-receipt of Early Intervention Services. This finding supports the idea that

states with stronger EHDI programs are better at linking families who have children

with hearing loss to the appropriate programs and resources. These results indicate

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that there is an association between programs at the state level and experiences reported at the individual family level within the state.

The results for unmet need were only significant in the model that did not adjust for the control variables. Families who lived in states with weaker EHDI programs, as indicated by high lost-to-system percentages for early intervention, were 80 percent less likely to report unmet need. Similarly, not controlling for demographic and socioeconomic family characteristics, an association was indicated between living in a state with a weaker EHDI program and parent report of a lack of access to care. Families were almost twice as likely to report the greatest difficulties accessing care in states that had higher lost-to-system percentages for early intervention. However, as with unmet need, this association lost significance after adjusting for the control variables. One control variable, in particular, that may explain these outcomes is insurance; not having insurance made families nearly ten times as likely to report unmet need and seven times as likely to report a lack of access to care. These results demonstrate the importance of including family characteristics when examining associations between state-level aggregate data representing program effectiveness and family-level outcomes. Not taking into account important sociodemographic variables could have a substantial impact on the interpretation of results eventually leading to the inaccurate translation of research into policy or practice.

Living in a state with weaker EHDI programs, as related to lost-to-system percentages for early intervention, was associated with poorer reported family-centered communication. This finding is important because family-centered

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communication is the cornerstone of linking families to early intervention to maximize the possibility that children with hearing loss will experience optimal outcomes in health and language development. Strong EHDI programs work with families to ensure that parents are aware of the risks of not seeking follow-up services, such as the short window of opportunity for language development, and the benefits of providing their young children with hearing loss early and optimal access to language and communication.

There was no association between the strength of the EHDI program, via its performance regarding linkage to early intervention, and parent report of a lack of coordinated care. Given that there is no significant difference between report of problems with coordination of care between states with strong EHDI programs and states with weak EHDI programs, this finding may indicate some possible scenarios: 1) all of the EHDI programs are similarly effective in assisting families with coordination of care, which is not likely; or 2) the measure of coordinated care used in this study was not defined well enough to capture the variety of experiences that families face in navigating the health care system. Care coordination was defined by four variables: problem getting a referral in the past year, a lack of satisfaction with the communication between doctors and other programs (e.g., school), a lack of satisfaction with the communication between usual doctors and other health care providers, and needing extra help to coordinate care among different providers. This measure may have revealed more disparities if it assessed additional medical home quality indicators such as whether coordinated services were offered in a proactive manner, whether providers and case managers shared medical and service plan

records, or if providers and case managers worked together to create a holistic care plan for the CSHCN. For example, families that do not report dissatisfaction with communication between their providers, or between their providers and other programs, may still not have received coordinated care in the manner that is recommended by MCHB and state EHDI programs.

> ***Hypothesis 3. After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss living in <u>poverty and who reside in states with weaker EHDI programs (based on lost-to-system percentages for audiological diagnosis)</u>, will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than those living in poverty in states with stronger EHDI programs.***

This hypothesis was not supported for the outcome variables under study and most findings were not significant. For unmet need, however, the findings were significant, but contradicted what was predicted. After controlling for a number of demographic and socioeconomic variables, poverty status (i.e., having an income less than or equal to 185 percent of the Federal Poverty Limit (FPL)) was found to be significantly related to unmet need only when it was examined in combination with the effect of the strength of the state's system indicated by its lost-to-system percentage for audiological diagnosis. Lower income families were over six and a half times more likely to report unmet need if they lived in a state with low lost-to-system percentages for audiological diagnosis than were poor families who lived in states with less effective programs. The possible explanations for these results may be similar to those for education, particularly considering the strong correlations between education and income. As discussed in the section on education, it may be that families with lower incomes who lived in states with lower lost-to-system

percentages for audiological diagnosis were more aware of the need for audiological

assessment and/or hearing aids/care as a result of their states' strong EHDI programs,

and therefore more likely to report unmet need if they did not receive appropriate

hearing care for their child. That families living in poverty in higher lost-to-system

states with regard to audiological diagnosis report much less unmet need may reflect

a lack of awareness for necessary hearing care services, which would impact their

recognition and reporting of unmet need. Only parents who know that they need

hearing aids/hearing care for their child would report unmet need if they do not

receive this care. Additionally, using the NS-CSHCN data to assess associations

between characteristics of families with CSHCN and state lost-to-system data for

audiological diagnosis may not be ideal. As only families with children who are

identified as having special health care needs are in the NS-CSHCN, the data may not

represent a large percentage of families who are lost-to-system for audiological

diagnosis.

>   ***Hypothesis 4. After controlling for family characteristics, child's age, race,
>   language, and insurance status, parents of children with hearing loss living
>   in <u>poverty and who reside in states with weaker EHDI programs (based on
>   lost-to-system percentages for linkage to early intervention)</u>, will report less
>   access to services, greater unmet need, less coordinated care, worse family-
>   centered communication, and less use of Early Intervention Services than
>   those living in poverty in states with stronger EHDI programs.***

Hypothesis 4 was supported for two of the outcome variables: non-receipt of

Early Intervention Services and lack of coordinated care. After controlling for a

number of demographic and socioeconomic variables, the effect of poverty status

(i.e., having an income less than or equal to 185 percent of the Federal Poverty Limit

(FPL)) was found to be significant only when it was examined in combination with

the effect of the strength of the state's early intervention system, as determined by its lost-to-system percentages. Families with an income equal to or less than 185 percent of the FPL, who lived in states with higher levels of lost-to-system percentages for Early Intervention Services, were approximately six and a half times as likely to have reported that their children did not receive early intervention than were poor families who lived in states with lower levels of lost-to-system percentages. This is a finding of critical importance, as it demonstrates that poor families are far more likely to be negatively impacted in states that have weaker EHDI programs, as assessed by linkage to early intervention percentages. Families that have larger incomes are more likely have additional resources to seek out services, family education, and care that counteract the effect of ineffective EHDI programs. Poor families may not be able to access recommended care for a number of reasons, such as having less flexibility to take time off from work to attend medical appointments or lacking transportation to visit specialists who may not be in their immediate geographical area. A new resource guide for EHDI coordinators highlights the increased risk that poverty may pose for a family with a child with hearing loss, and states that "effective providers acknowledge the additional challenges resulting from poverty, recognizing how they might interact and influence family goals and priorities for the child with hearing loss in order to provide comprehensive service delivery" (Voss & Lenihan, p. 26-5, 2015). The resource guide notes that poor families who have children with disabilities need more than the usual interventions for hearing loss, but also rely on community resources to help fulfill some of their basic needs (Voss & Lenihan, 2015).

The interaction of poverty and living in a state with a weak EHDI program, as determined by lost-to-system percentages for early intervention, was also significant for parent report of a lack of coordinated care. Families that earned equal to or less than 185 percent of the FPL in states that had weaker EHDI programs (medium) reported less coordinated care than did poor families in states with more effective programs. This finding also supports the notion described above that families with greater means who live in states with less effective EHDI programs, as determined by linkage to early intervention statistics, may be better equipped to maneuver within the components of the health care system than families with less resources who live in similar states. These results support the findings of other studies that show differences in early intervention enrollment by region, due to differences in state policies, which are further exacerbated by poverty (Litt & Perrin, 2014; McManus et al., 2009).

> ***Hypothesis 5. After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss, and who have <u>lower levels of education and reside in states with weaker EHDI programs (related to audiological diagnosis)</u>, will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents with lower education levels in states with stronger EHDI programs.***

This hypothesis was not supported. Only the association with unmet need was deemed significant, but in the opposite direction than predicted. After controlling for a number of demographic and socioeconomic variables, the effect of parental education on unmet need was found to be significant when it was examined in combination with the effect of the strength of the state's EHDI system indicated by its lost-to-system percentage for audiological diagnosis. Although the findings were the

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opposite of what was expected, they are not necessarily illogical in hindsight. Parents with a high school education or less were considerably less likely to report unmet need if they lived in a state with high lost-to-system percentages for audiological diagnosis than were parents who had less than a high school education who lived in a state with low lost-to-system percentages, meaning that less educated parents were more likely to report unmet need in states with more effective EHDI programs, as assessed by their outcomes for audiological diagnosis.

There are a few possible explanations for these results. One may be that this sample had a very small number of cases, slightly more than five percent, who reported unmet need. Another possibility may be that lost-to-system for audiological diagnosis may not be a good measure for unmet need as defined in this study, "Did the [child with hearing loss] receive all of the hearing aids or hearing care that (he/she) needed?" More likely, it may be that less educated parents who lived in states with lower lost-to-system percentages for audiological diagnosis were more aware of the need for audiological assessment and/or hearing aids/care as a result of the successful efforts of their state EHDI programs. Assuming that less educated families are less likely to receive necessary care than more educated families, in general, less educated families in states with stronger EHDI programs will have increased awareness of the care they should receive and will be more likely to report unmet need if they did not receive appropriate hearing care for their child. The lower reporting of unmet need by less educated parents in higher lost-to-system states with regard to audiological diagnosis may reflect a lack of awareness for necessary hearing care services. Only parents who are aware of the importance of hearing aids/hearing

care for children with hearing loss would report unmet need if they did not receive

this care. Parent report of unmet need is a perception, not necessarily reality. A

better measure would query parents about unmet need only if it was first determined

that they were aware that specific medical care was needed for their child.

> ***Hypothesis 6. After controlling for family characteristics, child's age, race, language, and insurance status, parents of children with hearing loss, and who have <u>lower levels of education and reside in states with weaker EHDI programs (based on lost-to-system percentages for linkage to early intervention)</u>, will report less access to services, greater unmet need, less coordinated care, worse family-centered communication, and less use of Early Intervention Services than parents with lower education levels in states with stronger EHDI programs.***

This hypothesis was supported for one of the outcome variables: non-receipt

of Early Intervention Services. After controlling for a number of demographic and

socioeconomic variables, the effect of parental education was found to be significant

only when it was examined in combination with the effect of the strength of the

state's early intervention system, as determined by its lost-to-system percentages.

Parents with an education level of high school or less, who lived in states with higher

levels of lost-to-system percentages for Early Intervention Services, were three to

four times more likely to have reported that their children did not receive early

intervention than were less educated parents who lived in states with lower lost-to-

system percentages. This finding indicates that states with stronger early intervention

systems can counteract the effect of having a lower level of education. Intuitively,

one would assume that parents with greater amounts of education would be likely to

be more aware of the need for additional services for children with special health care

needs, or learn how to access these services, than parents with lower levels of

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education. However, states with effective EHDI programs can level the playing field for less educated families by implementing strategies that have been shown to improve EHDI outcomes, such as having comprehensive and integrated data systems in place to track and monitor families that need follow-up services, having strong interagency collaborations between the entities along the spectrum of care for children with hearing loss, providing education to families about hearing loss and appropriate interventions, and increasing access to underserved areas (Hoffman, Munoz, Bradham and Nelson, 2011).

Study Limitations

Cross-Sectional Research Design

This study used a cross-sectional research design incorporating the data from two surveys that are cross-sectional in nature: CDC's 2011 Hearing Screening and Follow-Up Survey and the 2009-2010 National Survey of Children with Special Health Care Needs. Although cross-sectional surveys are useful for providing descriptive information and finding associations among variables of interest, they do not provide information about change in individual families over time and do not allow for the determination of causal conclusions from the results.

Internal Validity

Internal validity issues exist at two main levels: 1) within the composite variables that were generated for this study and 2) among the two surveys that were linked for analysis. Internal validity for the composite variables was checked via tests for Cronbach's alpha, for overall fit, and through correlation analyses for intra-

variable validity. Some of the composite variables were better indicators of the issue

being measured than others; "lack of communication," made up of eight variables,

had a high Cronbach's alpha of 0.90, whereas "lack of coordinated care," comprising

four variables, had a low Cronbach's alpha of 0.62. Another issue is that the two

surveys supplying the data may not be appropriately matched. Given that this study

uses data from the 2009-2010 NS-CSHCN, it was paired with the aggregate state

EHDI data for 2011. The state EHDI data reflects newborn hearing screening

percentages for that year; the NS-CSHCN survey for 2009-2010 includes children 0

to 5 years of age. The strength of the EHDI program in 2011 may not be applicable

to families with older children. However, it was used as an overall indicator of the

general strength of the EHDI program for each state with the assumption that states

will be consistently strong or weak with respect to their EHDI program over time.

We assume that families living in a state with a stronger EHDI program will report

higher satisfaction on quality of care and receipt of care measures.

 Sample Size

 Given that the 2009-2010 NS-CSHCN had a total sample size of 40,242

children with special health care needs, this study had a rather small sample size

(n=684). This sample size is particularly of concern because the data are analyzed by

state. The number of children with hearing loss in each state ranged from 7 to 26;

these small numbers most likely affected the power of the analyses and may have

contributed to the lack of findings for several outcome variables. Combining data

over different survey years would have helped increase the sample size and power,

but the NS-CSHCN is fairly new, having been conducted only three times (i.e., the periods of 2001, 2005-2006, and 2009-2010), and there were significant changes between the 2005-2006 and 2009-2010 surveys in some of the key variables examined here (e.g., family-centered communication subcomponents are not comparable over survey years) (Data Resource Center, 2011).

Eligibility Criteria

One of the greatest weaknesses of this study is the way in which a child with hearing loss is defined. The 2009-2010 survey did not have a question asking about a specific diagnosis for hearing loss. Therefore, to create a variable indicating hearing loss, this study used a question about necessary hearing aids/hearing care and a question regarding whether the CSHCN had difficulty hearing. Although it is likely that a high percentage of those who answered affirmatively to these questions do indeed have children with diagnosed hearing loss, these questions would also capture children with temporary conditions, such as hearing issues related to repeat ear infections or other injury. If it were true that a large number of children in this study's sample actually did not have newborn hearing loss, the associations between the outcomes and the state indicators regarding lost-to-system for audiological diagnosis and linkage to early intervention.

Missing Data in Sample

As discussed in Chapter 3, after other corrective measures were performed to optimize the data, only observations with no missing data for the independent variables and controls were included in the sample. In order to minimize missing

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data due to non-response, legitimate skips were included in the non-problematic response categories for two-part questions. Also, to account for missing data in one or more of the variables comprising the composite dependent variables, average index measures were used. Missing data are a limitation in this study because they reduce the overall sample size. For example, by removing the observations that did not have state LTS data, the sample size decreased by nearly 100 CSHCN, which is a large drop given the small size of the uncorrected sample to begin with.

Nonresponse Bias

The methodology report for the 2009-2010 NS-CSHCN describes the potential for response bias noting that there may be differences between the respondents and those who elected not to participate. The 2009-2010 survey was the first to use cell phone numbers to expand reach into different segments of the population, such as households that lack land lines; however, a segment of the population still was not well-represented, such as the homeless or migrant worker.

Parent Report/Under- and Over-Report/Recall Bias

The NS-CSHCN data captures only parent reports of health status, provision of care, and the quality of their children's health care utilization; therefore, it reflects parental knowledge and awareness. Parents may not be aware of care that their children should have received, and, as such, may not indicate having experienced problems on the satisfaction of care measures. Also, the data have not been validated against health care provider records, so it is possible that some of the responses could be inaccurate. Furthermore, parents are asked about events that took place over the

past 12 months, or since the birth of the child if younger than 12 months; they may

not be likely to recall specific details about their child's health care utilization. This

is particularly relevant to this population because CSHCN typically have more health

care issues, more health care-related visits, and more health care providers than a

non-CSHCN. Unless the parent has the child's records, or a log of medical

appointments, at the time of the interview, it may be quite likely that their recall may

not be as good as they think it to be.

Variable Definition

Although the variables used within this study were carefully chosen and

defined, they may not have been accurate representations of the issue under analysis.

For example, "not insured" was defined as 1) currently uninsured or 2) uninsured at

any time over the past year. We cannot discern the duration of being uninsured; some

cases may have had long stretches of being uninsured, others may have been affected

briefly due to a short-lived experience, such as a job change with a break between

employment. Therefore, the characteristics of the families meeting the criteria for

"not insured" may be very dissimilar, which would affect the strength of the analyses

using this variable.

Implications and Future Directions

Several of the hypotheses presented in this paper were not supported due to a

lack of significance or due to results that were in the opposite direction from what

was originally predicted. However, a number of interesting findings may prove to be

useful contributions to the evidence base in the areas of special health care needs and

childhood hearing loss. Furthermore, having examined the data available through the EHDI Hearing Screening and Follow-Up Survey and the NS-CSHCN, a few changes that could potentially improve health services systems and quality of care for families of children with hearing loss are recommended.

Policy and Program-Level Implications

To our knowledge, this is the first study to link state-level data from the CDC Early Hearing Detection and Intervention (EHDI) Program's Hearing Screening and Follow-Up Survey (HSFS) to family-level data from the National Survey of Children with Special Health Care Needs (NS-CSHCN). Although individual state EHDI programs may collect family-level data related to health care services and developmental outcomes for children with hearing loss, these data are not available at the national level or easily accessible to researchers in the manner of typical CDC datasets. Furthermore, the amount and type of data collected vary and are not standardized among the states, with the exception of the minimal core data required by the CDC EHDI program in aggregate form (Uhler, Thomson, Cyr, Gabbard, & Yoshinaga-Itano, 2014). Linking data elements from the two surveys enabled this study to examine family characteristics in relationship to the effectiveness of state EHDI programs to determine whether together, or singly, there were associations with reports of quality of care measures. Policymakers and EHDI program evaluators who use the EHDI HSFS data in decision-making may find it worthwhile to examine the data in combination with the NS-CSHCN data as another means of assessing the

impact of the state EHDI programs on standardized quality of care measures within individual states and on a national level.

Furthermore, the results of this study demonstrated that family-level characteristics may be important considerations if data from the two surveys are used jointly to determine the effectiveness of EHDI programs on family-level quality of care indicators, such as unmet need. Significant associations were found between the strength of the EHDI programs, as determined by lost-to-system percentages, and some of the quality of care indicators. However, most of these associations were no longer significant after adjusting for family-level characteristics, such as insurance status. As such, policymakers, program evaluators, and program coordinators should use caution if they do use data from the two surveys to assess the impact of state-level program effectiveness on family-level outcomes, otherwise invalid associations may be ascribed to the effect of the EHDI program on family-level quality measures.

All states and territories are required to perform annual evaluations of their EHDI programs if they receive MCHB funding or have a cooperative agreement with CDC (Foust, 2015). These reports may be rich with information about hospital performance, family demographics, screening and diagnostic data, physician attitudes and knowledge about hearing loss, and parent perceptions of the EHDI program, to name a few fields that may be tracked (Foust, 2015). However, as mentioned earlier, these data are not standardized, nor does they reside in an easily accessible archive that would enable researchers to assess outcomes across states or nationally. The reported information would most likely not reflect the inputs of families who are considered "lost-to-system" either. Linking the aggregate HSFS data to the NS-

CSHCN provides another mechanism for objectively assessing the impact of the state EHDI programs in a more removed way. Combining the inputs from the individual state evaluations and the outputs of this type of research could potentially identify areas for improvement and allow for targeted interventions.

Focus on Poverty and Education

Given the findings presented here regarding the interactive effects of poverty and education with the EHDI program, it is recommended that EHDI programs in states with high and medium lost-to-system percentages for linkage to early intervention pay particular attention to the populations that are less educated and/or are lower-income. (As a reminder, low-income families in states with high lost-to-system percentages for linkage to early intervention were nearly six and a half times as likely not to have received early intervention as were low-income families in states with low lost-to-system percentages. Families with lower education levels were three to four times as likely to not receive early intervention as families with similar education levels in states with low lost-to-system percentages.) If a state has limited resources, using them to target populations that are more disadvantaged by poverty and low education might be a more effective way to reduce the number of families that do not receive early intervention services than applying a less targeted statewide approach. The results seem to indicate that families with greater resources (i.e., education and income) will connect with necessary services, even in states that have high lost-to-system percentages for linkage to early intervention.

Although the findings seem to indicate the opposite for the same low-income and less educated populations when it comes to states with high lost-to-system (LTS) percentages for audiological diagnosis and report of unmet need (i.e., both low-income and less educated families in states with **high** LTS rates were highly unlikely to report unmet need), it is believed that this is due to a lack of awareness of need for hearing screening and treatment in states with higher LTS rates for audiological diagnosis. States with stronger EHDI programs would be more likely to have more effective outreach and education programs for families that do not pass the hearing screening. Families that are poor or lower-educated in these states would be more likely to have been informed about the courses of action that they should follow and of the specialized care that their children need, but they still may be at a disadvantage in accessing these services, and, therefore, report greater unmet need. Poor and less educated families in states with higher LTS percentages for audiological diagnosis would be less likely to report unmet need if they have not received information about recommended care. As such, states with high LTS percentages for audiological diagnosis may want to consider targeted outreach and awareness campaigns in poor regions of the state, which are also most likely to have less educated populations. Even though this does not address the issue of unmet need, it would better ensure that families are receiving the critical information they need to begin the process of seeking care and services for their children with hearing loss.

<u>Recommendations for the NS-CSHCN</u>

Studying the outcomes for children with hearing loss is not a simple task using the NS-CSHCN. The 2009-2010 survey tracks "functional difficulties" and "health conditions" of the children with special health care needs. The list of "health conditions" contains a list of mostly specific diagnoses, such as Down Syndrome, diabetes, or cystic fibrosis; it does not contain diagnosed hearing loss as a separate condition. To determine health conditions, the participant is asked, "For each condition, please tell me if a doctor or other health care provider ever told you that [child's name] had the condition, even if [he/she] does not have the condition now" (Child and Adolescent Health Measurement Initiative (CAHMI), 2012). That question is followed by, "does [child's name] currently have [condition]?" Having an issue with hearing is captured as a "functional difficulty" via the question, "The next questions are about ways [child's name] might experience difficulties due to [his/her] health. Would you say that [he/she] experiences a lot, a little, or not difficulty with…hearing even when using a hearing aid or other device?" (CAHMI, 2012). As such, it is difficult to ascertain which children in the sample have diagnosed hearing loss. A child without diagnosed hearing loss may have "a little" or "a lot" of difficulty hearing as the result of a temporary condition, such as a serious ear infection. In contrast, a parent who has a child with hearing loss may answer "no difficulty" to this question if she does not think that her child has trouble hearing when using a hearing aid or cochlear implant. By not having "diagnosed hearing loss" categorized as a health condition, the responses are vague and open to interpretation, which means that the NS-CSHCN does not provide definitive data for

children with diagnosed hearing loss. To be included in this study's sample, the respondent must have answered: 1) that the child experiences "a lot" or "a little" difficulty hearing, or 2) "yes" to a question asking whether the child needed hearing aids or hearing care over the past year. Although it is hoped that these eligibility criteria captured most of the children with hearing loss in the NS-CSHCN, we cannot be certain if the sample contains children who do not have diagnosed hearing loss or whether we captured all of the children with hearing loss in the 2009-2010 NS-CSHCN sample.

Given that CDC and HRSA/MCHB are expending great efforts and resources via the EHDI programs to improve the quality of care for children with hearing loss, it would seem that the NS-CSHCN would be an opportune tool to learn more about the families of children with hearing loss and be able to identify specifically which CSHCN in the sample have diagnosed hearing loss. Although the EHDI program captures individual-level data within their own states, having access to family-level information for hearing loss as a condition from a nationally-representative survey would better enable researchers to analyze relationships and perhaps uncover associations that could be used to improve health and education services for children with hearing loss and their families. A second recommendation for the NS-CSHCN is that response options should be added to the question regarding unmet need for hearing aids/hearing care. For many of the unmet need topics, there is a follow-up question asking participants to indicate why they were unable to get the service. There are 15 specific responses (e.g., "cost was too much," "did not know where to go for treatment," "not convenient times/could not get appointment"), or the

respondent could select "other," "don't know," or refuse to answer (NS-CSHCN, 2009). However, this is not asked after the question regarding unmet need for hearing aids/hearing care. Again, given the efforts of the EHDI program to better understand barriers to care and to improve follow-up and health outcomes, it would be advantageous for the NS-CSHCN to collect this sort of information with regard to families of children with diagnosed hearing loss. The last recommendation for improving the utility of the NS-CSHCN was originally going to be that it occur more frequently to allow for better tracking of conditions and trending of data. However, a recent visit to the MCHB-sponsored Data Resource Center for Child and Adolescent Health website revealed that the NS-CSHCN will become an annual survey beginning in 2016-2017 (Data Resource Center, 2015).

Implications for Future Studies

This exploratory study of associations between the effectiveness of EHDI state programs, as measured by LTS percentages, and family characteristics on the report of inadequate care among families of young children with hearing loss has generated interesting findings that may be worth probing further. In particular, the findings regarding the differential effects of state programs on parent report of unmet need and non-receipt of early intervention by income and education levels may be of interest to health services researchers and those working in systems quality improvement. Given the minimal impact that the LTS for audiological follow-up seemed to have on outcomes, it would be prudent to focus primarily on the associations with LTS for linkage to early intervention when examining outcomes

using the National Survey for Children with Special Health Care Needs. Further

study using a similar approach of linking state EHDI data with family-level NS-

CSHCN data, but perhaps with larger sample sizes and/or with variables defined

differently, may provide HRSA and CDC with additional insights about the strengths

and weakness of their programs such that interventions are targeted to the families

and state programs that most need them.

Summary and Key Points

Although a low-incidence disability in the U.S., congenital hearing loss may

pose a risk to a child's speech, language, cognitive, and social-emotional

development. Early detection and intervention efforts at the state and national levels

have demonstrated greatly improved outcomes for these children, however there is

much variability in the effectiveness of state programs, particularly in terms of

tracking and reporting children identified to be at-risk. A large percentage of children

are "lost to system (LTS)," meaning that they did not receive recommended care or

that it was not reported. To explore associations between LTS percentages of the

state Early Hearing Detection and Intervention (EHDI) programs and family-level

characteristics on parent report of inadequate care and non-receipt of services, this

study linked state-level EHDI data with family-level data from the National Survey

on Children with Special Health Care Needs. The results indicated that living in

states with less effective EHDI programs was associated with an increased likelihood

of not receiving early intervention services (EIS) and of reporting poor family-

centered communication. Sibling classification affected both receipt of EIS and

report of unmet need. Single mothers were less likely to report increased difficulty

accessing to care. Low-income and less educated families, separately, living in states

with less effective EHDI programs were more likely to report non-receipt of EIS than

were similar family types in states with more effective EHDI programs. Both low-

income and less educated families, separately, living in states with higher LTS

percentages for early intervention, were less likely to report unmet need compared to

similar families in states with more effective programs, which may indicate a lack of

awareness of the need for specialized care. Low-income families who lived in states

with less effective programs were also more likely to report less coordinated care than

were low-income families from states with stronger programs. Disadvantaged

families may have more difficulty navigating the health care system without the

assistance of the intervention programs.

This study supports the conclusion that both family characteristics and the

effectiveness of state programs may be associated with quality of care outcomes. It

appears that less effective state programs are associated with disadvantaged families'

service receipt report more than that of advantaged families. These findings are

important because they may provide insights into ways efforts can be improved to

better serve families within states that have greater LTS percentages. States may also

benefit by gaining a better understanding of the types of families within their states

that report not receiving services so that programs can be designed to target these

families and perhaps reduce EHDI LTS percentages within their states.

Further research using this approach of linking state-level data to family-level

data may provide national and state policymakers and program managers a more

complete picture of the quality and utilization of services for families of children with hearing loss. The ultimate goal is ensuring that all babies born with hearing loss receive the care and services needed to optimize developmental outcomes and quality of life.

Appendices

Table 14. Correlation coefficients for the independent variables

Pearson Correlation Coefficients, N = 684
Prob > |r| under H0: Rho=0

	Education	Poverty	Single Mom	No Siblings	Has siblings (none w/ special needs)	Has siblings (1+ has special needs)	Child Age 0 to 2 yrs	Child Age 3 to 5 yrs	Race: White	Race: Black	Race: Hispanic	Race: Other	Primary Language not English	No Insurance
Education	1.00	0.45 <.0001	0.22 <.0001	-0.05 0.22	0.03 0.49	0.02 0.62	0.02 0.53	-0.02 0.53	-0.16 <.0001	0.03 0.44	0.22 <.0001	-0.04 0.36	0.28 <.0001	-0.02 0.65
Poverty	0.45 <.0001	1.00	0.27 <.0001	-0.03 0.39	-0.05 0.24	0.09 0.02	0.08 0.03	-0.08 0.03	-0.28 <.0001	0.11 0.00	0.21 <.0001	0.07 0.06	0.23 <.0001	0.12 0.00
Single Mom	0.22 <.0001	0.27 <.0001	1.00	0.17 <.0001	0.09 0.01	-0.03 0.37	0.03 0.37	-0.03 0.37	-0.20 <.0001	0.22 <.0001	0.07 0.08	0.04 0.31	-0.09 0.02	0.01 0.79
No Siblings	-0.05 0.22	-0.03 0.39	0.17 <.0001	1.00	-0.64 <.0001	-0.31 <.0001	0.08 0.03	-0.08 0.03	0.01 0.78	0.10 0.01	-0.05 0.21	-0.01 0.85	-0.09 0.02	-0.01 0.79
Has siblings (no sp needs)	0.03 0.49	-0.05 0.24	0.09 0.01	-0.64 <.0001	1.00	-0.54 <.0001	-0.04 0.28	0.04 0.28	0.00 0.75	-0.08 0.05	0.05 0.17	-0.02 0.63	0.11 0.00	0.01 0.76
Has siblings (1+ w/ sp needs)	0.02 0.62	0.09 0.02	-0.03 0.37	-0.31 <.0001	-0.54 <.0001	1.00	-0.04 0.31	0.04 0.31	0.00 0.93	0.05 0.17	-0.01 0.75	0.03 0.42	-0.05 0.24	0.00 0.93
Child Age 0 to 2 yrs	0.02 0.53	0.08 0.03	0.03 0.37	0.08 0.03	-0.04 0.28	-0.04 0.31	1.00	-1.00 <.0001	-0.05 0.23	0.02 0.64	0.07 0.09	-0.02 0.60	0.10 0.01	-0.01 0.83
Child Age 3 to 5 yrs	-0.02 0.53	-0.08 0.03	-0.03 0.37	-0.08 0.03	0.04 0.28	0.04 0.31	-1.00 <.0001	1.00	0.05 0.23	-0.02 0.64	-0.07 0.09	0.02 0.60	-0.10 0.01	0.01 0.83
Race: White	-0.16 <.0001	-0.28 <.0001	-0.20 <.0001	0.01 0.78	0.00 0.75	0.00 0.93	-0.05 0.23	0.05 0.23	1.00	-0.36 <.0001	-0.58 <.0001	-0.51 <.0001	-0.40 <.0001	-0.09 0.01
Race: Black	0.03 0.44	0.11 0.00	0.22 <.0001	0.10 0.01	-0.08 0.05	0.05 0.17	0.02 0.64	-0.02 0.64	-0.36 <.0001	1.00	-0.13 0.00	-0.18 <.0001	0.06 0.11	-0.04 0.24
Race: Hispanic	0.22 <.0001	0.21 <.0001	0.07 0.08	-0.05 0.21	0.05 0.17	-0.01 0.75	0.07 0.09	-0.07 0.09	-0.58 <.0001	-0.13 0.00	1.00	-0.18 <.0001	0.55 <.0001	0.05 0.16
Race: Other	-0.04 0.36	0.07 0.06	0.04 0.31	-0.01 0.85	-0.02 0.63	0.03 0.42	-0.02 0.60	0.02 0.60	-0.51 <.0001	-0.18 <.0001	-0.18 <.0001	1.00	0.02 0.67	0.11 0.00
Primary Language not English	0.28 <.0001	0.23 <.0001	-0.09 0.02	-0.09 0.02	0.11 0.00	-0.05 0.24	0.10 0.01	-0.10 0.01	-0.40 <.0001	0.06 0.11	0.55 <.0001	0.02 0.67	1.00	0.08 0.05
No Insurance	-0.02 0.65	0.12 0.00	0.01 0.79	-0.01 0.79	0.01 0.76	0.00 0.93	-0.01 0.83	0.01 0.83	-0.09 0.01	-0.04 0.24	0.05 0.16	0.11 0.00	0.08 0.05	1.00

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Table 15. Correlation coefficients for the dependent variables

	Non-Receipt of Early Intervention (Phi Coefficient)	Unmet Need (Phi Coefficient)	Lack of Communication (Point Biserial Coefficient)	Lack of Access to Care (Spearman's Rank)	Lack of Coordinated Care (Point Biserial Coefficient)
	Correlation Coefficients				
	Prob > |r| under H0: Rho=0				
	Number of Observations				
Non-Receipt of Early Intervention	1.00	0.08	0.02	-0.03	0.02
		0.05	0.62	0.47	0.61
	684	683	684	684.00	684
Unmet Need	0.08	1.00	0.10	0.11	0.11
	0.05		0.01	0.004	0.003
	683	683	683	683.00	683
Lack of Communication	0.02	0.10	1.00	0.39	0.57
	0.62	0.01		<.0001	<.0001
	684	683	684	684.00	684
Lack of Access to Care	-0.03	0.11	0.39	1.00	0.41
	0.47	0.004	<.0001		<.0001
	684	683	684	684.00	684
Lack of Coordinated Care	0.02	0.11	0.57	0.41	1.00
	0.61	0.003	<.0001	<.0001	
	684	683	684	684.00	684

Table 16. Correlation coefficients for the state policy variables

	High LTS Audiology	Medium LTS Audiology	Low LTS Audiology	High LTS Early Intervention	Medium LTS Early Intervention	Low LTS Early Intervention
	Correlation Coefficients, N = 684					
	Prob > |r| under H0: Rho=0					
High LTS Audiology	1.00	-0.52	-0.38	0.41	-0.14	-0.25
		<.0001	<.0001	<.0001	0.00	<.0001
Medium LTS Audiology	-0.52	1.00	-0.59	-0.24	0.30	-0.11
	<.0001		<.0001	<.0001	<.0001	0.01
Low LTS Audiology	-0.38	-0.59	1.00	-0.13	-0.19	0.35
	<.0001	<.0001		0.00	<.0001	<.0001
High LTS Early Intervention	0.41	-0.24	-0.13	1.00	-0.57	-0.34
	<.0001	<.0001	0.00		<.0001	<.0001
Medium LTS Early Intervention	-0.14	0.30	-0.19	-0.57	1.00	-0.57
	0.00	<.0001	<.0001	<.0001		<.0001
Low LTS Early Intervention	-0.25	-0.11	0.35	-0.34	-0.57	1.00
	<.0001	0.01	<.0001	<.0001	<.0001	

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