Addressing lost to intervention: A Public Health Approach to Early Hearing Detection and Intervention

Torri Ann Woodruff, PhD

University of Connecticut, 2022

In the United States during 2019, 5,934 infants were identified as D/deaf or hard of hearing via Early Hearing Detection and Intervention (EHDI) programs (CDC, 2019b). However, over 1/3 of those children and their families are lost to intervention (LTI) and not documented as having accessed to early intervention services (CDC, 2019b). The most commonly known reason for not accessing services, besides those that are logistical in nature, is that the child’s family refused services (CDC, 2021c). These families are refusing services that are supported in the research, outlined by the federal government, implemented at the state level, and critical to the inherent structure of EHDI. Not having access to early intervention is concerning, as it places children at a developmental disadvantage due to a lack of linguistic access. This document explores the contributors to this service refusal including the accessibility of information, EHDI policy, and personal decision making followed by a discussion of a novel intervention to address service refusal. This is a unique line of programmatic inquiry focused on understanding and addressing the individual needs of families beginning to navigate early intervention and their journey with hearing.
Addressing lost to intervention: A Public Health Approach to Early Hearing Detection and Intervention

Presented by
Torri Ann Woodruff

B.A., University of Connecticut, 2015

M.S., Gallaudet University, 2017

A Dissertation
Submitted in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy
at the
University of Connecticut
2022
Doctor of Philosophy Dissertation

Addressing lost to intervention: A Public Health Approach to Early Hearing Detection and Intervention

Presented by
Torri Ann Woodruff, B.A., M.S.

Approved by

Major Advisor: Kathleen Cienkowski
Associate Advisor: Mary Beth Bruder
  Associate Advisor: Kim Gans
Associate Advisor: Bernard Grela
Associate Advisor: Beth Russell
Associate Advisor: Sarah Woulfin

University of Connecticut

2022
Publications during Candidacy

Manuscripts discussed in this bound are bolded and first-author status is denoted with an asterisk.


Conference presentations


Acknowledgments

This dissertation was completed during the COVID-19 pandemic. The time and energy of everyone who was involved is greatly appreciated as plans shifted in the name of public health.

Thank you to my committee, Dr. Kim Gans, Dr. Beth Russell, Dr. Bernard Grela, Dr. Sarah Woulfin, and Dr. Mary Beth Bruder for serving as a personal reservoir of knowledge as I worked on this and always providing feedback, guidance, and support.

Thank you to my major advisor Dr. Kathleen Cienkowski for welcoming me into her lab as an undergraduate student and being an exemplary model of what being a researcher, mentor, and instructor is all about. It is shocking to me that about a decade ago I sent my first email to you that was far too long. Thank you for teaching me so much, including the value of brevity.

Thank you to my outside readers who took the time to provide their unique view on my work.

Thank you to the instructors, clinicians, and mentors, like Dr. Claire Marcus Bernstein, who encouraged me to seek out a path in research and showed me the power of quality care.

Thank you to the participants who have enrolled over the years in the various studies listed. You pushed forward the field’s understanding of EHDI and made a lasting impression on me.

Thank you to my family (born to, chosen, human, canine, and rabbit). After years of listening to me proofread manuscripts out loud, practice talks, or go into a lecture on EHDI over sushi, your professional student is graduating, and the end is in sight.
As it is a tradition for major events in my life, I have to mention The Road not Taken. While our traveler wraps up a short walk, the final stanza echoes how I feel after following the winding path that led me to this dissertation.

Two roads diverged in a wood, and I—

I took the one less traveled by,

And that has made all the difference.
# Table of Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHAPTER 1</td>
<td>1</td>
</tr>
<tr>
<td>CHAPTER 2</td>
<td>11</td>
</tr>
<tr>
<td>CHAPTER 3</td>
<td>27</td>
</tr>
<tr>
<td>CHAPTER 4</td>
<td>33</td>
</tr>
<tr>
<td>CHAPTER 5</td>
<td>70</td>
</tr>
<tr>
<td>CHAPTER 6</td>
<td>97</td>
</tr>
<tr>
<td>CHAPTER 7</td>
<td>144</td>
</tr>
<tr>
<td>CHAPTER 8</td>
<td>176</td>
</tr>
<tr>
<td>CHAPTER 9</td>
<td>196</td>
</tr>
</tbody>
</table>
Significance

Early Hearing Detection and Intervention (EDHI) programs across the United States provide a mechanism to screen, diagnose, and intervene with children who have hearing thresholds outside of the typical range (Early Hearing Detection and Intervention Act of 2017). Of the 5,934 infants identified through EHDI in 2019, 2,272 of them, over one third, were not recorded as having any early intervention services (CDC, 2021a). When difficulty accessing language because of hearing is not addressed, the child may be at risk for language deprivation and long-term negative impacts on language learning and mental health (Hall, 2017). Early intervention has a long track record of supporting children as they acquire language and positive reception from families once enrolled (National Center for Hearing Assessment and Management, 2019; Yoshinaga-Itano, 1999; 2003; 2013). Consequently, early intervention is explicitly called for in both federal legislation and the 2019 position statement of the Joint Committee on Infant Hearing (JCIH; Early Hearing Detection and Intervention Act of 2017; JCIH, 2019). Current national data sets suggest that parental refusal of early intervention services is one key element that contributes to disengagement in early intervention (CDC, 2021c). Over the last 20 years, research has explored the best possible recommendations for screening, diagnosing, and intervening along with the impact that intervention services have on children. Despite this body of work, there has been significantly less work on follow-through to early intervention services following hearing level diagnosis. The current research will explore barriers and facilitators to
enrollment in early intervention for children who are identified as D/deaf or hard of hearing through EHDI programs in the United States. It also begins to answer the question of whether parent education, designed according to intervention mapping, can impact parental perceptions of interventions.

Lost to Follow Up in Early Hearing Detection and Intervention

Aim 1 of this bound dissertation is to better understand why children who are D/deaf or hard of hearing are not enrolled in early intervention services to support language development. This is achieved through the inclusion of papers published on the topics of health literacy, EHDI program structure, and the development of a model to describe lost to intervention at the national level. EHDI programs exist in every state and territory of the United States (White, 2019). The procedure for accessing intervention services has three steps: screening by one month of age, diagnosis of hearing levels by three months of age, and intervention services as needed by six months of age (see Figure 1; JCIH, 2019). Children who do not make it to the next clinically indicated step following screening in Figure 1 are deemed lost to diagnosis (LTD) if they do not have a hearing evaluation or lost to intervention (LTI) if they do not enroll in early intervention. The leading known reasons for over 15,000 children being LTD are an inability to contact the family (over 3,000) and the family being unresponsive to attempts to contact (over 5,000; CDC, 2021d). These values represent data from the United States, but are consistent with various reports from around the globe citing logistical challenges that serve as barriers to diagnostic services (Kanji & Krabbenhoft, 2018; Khoze-Shangase, 2019; Liu, Farrell, MacNeil, Stone, & Barfield, 2008; Scheepers, Swanepoel, & le Roux, 2014).
Currently, the transition from screening to diagnosis has a solid foundation within the literature base. Protocol recommendations include setting up diagnostic appointments before the child leaves the hospital, having an audiologist oversee screening programs, providing materials in multiple languages, and allowing rescreening to occur outside of the hospital itself (Hunter, Meinzen-Derr, Wiley, Horvath, Kothari, & Wexelblatt, 2016; Liu et al., 2008; JCIH, 2019; Thompson & Yoshinaga-Itano, 2018; Tran, Schindelar, Ibieta, Webb, Jumonville, Pea, & Berry, 2017). A training designed for newborn hearing screeners on the national level provides scripts to use when informing families that their child requires diagnostic services to support follow-up for diagnostic testing (National Center for Hearing Assessment and Management, 2010). There are evidence-based strides being made at the state and national levels by programs to ensure children receive diagnostic services and are not LTD. Now, research must pivot its attention to ensuring that those children who need it are able to access intervention services.

There is limited work on what drives enrollment to early intervention, and what impacts children who are LTI, the focus of this dissertation. This limit in research may be due to the relatively small population of children who are LTI compared to those who are LTD, given that some children who are LTD are expected to have hearing in the typical range and not need intervention services at all. At the national level, the most reported known reason for LTI is that parents declined early intervention (CDC, 2021c). This is intrinsically different from an inability to contact or families not responding because refusal is active disengagement.
While underreported currently, the same logistical barriers to accessing diagnostic services, such as financial status, rurality of the home, and care coordination are not anticipated within this population (Cunningham, Thompson, McKiever, Dickinson, Furniss, & Allison, 2018; Kanji & Krabbenhoft, 2018; Khoza-Shangase, 2019; Liu et al., 2008; Scheepers et al., 2014). Early intervention for many children who are identified through EHDI is covered under part C of the Individuals with Disabilities Education Act (IDEA) of 2004. Here, access to intervention is considered an entitlement service with some services provided free of charge and others governed by a sliding fee scale (IDEA of 2004). Within early intervention, many services are provided in the child’s natural environment, meaning that providers travel to the home or location where the child is naturally present at a time that works for the family (IDEA of 2004). Even with these modifications to support engagement, parents continue to refuse these services. In determining why these families refuse services, the feasibility and applicability of behavior change modules centered around early intervention enrollment.

**Use of intervention mapping in the development of public health programs**

Aim 2 of this dissertation is to utilize intervention mapping capitalizing on the other works in this bound dissertation to guide the creation of a parent education program to support enrollment in early intervention. There are six steps to intervention mapping, as seen in Figure 2 (Bartholomew Eldridge, Markham, Ruiter, Fernandez, Kok, & Parcel, 2016). This protocol has been used in various public health topics to drive programs and researchers towards theory-based, community-centered, and
research-driven interventions (Bartholomew Eldridge et al., 2016; Majid, Kim, Cako, & Gagliardi, 2018).

Intervention mapping exists to bridge the translational gap between behavior change theory, research on behavior change interventions, and public health initiatives (Bartholomew Eldridge et al., 2016). Within EHDI, there is a need to translate what research tells us about the benefits of early intervention into information that is useable by parents and providers when making enrollment decisions. At the same time, treating EHDI as a public health service, since it is governed by public health law, represents the level at which an intervention to address this problem would need to be implemented in the population (Early Hearing Detection and Intervention Act of 2017).

Specifically, in terms of EHDI-related research, intervention mapping is uniquely poised to capitalize on the strong tradition of and legislative push for parent, advocate, and professional input on program development (Early Hearing Detection and Intervention Act of 2017). The evaluation of intervention programs is explicitly built into intervention mapping and is unfortunately overlooked in the literature (Majid et al., 2018). This dissertation will contribute to the small base of evaluated intervention mapping programs, providing a better understanding of the impact that the protocol has on program development. The results from the work conducted as a part of Aim 1 informed theory by culminating in a model of why LTI happens in EHDI and further delineating the connection between newborn hearing screening and public health. These foundations are where Aim 2, the intention to pilot a novel LTI program that can be marketed to state-level EHDI implementers, finds its applicability and strength.
Summary. National data on children who are identified through EHDI shows that children are not universally accessing intervention services. These children are at risk of the negative sequelae of language deprivation. This study will help develop an intervention to overcome this through education, as seen in Figure 4.

Overview of thesis chapters

This bound dissertation highlights that EHDI is a public health program and can benefit from considering the connection between EHDI and public health. The manuscripts included in this bound dissertation delineate the start of a programmatic line of research into LTI in EHDI and the need for tailored services to address this need. Called for at the state and national level by a number of different stakeholder groups and legislative actions, EHDI as a system is set to serve the American population for years to come. As a pillar of care within the pediatric audiology community, EHDI ensures access to care across the service continuum, and it is time that there is a concerted effort to look at accessing early intervention for this population.

The following chapters of this bound dissertation will briefly acquaint you with the challenge of LTI in EHDI programs within the United States. Potential contributors to the challenge of LTI and a new method of addressing LTI in EHDI are presented as bound publications. The last chapter takes a holistic approach to this programmatic line of work and the foundation it sets for a productive research career and system change approach to meeting family needs in EHDI.
Background

What is Early Hearing Detection and Intervention?

Early Hearing Detection and Intervention (EHDI) programs are the structure of services in the United States that guide universal newborn hearing screening, referral-based audiologic evaluations, and access to early intervention services for children who are identified as D/deaf and hard of hearing (Early Hearing Detection and Intervention Act of 2017). While the clinical service of newborn hearing screening has been available in some form for over 50 years, the average age of identification for children who were D/deaf and hard of hearing in the late 1980s and early 1990s hovered around two years of age (White, 2019). While diagnostic services were possible, many of the children who would later be identified as D/deaf or hard of hearing were not being assessed at an early age or screened at birth based on risk factors (White, 2019). Children who are not identified as D/deaf or hard of hearing until 2 years of age would not receive the early intervention services they are entitled to by the IDEA, and thus miss critical opportunities for language learning (IDEA of 2004).

In response to this concern, the National Institutes of Health (NIH) recommended the screening of hearing for all newborns (White, 2019). Universal screening works towards ensuring that children have access to the diagnostic evaluations necessary to be identified as D/deaf or hard of hearing. This recommendation was met with a range of responses from adamant disapproval (Bess & Paradise, 1994) to staunch support with implementation research to bolster claims of utility (White & Maxon, 1995). While Hawaii enacted newborn hearing screening legislation in 1990, the implementation of this practice in Rhode Island in 1999 served
as a catalyst for EHDI programs across the country and the rise of universal screenings by highlighting the logistical tools, considerations, and eventual clinical utility of the service (National Center for Hearing Assessment and Management, 2016). Newborn hearing screening programs were developed and implemented at the state level across the country until 2010 when the Early Hearing Detection Act was codified into US public health law (National Center for Hearing Assessment and Management, 2018). The Early Hearing Detection and Intervention Act ensures funding at the state and federal level to administer and track newborn hearing screening, diagnostic, and intervention services (both Part C and non-Part C).

While governed and funded at the national level by the Early Hearing Detection and Intervention Act of 2017, states have the flexibility to design and implement their specific program of screening, identifying, and supporting children who are D/deaf and hard of hearing in the way they deem most fit. The decisions and recommendations of states typically fall in line with the Joint Committee on Infant Hearing’s (2007, 2013, 2019) position statements. The JCIH is a group of professionals working in the realm of early hearing detection and intervention who make recommendations about standards of care based on current research (JCIH, 2019). Arguably, the most referenced guideline from the JCIH is their 1-3-6 paradigm. The expectation is that, at a minimum, all children will receive a hearing screening by one month of age, those who refer will receive a diagnostic evaluation by three months of age, and children who are identified as D/deaf or hard of hearing will be enrolled in early intervention by six months of age (JCIH, 2007, 2013, 2019).
As a nationwide system in 2019, 3,604,761 children (98.4%) had their hearing screened. Of those screened, 61,475 (1.7%) were referred for diagnostic testing, and 5,934 children were identified as D/deaf or hard of hearing (CDC, 2021b). Less than two thirds (3,662) of the children identified as D/deaf or hard of hearing were reported to have enrolled in early intervention services (CDC, 2021b). Current implementations of EHDI have done a phenomenal job in under 30 years of transitioning from a risk-based screening system to that of a universal program, screening over 97% of newborns for hearing differences (CDC, 2021b). Over 79.1% of children who are referred by EHDI for diagnostic testing receive confirmation of hearing levels before three months of age (CDC, 2021b). This increases opportunities for linguistic growth and access compared to their peers who are D/deaf or hard of hearing in the late 1980s who would be waiting another 20 months for support (White, 2019). Over one third of these children who would benefit from early detection of hearing differences are not accessing developmentally appropriate supports (CDC, 2021b). This conflict between increased screening and identification, but a drop-off in early intervention enrollment is counterintuitive to the goals of EHDI, JCIH, and limits the true power of this system.

**What is lost to intervention?**

Children and families who do not make it to early intervention services following identification are lost to intervention (LTI). Specifically, this population is made up of children who have been identified as D/deaf or hard of hearing and have a developmental risk factor according to the IDEA but are not receiving support for themselves or their families. In the current national data set, when expanded descriptors
were implemented, the most commonly reported known reason for children being LTI is “Parents/Family declined the services” (CDC, 2021c).

There is little in the literature that focuses specifically on why families decline early intervention. While barriers to accessing care and program evaluation/improvement programs exist for EHDI, much of the work looks at children who are lost to rescreening or identification. Children who are lost to identification represent a larger population than those who are lost to intervention. Those who are lost to identification present with at least one hearing risk factor (referral on a hearing screening) but include children who are and are not D/deaf or hard of hearing. Works such as Hunter et al. (2016), Cockfield et al. (2012), Yarbrough Watts, Miller, & Murdock (2018) discuss programs aimed at supporting families in navigating the EHDI system following screening and before identification to mitigate lost to identification. Similarly, many studies on barriers to care coincide with national data reflecting logistical challenges in accessing services as drivers behind lost to screening and identification (see Chapter 6 for a robust discussion of this). States have programs to support children and families as they access early intervention care, but this is not being reflected in the literature and efforts to address the problem of LTI are not being elevated and evaluated by the broader scientific community. Work specifically looking at LTI is limited; however, there is a growing body of work coming out of the University of Connecticut that seeks to systematically break down the elements of LTI and ultimately suggest a course of action to best support these children and families (Woodruff & Cienkowski, 2021; Woodruff & Luts, 2020).
Early Hearing Detection and Intervention (EHDI) Within the Medical Home: Implications for Policy and Practice

Torri Ann Woodruff, MS; Tara M. Lutz, PhD, MPH, MCHES

The pediatric medical home is a model to provide quality health care to a child that is coordinated and overseen by a team of professionals who are grounded in family-centered practice (Cleveland Clinic, 2012; Munoz, Nelson, Bradham, Hoffman, & Houston, 2011). The medical home can be a centralized, consolidated, and comprehensive approach to address concerns for a child and can bolster the early intervention goals of Early Hearing Detection and Intervention (EHDI; Buchino et al., 2019; Munoz, Shisler, Moeller, & White, 2009; Munoz et al., 2011). With early access to screening information for children who are D/deaf or hard of hearing, the medical home plays a role in early diagnostic services and follow-up care that are critical to EHDI. This connection allows for discussion of how the medical home can exist and be supported within the context of existing service provision systems as a potential preemptive intervention to address the needs of children and families. By reviewing publicly accessible materials, the state of Connecticut can be used as a case study to look at various methods of medical home engagement with the outcome of supporting EHDI-based benchmarks (Connecticut Department of Public Health, 2014, 2018). At the same time, a novel means of data collection through the medical home is proposed. Key words: deafness, Early Hearing Detection and Intervention, hearing, medical home, patient care team, patient-centered care

**WHAT IS A MEDICAL HOME?**

The medical home is not a physical location. It is a method for the organization and provision of health care (Asarnow, Kolk, Miranda, & Kazak, 2017). The concept of the medical home combines medical professionalism with care coordination and is the foundation for family-centered care. In a prototypic pediatric medical home for a child who has been identified as D/deaf or hard
of hearing, the primary care provider (PCP) is a pediatrician and there is an interdisciplinary team of related professionals, such as speech pathologists and developmental pediatricians, who follow a child and his or her family to provide managed, comprehensive, individualized care during all phases of diagnosis and treatment (Braddock, Snyder, Neubauer, & Fischer, 2012; Cleveland Clinic, 2012; Munoz, Nelson, Bradham, Hoffman, & Houston, 2011). However, it should be noted that in the reality of care provision, specifically for children with special health care needs living in rural environments, general practitioners, nurse practitioners, and physician assistants are more likely to be the individual providing care (Skinner & Slifkin, 2007).

Team-based care is the model of service provision where services are developed and provided by a small workgroup with shared responsibility and collective identity related to the support of the child or family (Coufal & Woods, 2018). Within the team, various specialty areas, represented by members, utilize a collaborative process with each discipline providing context and referrals for the others. In the “Medical Home Portal” associated with a number of states, including Montana and the Rural Institute, information for providers includes directories for audiological referral, links to protocols for lost to follow-up reduction, and testimonials from providers in different professions (including a pediatrician and a social work student; Early Hearing Detection and Intervention Program, 2012; Medical Home Portal—Montana; 2020a, 2020b). For example, an audiologist working on proper left and right hearing aid insertion, according to color markers on the devices with a child who is D/deaf or hard of hearing and legally blind, can benefit from the knowledge that a pediatric ophthalmologist, another member of the team, has about that child’s access to color information.

Outside of professional medical knowledge and a team approach, the tenets of the medical home include comprehensive care, patient-centered services, coordinated care, and a focus on quality and safety (Hing, Kurtzman, Lau, Taplin, & Bindman, 2017). For example, in the population of older adults who use Medicare, access to a medical home, and therefore the continuity of care provided by the medical home, has been associated with a decrease in Medicare spending (Perry, McCall, Wensky, & Haber, 2016). Although the medical home presents as a cost-of-care initiative in adult populations, the concept itself has its early roots grounded in strategically supporting children with special health care needs and has now evolved to focus on comprehensive care for all children throughout the life course by adapting as individuals grow and develop (American Academy of Pediatrics [AAP], 2002; Asarnow et al., 2017). As such, the health care provided by the medical home not only is responsive to immediate medical needs but also has preventive and long-term applications (AAP, 2002; Asarnow et al., 2017).

When working with children with special health care needs, the interdisciplinary, team-based medical home model incorporates all aspects of the aforementioned service delivery model to provide accessible, continuous, family-centered, culturally effective, and compassionate health care (AAP, 2002; Asarnow et al., 2017; & Farel, 2007; Nickel, Cooley, McAllister, & Sampson-Fang, 2003). The medical home for children with special health care needs goes beyond the basic tenets of the medical home by including uniquely family-oriented components. See Figure 1 for a graphical representation of this interconnectivity.

These additional four parameters are modifications to the standard in order to account for the unique needs of the family and the impact of entitlement services, such as early intervention and universal screening. Concerning pediatric hearing levels, it is also critical to ensure that decisions made around early intervention and language access are made proactively, based on potential need and access concerns, rather than in response to delay or deprivation (American Academy of Pediatrics EHDI Experts and Staff, 2019).
WHAT IS EARLY HEARING DETECTION AND INTERVENTION?

At birth, all children in the United States have the opportunity to be screened for a number of diagnoses. At its core, newborn screenings (NBS) are a way for the health care community to identify newborns who may require additional testing or services. Boyle, Bocchini, and Kelly (2014) highlighted that this is not a test to see whether a child has a specific diagnosis; instead, it is “a complex system that includes the initial screen to identify infants with a high probability of having the condition, a follow-up diagnostic test to identify true cases, and the ongoing treatment of the condition” (p. 961).

For NBS, the Recommended Uniform Screening Panel (RUSP) consists of a core 35 diagnoses including metabolic, endocrine, hemoglobin, and other disorders that the Secretary of the Department of Health and Human Services recommends being screened for at birth across the United States (Boyle et al., 2014; Health Resources & Services Administration, 2019). From there, states can choose to expand on those to meet the needs of their population. Since the first iteration of the RUSP, hearing loss has been one of the core conditions that is screened for at birth through newborn hearing screening ([NBHS]; Grosse et al., 2017; Health Resources & Services Administration, 2019; National Institutes of Health, 2017). The incorporation of hearing loss as part of the RUSP demonstrates the importance of identifying children as D/deaf or hard of hearing early, as undiagnosed hearing levels can have a profound impact on development. Yet, as summarized by DesGeorges (2003), “deafness is different” and “[t]he journey a family goes through upon the discovery of a child with hearing loss very soon takes a departure from the typical ‘medical model’…” (p. 90). With this, discussions around the impact of hearing need to consider there are multiple meanings behind hearing levels in addition to language development, such as culture and diversity (Bauman & Murray, 2009).

Birth through newborn hearing screening is a subsection of NBS that is conducted as part of the Early Hearing Detection and Intervention (EHDI), as described most recently at the federal level in the Early Hearing Detection and Intervention Act of 2017. This Act codifies the role of NBHS using broad statements of requirement for program implementation and goals where, embracing federalism, states can explicitly delineate how these requirements will be implemented in the form of guidelines and protocols. In accordance with the Act, state funding opportunities were created.
to support states to develop and monitor screening, diagnosis, and intervention services for children who are D/deaf or hard of hearing while also expanding the evidence base for recommended practices for effective models of these systems. The Act emphasizes training personnel and the importance of family-centered decision-making. With this emphasis on family-centered decision-making, state-level implementations of EHDI must take into account the unique elements of hearing levels referenced by DesGeorges (2005) and meet a wide range of needs related to the cultural implications of hearing levels.

States are required to collect EDHI data (Early Hearing Detection and Intervention Act of 2017). These data are reported to the Centers for Disease Control and Prevention (CDC) in order to improve data collection, conduct applied research on child outcomes, ensure the quality of programs, support systems in implementation, and take an aggregate look at screening, diagnosis, and intervention utilization (CDC, 2019c; Early Hearing Detection and Intervention Act of 2017). Based on state-reported data, the national prevalence for hearing levels outside of the typical range in children during 2016 was consistent with past years at 1.7 per 1,000 at the national level (CDC, 2013, 2014, 2016a, 2016b, 2019c, 2019d, 2019e). At the state and territory level, incidences ranging from 0.0 per 1,000 in Palau to 11.1 per 1,000 in the Marshall Islands were reported (CDC, 2019c, 2019d). In the state of Connecticut, the incidence was 2.2 per 1,000 children screened (CDC, 2019d). Yet broadly, hearing changes and differences, including adult-onset hearing loss, are termed “a hidden disability” and people tend to not be aware or fully informed of newborn hearing screening services (Cohen, Labadie, & Haynes, 2005; Krishnan, Lawler, & Van Hynie, 2017; Mackenzie & Smith, 2009; Ravi, Gunjewate, Yerraguntla, Rajashekar, & Lewis, 2016).

With the wide range of perspectives, cultures, labels used, and education on EHDI, a brief discussion of these terms is warranted. Hearing loss is a common descriptor used to define hearing sensitivity that is outside of the typical range and is the term that is used explicitly by the RUSP (American Speech-Language-Hearing Association, 2020; Health Resources & Services Administration, 2019). The use of the term “hearing levels” comes from the Joint Committee on Infant Hearing (2019) acknowledgment that this terminology may be more culturally sensitive and in the case of congenital hearing levels, there has been no hearing “loss.” The phrase “D/deaf or hard of hearing” throughout this document is implemented with the same goal for cultural sensitivity and inclusion as the Joint Committee on Infant Hearing (2019). Utilizing this phrase and the combination of capitalization and terms “deaf” and “hard of hearing” addresses the wide range of labels and cultural identities that may be encompassed by the population that is being discussed (National Association of the Deaf, 2020).

Encapsulated in the first three goals of the National Center for Hearing Assessment and Management’s (2019a), national goals for EHDI is a three-pronged approach to services that is in line with expectations in the Early Hearing Detection and Intervention Act of 2017 and recommendations from the Joint Committee on Infant Hearing (2007), consisting of hearing screening, diagnosis of hearing levels, and interventions services where appropriate (American Academy of Pediatrics, 2018). These milestones are tied to the timeline for delivering services: All newborns should receive a hearing screening by 1 month of age; for those who are referred on the basis of the results of their screening, hearing levels should be diagnosed by 3 months of age; those who are identified as D/deaf or hard of hearing should have early intervention services initiated by 6 months of age.

The first milestone is the screening of all newborns, regardless of hearing-related indicators or risk factors, by 1 month of age (White, 2019). Of the 3,852,497 births reported to Vital Records in 2016, 97.5% were screened through a state-level implementation of EHDI and 94.8% were screened by 1 month of age (CDC, 2018b, 2018d). In
the 1990s, with the improvement and implementation of otoacoustic emissions and auditory brainstem response (ABR) testing, screening protocols with improved diagnostic value and economic administration became possible (White, 2019). Auditory brainstem response testing is a common protocol that uses physiological responses to sounds in order to estimate hearing levels without the need for subjective behavioral responses. An ABR can provide diagnostic information around hearing levels, including type and degree (Purdy & Kelly, 2014). For 50%-60% of infants, a genetic etiology for present hearing levels can be identified (CDC, 2018a). However, etiology is not directly discernible from hearing screening or audiometric assessment alone.

These screenings lay the foundation for the second milestone of EHDI that children who are referred on their NBS receive a diagnostic evaluation and diagnosis if indicated by 3 months of age (White, 2019). If a child’s NBHS results indicate the need for further testing to determine hearing levels, both the child and the family are referred to receive diagnostic assessments that may occur during a separate appointment and potentially at another facility entirely. At this stage of the family’s journey within EHDI, it is possible to track changes in the age of identification that occur during periods where EHDI is enacted to direct children who are D/deaf or hard of hearing to diagnostic services. White (2019) presents a chart looking at studies from the 1980s into the 21st century reporting on the mean age of identification for children who are D/deaf or hard of hearing. From 1987 to 2013, the mean age of diagnosis dropped from its peak at 35 to 2 months (White, 2019).

Diagnosing children at earlier ages leads directly into the third milestone of EHDI that children who are D/deaf or hard of hearing receive early intervention services by 6 months of age (White, 2019). In 2016, 67.3% of all children who were identified as D/deaf or hard of hearing were enrolled in early intervention services in their state by 6 months of age (CDC, 2018c). This statistic equates to more than half of the children identified as D/deaf or hard of hearing in 2016 enrolling in early intervention programs over a year before their 1987 counterparts would even be identified at, between 19 and 35 months of age (White, 2019). These early months can be used in services to support language development, regardless of modality, and this is regarded as critical for improving the outcomes of these children (Munoz et al., 2011). See Figure 2 for a visual representation of the timeline for these services.

The next three national goals for EHDI transition from service delivery milestones and into systems of care. The fourth goals centers on addressing the needs of children with late-onset, progressive, or acquired hearing loss (National Center for Hearing Assessment and

![Figure 2. A visual timeline of services related to newborn hearing detection and intervention (AAP, 2018; Cockfield, Garner, & Borders, 2012; Joint Committee on Infant Hearing, 2007).](image-url)
Management, 2019a). For these children with late-onset or progressive hearing loss, performance objectives call for identification by all providers of individuals with risk factors and the monitoring of these children at the state level (National Center for Hearing Assessment and Management, 2019a).

For children with acquired hearing loss, a state-level identification program is requisite to move children through the identification and intervention procedures that meet their needs (National Center for Hearing Assessment and Management, 2019a). Of specific relevance for this article are goals five and six, which are centered around the support of a medical home and data tracking and surveillance to address lost to follow-up (National Center for Hearing Assessment and Management, 2019a).

**HOW CAN THE MEDICAL HOME BE INTEGRATED WITH AND BE SUPPORTIVE OF EHDI?**

For children who are diagnosed as D/deaf or hard of hearing, the key members of the care team can include birth hospitals, families, the PCP, audiologists, otolaryngologists, geneticists, speech-language pathologists, educators, early interventionists, and care coordinators all within the medical home (Connecticut Department of Public Health, 2014; Joint Committee on Infant Hearing, 2007). Other members of the care team who are usually brought in and coordinated by the medical home to meet the specific needs of children with co-occurring diagnoses include ophthalmologists, developmental pediatricians, neurologists, cardiologists, and nephrologists (Connecticut Department of Public Health, 2014; Joint Committee on Infant Hearing, 2007).

With this many components to the EHDI system, the idea of teaming among providers and families co-occurs with the implementation of the medical home, given the shared need for collaboration among these individuals for children who are D/deaf or hard of hearing. This need and overlap are consistent with the fifth national goal of EHDI, to ensure medical homes for all children identified. See Figure 3 to observe overlap in service providers within EHDI and the medical home.

This care team begins assembling at the time of referral when the birth hospital (or transfer hospital) shares the screening results with the family, the PCP, and the state department that implements EHDI. This step is critical, given that one of the performance objectives for EHDI programs includes the documentation of a child’s PCP and documentation that information about NBS has been shared.

**Figure 3.** Potentially shared service providers under a medical home and Early Hearing Detection and Intervention. PCP = primary care provider. (Connecticut Department of Public Health, 2014; Joint Committee on Infant Hearing, 2007).
with this provider (National Center for Hearing Assessment and Management, 2019a). Yet, when assessments and screenings, including hearing screenings, are performed external to the PCP, there can be a communication breakdown where results are not provided back to the PCP and the medical home. This lack of communication can limit the PCP’s understanding of the need to refer children who are D/deaf or hard of hearing to specialties (such as genetics and otolaryngology; Munoz, Shisler, Moeller, & White, 2009; Munoz et al., 2011).

Challenges in communication are further exacerbated by the lack of knowledge PCPs have reported around hearing-related topics such as hearing aids and cochlear implants (Munoz et al., 2009). Lack of knowledge severely impacts PCPs’ ability to follow through with their duty to link families and children to services and is a factor that is used in the evaluation of the medical home for children who are D/deaf or hard of hearing (Bright Futures, 2019; National Center for Hearing Assessment and Management, 2019a). Among this list is a performance indicator for the National EHDI goal of establishing a medical home for every child who is identified as D/deaf or hard of hearing, which is “documentation in each family plan or IFSP of collaboration between the early intervention systems and the medical home” (National Center for Hearing Assessment and Management, 2019a). This required documentation supports using the medical home as a means of reducing lost to follow-up by ensuring that the medical home is explicitly tied to early intervention services.

Generally, the birth hospital has the responsibility of ensuring that the state-level agency responsible for the administration of EHDI and the PCP receives the screening results (Connecticut Department of Public Health, 2014; Rhode Island Department of Health, 2014; S. Stone, personal communication, April 24, 2019). These results are then provided to the medical home or PCP. It should be noted that the procedure for the notification of the state-level agency and how that information is shared with a medical home or PCP may vary from state to state with specific forms/flow charts (e.g., Iowa, Georgia, and Rhode Island), personnel (e.g., Georgia), or more general requirements around sharing these data through letters, newborn, or discharge summaries (e.g., Pennsylvania, Virginia, and Connecticut); however, they all share the same requirement for the sharing of screening results (Connecticut Department of Public Health, 2014; Early Hearing Detection and Intervention Act of 2017; Georgia Department of Public Health, 2013; Iowa’s Early Hearing Detection & Intervention System, 2008; Joint Committee on Infant Hearing, 2007; Pennsylvania Department of Health, 2013; Rhode Island Department of Health, 2014; Virginia Department of Health, 2011; S. Stone, personal communication, April 24, 2019).

For example, specifically in the state of Connecticut’s guidelines for EHDI, a medical home should be established when a child is referred for his or her NBHS. The medical home is established by sharing results among the individuals who will comprise the medical home (Connecticut Department of Public Health, 2014). Per state guidance, it is encouraged that the appointment for the child to undergo diagnostic evaluation by an audiologist be scheduled prior to birth hospital discharge (Connecticut Department of Public Health, 2014). This can be done by the birthing hospital or, once the medical home is established and the role of EDHI is assumed within that care coordination, done so via referral by the PCP. The role the medical home plays in coordination of care is highlighted when the need for specialists to be a part of the care team is present. Of the roughly 50% of children with a genetic etiology for their hearing levels, one third have a syndromic diagnosis (Ridley, 2009). Compounding this with the fact that 30%–40% of all children who are D/deaf or hard of hearing will present with additional developmental delays or disabilities, there is usually a need to have multiple health care specialists and providers on a care team managed in a medical home to appropriately
address the individual needs of the child. For example, an ophthalmologist should be part of the medical home for a child with a diagnosis of Usher’s syndrome as it is associated with visual and auditory system differences (Connecticut Department of Public Health, 2014; Joint Committee on Infant Hearing, 2007). It is the medical home that can follow children and their families throughout the life course and can use referrals to specialists to meet the child’s individual needs. Having a medical home that includes the PCP supports the reinforcement of early intervention, diagnostic direction, and communication option messages that can come from all members of the team (American Academy of Pediatrics EHDI Experts and Staff, 2019). When assessing communication between team members, Munoz et al. (2011) found that collaboration between providers is considered one element that strengthens the application of the medical home in EHDI. No one provider can address all areas of need within the family or child. Given the complex nature of pediatric hearing and the number of families served by EHDI, the team-based medical home is requisite to quality health care.

State policies can reinforce the role of the PCP within the medical home. Although not explicitly tied to EHDI implementation, of the 19 states awarded grants for State Disability and Health programs from the CDC, eight refer to medical homes explicitly on their online newborn hearing screening page within the office or department that manages the implementation of EHDI (CDC, 2019b; Iowa Department of Public Health, 2020; Kansas Department of Health and Environment, 2019; Maryland Department of Health, n.d.; Michigan Department of Health & Human Services, 2020; Montana Department of Public Health and Human Services, n.d.; Ohio Department of Health, 2019; Oregon Health Authority, n.d.). Connecticut makes this reference on its webpage as well, citing that all provider documents have been “geared toward . . . Medical Home Initiatives for Children and Youth with Special Healthcare Needs networks . . .” (Connecticut Department of Public Health, 2020).

However, across these different states and implementations, the degree that the concept of medical home is included varies (Iowa Department of Public Health, 2020; Kansas Department of Health and Environment, 2019; Maryland Department of Health, n.d.; Michigan Department of Health & Human Services, 2020; Montana Department of Public Health and Human Services, n.d.; Ohio Department of Health, 2019; Oregon Health Authority, n.d.).

Some states have strong statements on the need/inclusion of medical homes, such as the state of Michigan highlights in its affirmation that “[t]he primary care provider (PCP) directs and coordinates the evaluation and referral process within the child’s medical home,” followed by a list of steps and links to referral signs and risk factors (Michigan Department of Health & Human Services, 2020). Other states also provide explicit practice guidelines/learning opportunities around the integration of the medical home with EHDI such as Montana where providers are linked to the Montana Medical Home Portal with access to practice guidelines, service provision algorithms, and educational resources on hearing and other newborn diagnoses (Montana Department of Public Health and Human Services, n.d.).

State-level policies, recommendations, and guidance documents support the Joint Committee on Infant Hearing’s (2007) position statement that encourages birth hospitals to also gather information about a child’s PCP at the time of the screening in order to share results and thus reinforce the need for PCP referrals to audiology (Connecticut Department of Public Health, 2014). This sentiment has been echoed by EHDI coordinators. As a group, EHDI coordinators are individuals at the state level who are responsible for the oversight, implementation, and management of grants, laws, and rules around their state’s specific implementation of EHDI (National Center for Hearing Assessment and Management, 2019b). Coordinators have reported that involvement of the PCP and other related fields within the administration of
EHDI bolsters the involvement of the medical home from a policy perspective (Munoz et al., 2011). The medical home is vital for the coordination of services for these children and families. As such, it occupies a position as the central hub for information about the child’s health, including hearing. There are various approaches to strengthening the integration of EHDI with the medical home. In this discussion, two strategies that have been implemented in the state of Connecticut are discussed along with one potential extension to further the medical home.

**FAMILY INCLUSION IN THE MEDICAL HOME THROUGH INFORMATION SHARING AND PARTICIPATION**

Families of children who are D/deaf or hard of hearing play a critical role in service access. Under the current structure of Part C of the Individuals with Disabilities Education Act (IDEA), the Individualized Family Service Plan reaffirms both the inherent connection between families and services and the need for care outside of the patient-centered realm (Individuals with Disabilities Education Act of 2004). Family members are members of the team and actively engaged in the medical home through family-centered care. Within EHDI, there is room for state implementation to learn from the IDEA and Section 504 of the Vocational Rehabilitation Act in terms of family engagement. IDEA and Section 504 have procedures for parents and caregivers to provide input into the planning for their child (request reevaluations or requirements that they are present for planning meetings) in a way that is not explicitly laid out to the same degree in the current federal EHDI guidance (Connecticut Office of Early Childhood, 2016; Connecticut State Department of Education, 2007; Early Hearing Detection and Intervention Act of 2017; Office for Civil Rights, 2018; Rehabilitation Act of 1973; Wells, 2012).

The explicit requirement to include parents and caregivers in the development of an Individualized Education Program (IEP) or 504 plan per federal legislation allows the family to be actively involved and provide insight. Broadly, both IEPs and 504 plans are developed with input from a team that includes the family and delineates the services/accommodations that a child utilizes to access his or her education (Connecticut State Department of Education, 2007; Office for Civil Rights, 2018). Similarly, in Connecticut, the Family Plan of Care for Infants is a document that can be used voluntarily by parents and providers (Connecticut Department of Public Health, 2018). This document is available for parents and providers to print off the Internet on the Connecticut Department of Health web page (Connecticut Department of Public Health, 2018). It mimics IEPs and 504 plans in terms of family involvement and creates a space for families to note the relevant components of the medical home such as service providers, interventions, and needs (Connecticut Department of Public Health, 2018). This type of document, maintained by or with the family, may provide an opportunity to have consistent messaging around a child’s diagnostic status, plans for care, and referrals and can help overcome the communication and education challenges that have been identified by Munoz et al. (2009, 2011) for PCPs when it comes to referral of children and families. However, the major difference is that although the Family Plan of Care for Infants is a recommended tool, it is not required to be used during the process of screening or diagnosis. Because EHDI is the first diagnosis and support program related to hearing for families who will potentially utilize IEPs or 504 plans in the future for their child, continuity of parental involvement across both educational and health systems may be beneficial.

To monitor and assess the extent to which states incorporate EHDI recommendations and expectations for service provision, at the state level, policy makers need to acknowledge their role in the lives of families as the first source of information around their child’s hearing and the role that language access plays in development. Families may benefit from
connections to support services and community programs. Such services can include parent-to-parent networks, support groups, and educational programs at local, state, regional, and national levels. Research and programs need to be directed toward the explicit support and empowerment of families during this process and the inclusion of parent support and parent-to-parent representation in the medical home as a part of the care team.

**ENHANCING PARTICIPATION OF PRIMARY CARE PROVIDERS IN THE MEDICAL HOME THROUGH PROVIDER EDUCATION**

The medical home is an informational hub that can contribute to meeting EHDI screening, diagnostics, and intervention milestones, along with data collection needs. Children need to be appropriately referred to the specialty groups that meet their needs, and physicians, both PCPs and specialists, must be made aware that these co-occurring needs can and do exist in pediatric hearing. From these referrals, the appropriate transition to intervention services may be possible for both the child and the family. This furthering in the involvement of the medical home with EHDI is predicated on PCPs and other members of the medical home having a working knowledge of EHDI and pediatric hearing levels. However, for medical home involvement to be achieved, the gaps in physician training and the resulting educational needs of PCPs must be addressed. From there, specialists can be connected to educational resources and professional development opportunities within the context of the medical home.

An approach that is being implemented in many states, including Connecticut, is AAP’s Chapter Champions who serve as liaisons between pediatrician PCPs and the implementation of EHDI (AAP, 2017; Munoz et al., 2009, 2011). Along with early identification of the PCP for communication purposes, the use of Chapter Champions has been perceived by state EHDI coordinators as a means of strengthening the role of the medical home and EHDI as a whole (Munoz et al., 2011). The role of Chapter Champions is educational and connective in nature (AAP, 2020; Munoz et al., 2009). Chapter Champions are responsible for “educating fellow physicians and other stakeholders through grand rounds, newsletters, and personal contact” while working to influence state-level policy (AAP, 2020; Munoz et al., 2009). The information presented to providers who are part of medical homes needs to be succinct and follow the foundational topics of common missteps in EHDI, such as basic audiological knowledge, hearing management, and outcomes for these children and families (Munoz et al., 2009; Stewart & Bentley, 2019). Although this program is implemented by a pediatrician-based organization, statements around “other stakeholders” imply the potential for branching out and including nonpediatrician care providers.

One possible extension of this educational model that has been implemented is just-in-time education for providers. This approach has been implemented by the EHDI council of Kentucky as a way of providing directed education on pediatric hearing. When a PCP is part of a medical home for a child identified as D/deaf or hard of hearing or having risk factors around hearing levels, information is sent directly to the provider specifically about hearing (Buchino et al., 2019). The state EHDI team sends physicians just-in-time packets on hearing with guidelines for assessment in these populations (Buchino et al., 2019). This approach may be further applicable, given that it comes from a credible source within the provider’s state of practice and is not a formal class or meeting, as those can be challenging to access, given the time restraints of being a practicing physician (Munoz et al., 2009).

At the same time, team members of a medical home need to be cognizant of how each provider, within the context of the group, can meet needs associated with decreased access to services in the form of lost to follow-up and lost to intervention. Recent work in South Africa implemented qualitative interviewing to assess the factors that impact decisions to
follow up for newborn hearing services (Kanji & Krabbenhoft, 2018). Parents in this study simultaneously reported that having communication with the audiologist supported them accessing the service while having to travel for appointments in various buildings/locations hindered them (Kanji & Krabbenhoft, 2018). The medical home is already a center for communication and can further capitalize on this strength by working to create location-based networks where services can be accessed as a group or potentially in the same day/area. This impact may further the support that medical homes provide to rural families (Cunningham et al., 2017). Globally, the impact of an EHDI-inclusive pediatric medical home bolsters the goal of EHDI service delivery milestones through the support of continued collaboration between professionals and ultimately appropriate connections to services and providers to ensure needs are met in a family-centered and culturally respectful manner.

CENTRALIZATION OF DATA COLLECTION PROTOCOL FOR THE FUTURE

The federal EHDI system and state-based implementations, taken together as a public health initiative, continue to move toward meeting the screening and diagnosis milestones for children who are D/deaf or hard of hearing. However, these gains in screening and identification have not translated into these children universally enrolling into early intervention services as currently measured. The incorporation of EDHI into the medical home can support the streamlining of data collection and bolster the early intervention milestone of EHDI and national goals around medical home maintenance and data tracking.

Currently, accessing intervention services after diagnosis of hearing levels is calculated by determining the reported number of children who have enrolled in intervention programs provided by Part C of the IDEA and non-Part C services. However, this information is incomplete and does not provide insight into where children and families are lost in the transition into intervention services. Having a comprehensive indicator for intervention services that delineates specific points of entry into early intervention (e.g., Part C, non-Part C insurance-based, private pay fee for service, community organizations, and informal supports) may help determine where services are being accessed and which services are or are not being utilized to meet the needs of children and families.

Although reported at the national level as enrollment in Part C and non-Part C early intervention enrollments, this may not be representative of the full breadth of data. The services that are accounted for as non-part C in current publications are not delineated at the national level and may vary depending on the state’s data collection protocol (CDC, 2018e; National Center on Birth Defects and Developmental Disabilities, personal communication, June 13, 2019, and, July 5, 2019). This variability means that all states may not be reporting intervention data based on the same definition of intervention outside of Part C enrollment. Although this may be measuring some children who pursue interventions based on hearing levels, it may not universally account for those who access private services and are not reporting those who utilize informal supports across state lines. These informal supports may include parent-to-parent organizations or culturally Deaf families that have the infrastructure needed to provide communication access for a child. The current method of noting intervention services could be artificially inflating lost to intervention values and further complicate attempts to improve access and utilization of intervention services.

Developing, improving, and supporting data collection procedures to accurately capture all early intervention providers in the state (publicly funded, privately funded, and informal) would be logistically challenging. However, this could be a more comprehensive indicator of actual intervention service utilization and serve to support the continual monitoring of children in an effort to identify those who may be lost to follow up in
the EHDI system. One approach to address the need for streamlined data collection and capturing all early intervention access points would be to move from the current practice to a centralized model of care delivery where the medical home, as the hub for all services, is solely responsible for the input of data into records system(s). The medical home, regardless of the clinical background of the PCP, has access to all relevant providers, should already be following these children, and has a scope of practice that is consistent with data collection (Joint Committee on Infant Hearing, 2007).

The medical home provides services regardless of funding avenue, cultural identity, or specific needs to be met. Questions around development, screenings, and intervention services are consistent with case history expectations as laid out by the CDC (2019a), the AAP’s Bright Futures (2019) program, and the sharing of information that should be occurring within a team regarding services provided. This is the transition of reporting requirements from multiple individuals across every child to the medical home. Thus, this type of reporting does not fundamentally change the clinical encounter of any provider and it intrinsically supports the fifth and sixth goals of EHDI by essentially making a medical home, with the connection to other services and coordinated care, mandated by way of improving data tracking and lost to follow-up.

Centralizing the point of data reporting to the medical home can lead to redundancy in reported information (e.g., a speech-language pathologist sending his or her session notes to the PCP indicating intervention is being pursued and a parent reporting to the PCP that he or she is receiving intervention services within an appointment). This

Figure 4. Outline of article and three different approaches to medical home integration with Early Hearing Detection and Intervention.
redundancy supports the accuracy of data reporting through the use of corroborating sources and limits the impact of parental report while recognizing the wide variety of services and interventions available to families through public and private programs.

IMPLICATIONS

The implementation of EHDI as part of medical homes can be mutually beneficial. Medical homes are valuable as points of data collection and service coordination for EHDI. Information from EHDI, including screening results, supports the medical home in developing a comprehensive understanding of the unique needs of each child and family and a plan of care to address those needs and others. In addition, EHDI can provide vital hearing-related educational resources to ultimately provide better care to the child within the medical home. This educational resource role of EHDI within the medical home can be further strengthened by the continuing educational opportunities hosted by states, national conferences, and technical assistance agreements. Furthermore, PCPs may not recognize the value of these educational opportunities or, due to their schedules, have the time to access them until there is a need that calls for EHDI-related expertise (Munoz et al., 2009). Based on online state-level publicly accessible policies and materials from Connecticut, there is the possibility that policies and initiatives to foster the medical home have been missed or overlooked in this document. However, by reviewing publicly accessible materials, this review is poised to operate with similar information readily available to providers and families (Figure 4). When examining medical home supports, the inclusion of the medical home through information sharing, family participation, and provider education is a step toward full integration with the goal of meeting EHDI-based service provision milestones. The novel approach presented here is consistent with current moves regarding the inclusion of the medical home in EHDI. As support and recognized need for the medical home grow, EHDI is poised to benefit from continued systems improvement.

REFERENCES


Chapter 3

Readability of Online Hearing-Based Early Intervention Materials
Torri Ann Woodruff, MS1
Kathleen M. Cienkowski, PhD1
1Department of Speech, Language and Hearing Sciences,
University of Connecticut, Storrs, CT

Abstract

Purpose: A quantitative readability assessment of currently accessible online materials for parents of children who are deaf or hard of hearing (DHH).

Design: Consistent with current recommendations discussing grade-level of materials, Flesch-Kincaid Grade Level (FKGL) analysis, along with five other related measures, was conducted for each website. These analyses provide a readability score for each of the websites analyzed.

Study sample: The first five pages of results from a Google search of “early intervention deaf” and “early intervention hard of hearing” were compiled for readability assessment.

Results: Sixty-three websites were included in the analysis. Following article modification, inter- and intra-rater reliability were excellent (p < .002). All websites were analyzed based on FKGL, intended audience, page displayed on, and producer. All but one of the websites (n = 62) were written at a higher level than the recommended 6th-grade reading level (m = 12.62, SD = 2.65). There was no significant impact of the search page, intended audience, or producer on FKGL (p > .1).

Conclusion: Currently accessible online resources for parents looking at early intervention for children who are deaf or hard of hearing (DHH) are written at a level that may not be accessible. Materials may benefit from being revised and edited with readability and health literacy recommendations in mind.

Keywords: readability, early intervention

Acronyms: ARI = Automated Readability Index; CLI = Coleman-Liau Index; DHH = deaf or hard of hearing; ELD = early hearing detection and intervention; FKGL = Flesch-Kincaid Grade Level; FRES = Flesch Reading Ease Score; IFSP = Individualized Family Service Plan GFI = Gunning-Fog Index; LFUD = lost to follow-up/documentation; SMOG = Simple Measure of Gobbledygook

Acknowledgements: The authors are grateful to Jennifer Roy, who worked as a research assistant during the article modification stage of this study. The authors declare they have no conflicts of interest. This research did not receive any specific grant from funding agencies in the public, commercial, or not for profit sectors.

Correspondence concerning this article should be addressed to: Torri Ann Woodruff, MS, 2 Alethia Drive, U-1085, Storrs, CT 06269. Email: torri.woodruff@uconn.edu; Phone: 860-420-2161.

In 2017, Early Hearing Detection and deaf or hard of hearing (DHH) (EHDI) programs across the United States identified 6,537 children as having hearing thresholds outside of the typical range (CDC, 2019a). EHDI is a public health service that applies screening and follow-up care to the general population to maintain and improve the community’s overall health. The first goal of EHDI is to ensure that all children, regardless of risk factors, receive a hearing screening, ideally before one month of age (Joint Committee on Infant Hearing, 2019; White, 2019). For children who refer on their hearing screening, the goal is to schedule diagnostic evaluations by three months of age. Following the identification of children as deaf or hard of hearing (DHH), early intervention services are initiated as indicated.

At any point in this system of referrals and service providers, a child can be lost and not made it to the next clinically indicated step. These children who are lost to follow-up/documentation (LFUD) can contribute to the number of individuals who have delayed access to early intervention services. One way a child is LFUD is that they have been identified as being at risk for hearing differences via traditional screening measures, yet hearing levels have not been confirmed. This population can consist of children who are DHH and children who, for idiopathic or transient reasons, are referred for further testing after their initial screenings while they have hearing levels in the typical range. Alternatively, a child can be LFUD when they have been identified as DHH and have not enrolled in early intervention services. Children being LFUD after identification and before early intervention may be the most troubling element of LFUD.
Despite the federal mandate to provide hearing-related intervention services, children continue to go without support services and early intervention. Specifically, 2,837 (34.5%) children identified as DHH through EHDI programs across the United States did not receive early intervention services in 2017 and may be at risk for language deprivation (CDC, 2019b). Individuals who experience language deprivation may encounter challenges in learning languages, employment, and social-emotional development (Hall, 2017). In 2017, the most commonly reported reason for children not to get early intervention services, aside from “unknown,” is parents declined the service altogether (CDC, 2019b). The 2,837 members of this population have a developmental risk factor, and their families refuse developmental support.

Within the Early Hearing Detection and Intervention Act of 2017, the information made accessible to parents is explicitly discussed in terms of being “accurate, comprehensive, and, where appropriate, evidence-based, allowing families to make important decisions for their children in a timely way....” This statement is in stark contrast to the idea that one potential source of this disengagement with early intervention might be a lack of information about the role of early intervention. Within the literature, there are reports that parents of children who are DHH are looking for and/or need more information on early intervention topics such as what early intervention is (Khoza-Shangase, 2019; Larsen et al., 2012), the EHDI process (Krishnan et al., 2019; Pendersen & Olthoff, 2019), hearing aids and assistive technology (Haddad et al., 2019; Van der Spuy & Pottas, 2008), and parental support services (Haddad et al., 2019; Van der Spuy & Pottas, 2008). This expressed need for information may be indicative of a lack of accessible information to support decision making.

Aside from the call for appropriate information within the Early Hearing Detection and Intervention Act of 2017, various governmental and non-governmental organizations have made recommendations on how to ensure materials are accessible to the general public and available to be used in decision making. It is recommended that all health information, such as EHDI-based websites, be written at no greater than a 6th-grade reading level (Saferer & Keenan, 2005; Sax et al., 2019; U.S. Department of Health and Human Services, n.d.; Weiss, 2006). The purpose of this study was to assess the readability of commonly accessible information for parents on early intervention for children who are DHH using a similar methodology to Sax et al. (2019). From here, there can be future work to look at the necessity of editing online materials for increased readability and may serve as a mechanism for addressing lost to follow up. The potential compounding of inaccessible informational materials with a need for more information for parents of children who are DHH merits evaluation.

The concept of literacy is linked to health literacy. Health literacy is the skill of taking in, processing, and understanding health-related content such as information and needed services (American Speech-Language-Hearing Association, n.d.). The type of language used when providing information must be consistent with an individual’s literacy level. The literature has noted that audiologists tend to speak at a level of complexity that is not accessible or is vastly different from what an individual or family may be able to understand (Donald & Kelly-Campbell, 2016; Nair & Cienkowski, 2010). Given that health literacy is already a concern across the medical field, EHDI-based information for families is not exempt from this weakness or the need for a global overhaul in the documentation and general communication provided to families (Sax et al., 2019).

The accessibility of written materials in EHDI has been approached in terms of referral for diagnostic services following hearing screening. Sax et al. (2019) evaluated the readability of the top 55 links derived from a Google search of “failed newborn hearing screening” and materials from top medical institutions on the same topic. Their study concluded that “online patient education materials about the newborn hearing screen may be too difficult for the average reader” and serves as a call for material revision to be more inclusive of potential readers (p. 168). This information provides insight into potential risk factors for children not following through for hearing evaluations after referral on their screening. It also begs the question of how accessible materials for the next step in the EHDI system, early intervention, are to the average reader. This study continues this line of inquiry to assess if materials found online about early intervention for children who are DHH conform to readability recommendations.

**Materials and Method**

**Data Collection**

Google searches for “early intervention deaf” and “early intervention hear” were performed on February 4, 2020, and the first five pages of English language results were compiled. Google was selected as the search engine to be used based on the precedent in the literature to use this as the primary search tool and is supported by recent publications of the use of “conventional search engines” inclusive of Google (Ahmadian et al., 2020; Sax et al., 2019; Ting & Hu, 2014). The search term “early intervention” was selected to be broad enough to include services that families of children who are DHH can access, including those governed by Part C of the Individuals with Disabilities Education Act of 2004 and services that practitioners provide outside of that system. Both “deaf” and “hear” were selected to be used in conjunction with early intervention to represent the various terms that parents may have experience with or heard, including deaf, hearing loss, hearing impairment, hard of hearing, and hearing levels (Joint Committee on Infant Hearing [JCIH], 2019). This procedure led to 53 links in response to “early intervention deaf” and 50 links in response to “early intervention hear.”
Article Modification

Article modification is the process of preparing materials for readability analysis. The methods used here represent various readability analyses within the healthcare domain. Each link was opened and its contents copied entirely. The content was pasted as plain text into a Microsoft Word document. Documents were then modified by removing extraneous text as delineated by related studies (Badarudeen & Sabharwal, 2008, 2010; Flesch, 1948; Kong & Hu, 2015; Sax et al., 2019; Ting & Hu, 2014; Wong & Levi, 2016, 2017). Extraneous text includes navigation links, author information, dates, headers, titles, subheaders, acknowledgments, copyright notices, references, disclaimers, citations, feedback questionnaires, URLs, numbers, decimal points, bullets, abbreviations, paragraph breaks, colons, semicolons, dashes, captions, percentages, and charts/figures.

Readability Analysis

Implementing the methodology of Sax and colleague’s (2019) evaluation of newborn screening materials, this study has six assessment tools that create a rich data set. These include Flesch-Kincaid Grade Level (FKGL), Flesch Reading Ease Score (FRES), Gunning-Fog Index (GFI), Simple Measure of Gobbledygook (SMOG), Coleman-Liau Index (CLI), and Automated Readability Index (ARI). One online readability calculator was used for short samples (https://www.webpagex.com/tools/read-able) with a second calculator used for longer samples (https://www.readable.com/).

Statistical analysis was only conducted on FKGL. Current recommendations on the use of reliability calculations are to keep the grade level required to understand the material at a 6th-grade level, equivalent to being below 7th grade as the average adult reads at a level consistent with an 8th-grade education (Weiss, 2006; U.S. Department of Health and Human Services, n.d.). With this, the use of the FKGL to determine the grade level of a resource fits well with providing actionable steps to assess what materials are most accessible and is a consistent measure in the literature (Kong & Hu, 2015; Sax et al., 2019; Ting & Hu, 2014; Wong & Levi, 2016, 2017). The FKGL is based on the length of a sentence in words and the number of syllables in the words that make up the sentences (Flesch, 1948; Sax et al., 2019; Weiss, 2006). The formula provides the approximate grade level of education that is required to understand the text. All other reliability calculations are included to support claims from FKGL about the grade level needed to read a text as FKGL should vary with these other measures. In addition, these measures are additional metrics to determine correlation both between and within observers.

Two raters also reviewed materials to determine the intended audience. Materials were deemed to be parent-oriented when using the possessive tense in writing about the child, rights, or expectations (e.g., You and your child will work with the early intervention team to decide what services to access), or when the information was framed as an introduction to the topic of early intervention. Provider-oriented materials did not use the possessive or were framed as practice guidelines. The determination of the intended audience was conducted by the first author and a research assistant. Materials determined to be provider-oriented were included in the analysis as they are accessible and presented within the search results alongside parent-oriented materials. Thus, parents looking for parent-oriented materials could find these and review them as a part of their search. To determine the material source, each webpage was reviewed for the group that held the copyright, provided updates, or hosted the web page.

Statistical Analysis

Statistical analysis was completed using SPSS version 27. Descriptive statistics were calculated for all nominal categories. Statistical significance was set at .05 and calculated across groups using independent samples t-tests or ANOVAs.

Results

Before the statistical analysis of the readability scores was started, the reliability of the article modifications was assessed. This step was done to ensure that while keeping with the procedure of article modification, there was replicability in the methods. The first author repeated the editing process on 30 randomly selected links over one week after their original modification to provide intra-observer reliability data. To determine inter-observer reliability of the article modification process, a research assistant performed the editing process on another 30 randomly selected links and then calculated readability scores. Intra- and inter-rater reliability were calculated using intraclass correlation coefficients. Intra-rater and inter-rater reliability were significant for each measure of readability (p < .002).

Of the 103 links collected, 40 (38.8%) were excluded from analysis for being a video only (n = 1), being a dead link (n = 1), being contact information only that would have been erased during article modification for analysis (n = 2), being a list of links only that would have been erased during article modification for analysis (n = 2), primarily selling something (n = 3), being a job ad only (n = 4), being a duplicate of a link that was already accepted for analysis (n = 8), or being a journal article (n = 19).

This left 63 links for evaluation, with 24 (38.10%) derived from the search term “early intervention deaf,” 32 (50.79%) derived from the search term “early intervention hear,” and 7 (11.11%) links appearing in both searches. All but one of the webpages reviewed were written at a reading level above 6th-grade and thus not in line with literacy recommendations. The average FKGL of all documents (n = 63) was 12.62 (SD=2.65), with a range from 4.4 to 18.1 (see Figure 1). Of those links included in the evaluation, 49 (77.78%) targeted parents/the general public and 14 (22.22%) targeted professionals. Between raters, there was no
disagreement across any of the resources in terms of the intended audience. Forty-nine resources were deemed parent-oriented with a mean FKGL of 12.41 (SD = 2.74) and 14 were determined to be provider-oriented with a mean FKGL of 13.35 (SD = 2.28). Using an independent samples t-test, results indicate no significant difference in FKGL based on the intended audience (p > .17).

A majority of these links came from large reputable sources such as government websites (n = 22), advocacy groups (n = 14), educational systems (n = 12), hospitals and other healthcare providers (n = 7), or professional groups (n = 3). Only five results (7.93%) were from general media outlets. With a one-way ANOVA, there was not a significant impact of the information's source on the FKGL of the document (p > .1).

The search result page that resources were present on was also considered for analysis. Resources were grouped by the page on which the result was found, ranging from the first to the fifth page (see Figure 1). A one-way ANOVA revealed no significant impact of the display page on FKGL (p > .8).

Discussion
At the heart of pediatric audiology and early intervention services for children who are DHH is the family. Families shape a child’s trajectory by working with professionals to set developmental goals with the Individualized Family Service Plan (IFSP; Individuals with Disabilities Education Act of 2004). Before the IFSP, parents serve as gatekeepers who decide whether or not to enroll in early intervention services. As they make this decision, they may be referred to, find, or be provided information from friends, family, professionals, and the internet. The support that parents find must be at a level that is accessible to them and meets their literacy needs while scaffolding their health literacy and decision-making skills.

Accessibility of information is a critical component to meeting parents’ and caregivers’ educational needs around hearing-related topics such as early intervention. Overall, current online materials related to early intervention for children who are DHH are not written in a manner that is accessible according to health literacy guidelines (see Figure 1). Some of the most apparent drivers of high FKGL scores are long sentences and multisyllabic words (Flesch, 1948). Audiology-specific recommendations to address access concerns also call for the reduction of jargon, among other components. The intersection of long sentences, jargon, and many multisyllabic words can be seen in this sentence from a parent-oriented material used in the study with a FKGL of 18.1.

The U.S. Department of Education recently published IDEA and FERPA Confidentiality Provisions [PDF] (June 2014), a side-by-side comparison of the primary legal provisions and definitions in the Individuals with Disabilities Education Act (IDEA) Parts B and C and the Family Educational Rights and Privacy Act (FERPA) that relate to the confidentiality of personally identifiable information of children served under the IDEA. (NCHAM, 2020)

Although all of this information is critical for families to know and understand, the sentence length, vocabulary, and use of jargon may be challenging for a first-time reader or new parent to understand without support. Within early intervention, there may be situations where specific vocabulary and sentence structure is required. However, to work toward accessibility, there is a need for scaffolding to support understanding in these situations. These materials may not be accessible and thus are not working to address the stated and hypothesized lack of education that impacts
parents and, thus, children who are DHH as they enter early intervention.

This study, combined with other works on health literacy, patient education, and accessible materials, suggests that all sources of information, including government-sponsored sites, educational systems, and the general media, could benefit from making materials more accessible. Given that these results are consistent with Sax et al. (2019), it seems clear that both hearing screening and hearing-related early intervention could benefit from improved accessibility. Increased accessibility could be attained by implementing readability strategies as described by several national groups, including the U.S. Department of Health and Human Services (2020) and the American Speech-Language-Hearing Association (n.d.). When looking at readability scores, the grade level is impacted by a number of features, including syllables used in words and the length of sentences (Flesch, 1948; Weiss, 2006).

Although authors have been cautioned not to write with a readability formula in mind, potential strategies to support reading and lower required FKQL do exist. Remediation for current materials to improve readability and thus accessibility should include the use of short paragraphs that implement active voice, using one and two-syllable words, prioritizing information and considering the relative importance of information to be presented, reducing jargon, using simple pictures/graphics, and encouraging the potential use of audience assessment measures to determine if the material is accessible (American Speech-Language-Hearing Association, n.d.; U.S. Department of Health and Human Services, 2020, n.d.).

Of the webpages that parents and caregivers may access to learn about early intervention for children who are deaf or hard of hearing (DHH), the average readability score is higher than is recommended. Thus, parents and caregivers who turn to the internet as a source of information to help them make early intervention decisions may find inaccessible information. These results suggest that those who develop and maintain web-accessible content on early intervention for children who are DHH need to examine the role of readability in their materials. However, increased readability measures of English language materials do not explicitly address the needs for culturally- and linguistically-diverse materials on the same topics. This work can be considered a reminder to consider the current recommendations and strategies from reputable national resources to ensure accessibility of information.

References


Chapter 4
Examining Early Hearing Detection and Intervention through the Essential Services of Public Health

Abstract:
Early Hearing Detection and Intervention (EHDI) programs in the United States serve to support the screening, diagnostic evaluation, and eventual intervention to foster the development of children who are D/deaf and hard of hearing and their families. With this goal, EHDI is an inherently interdisciplinary system working to meet a diverse range of needs and individuals. This manuscript examines this system from the view point of public health. Public health as a discipline plays a crucial role in the EHDI system supporting the implementation of services in line with the legislation at the state and federal level. The ten essential services of public health provide a structure and vocabulary that can be used by clinical service providers, including educational and pediatric audiologists, to better conceptualize the EHDI system. This manuscript serves as an introduction for those in the realm of audiology to the ten essential services of public health and how this interdisciplinary perspective supports the various elements of family-centered care that are critical to clinical service provision.
Introduction to Early Hearing Detection and Intervention and the Role of Public Health

The overarching goal of Early Hearing Detection and Intervention (EHDI) is to ensure that all children receive hearing care services starting at birth (American Academy of Pediatrics, 2018; Joint Committee on Infant Hearing [JCIH], 2013; 2019). In 2019, the EHDI program in the United States has ensured access to screening service for 3,852,497 infants, ideally by one month of age to identify if they require a diagnostic evaluation (CDC, 2018b). Of those who require diagnostic evaluations based on screening results (65,156), only 47.5% do before three months of age (CDC, 2018c). From there, children who are identified as D/deaf or hard of hearing (6,337) should access early intervention services before six months of age (CDC, 2018c; JCIH, 2019). Eligibility for this entitlement program supports the critical access to services early in the life course (JCIH, 2019; Muñoz, Nelson, Bradham, Hoffman, & Houston, 2011; Yoshinaga-Itano, 1999, 2003, 2013). At any point in this system of referrals and service providers, a child and family may not make it to the next clinically indicated step. These children, who are lost to follow-up/documentation (LFUD), will have delayed access to services.

Warren and Levy (2021) consider the EHDI system the most prominent example of the successful implementation of hearing assessment programs. EHDI is a public health service governed by the Public Health Service Act (Early Hearing Detection and Intervention Act of 2017). EHDI is a public health service, and it should be evaluated against public health principles. As shown in Figure 1, one way to approach EHDI is to use the Centers for Disease Control and Prevention’s (CDC) (2014) ten essential
services of public health. A benefit of considering EHDI in this broader context is that it might provide a greater understanding of the systemic factors related to health, such as social determinants of health (SDOH), which impact how and why there are challenges with recommendation adherence in EHDI. From the public health perspective, there are vocabulary and standards that create a space to discuss the various points of service provision alongside the goal of EHDI and to address strengths and areas for growth. Throughout all the essential services, discussed and numbered below, the connection between EHDI and public health reaffirm one another.

1. Monitor Health Status to Identify Community Health Problems

According to the CDC, to monitor health status, public health programs can use health-related data to make information-driven choices around what needs or public health concerns may be present in a community (CDC, 2014). In the same vein, health-related data on newborns can speak to current and future public health program needs regarding EI and public education. This type of data can be collected through newborn screening. The Secretary of the Department of Health and Human Services recommends including 35 diagnoses, including hearing differences, in the newborn screening due to the long-term implications of delays in care (Boyle et al., 2014; Health Resources & Services Administration, 2019).

It is important to note that screenings are not able to determine specific diagnoses. The screening system helps detect lifelong and long-term diagnoses with the potential to impact individual and community health drastically but is not diagnostic (Boyle et al., 2014). Hearing screening is consistent with the goal of decreasing long-
term disability/challenges associated with a diagnosis by identifying newborns who should eventually enter into EI to support development (JCIH, 2019; White, 2019). Screening provides those working in public health positions opportunities to monitor pediatric hearing at the population level by collecting this initial screening data on almost all newborns (Boyle et al., 2014).

2. **Diagnose and investigate health problems and health hazards in the community**

As implemented by the Early Hearing Detection and Intervention Act of 2017, newborn hearing screening is available to children born in the United States of America, regardless of risk factors related to hearing. To ensure accessibility and be consistent with federal guidance, there is a need for services that are sensitive to race, ethnic identity, disability status, and religion (Early Hearing Detection and Intervention Act of 2017). This idea is echoed in qualitative assessments of satisfaction in families participating in various support services (Carpenter, 2003; Powell, 1990; Zionts, Zionts, Harrison, & Bellinger, 2003; Early Hearing Detection and Intervention Act of 2017).

It is essential to remember that hearing screening is only the first component of the EHDI system and is designed to refer children who are at an increased chance of hearing differences to diagnostic services (JCIH, 2018; 2019). After screening, identifying hearing levels allows the investigation into how hearing manifests across the pediatric population. For those working in public health, the process of identification provides insight into potential etiologies and population-level changes in hearing thresholds. Data on the incidence of hearing differences can be combined with
etiological data to identify underlying causes or co-occurring public health needs and future interventions to be developed to meet those needs.

For example, cytomegalovirus (CMV) has gained attention within the literature. The current JCIH position statement (2019) notes that congenital CMV (cCMV) can result in seizures, microcephaly, developmental delay, vision loss, and hearing differences. Given the connection between cCMV and pediatric hearing levels, data on newborns can provide insight into the incidence and prevalence of cCMV. Implementing cCMV screening in response to hearing screening results, while not universal, is a means of further investigating the etiology of childhood hearing levels and potentially determining the role that CMV plays at the community level with infant health. Within this context, the diagnostic component of EHDI can provide information that supports population-level questions around public health threats.

3. Inform, educate, and empower people about health issues

The EHDI system is predicated on sharing information. For the system to function, stakeholders, including families, must be aware of diagnostic labels, further referrals, and available supports. This process is ensured by coordinating governing bodies and mandated data reporting at the state, federal, and local levels. At the family level, the information shared is similar to screening results but must go further in terms of education, accessibility, and family empowerment. Family members must be informed of the child’s hearing levels through evaluation and explanation by professionals, educated on their intervention options, and empowered to make care and service provision decisions for themselves and the child (Early Hearing Detection and Intervention Act of 2017).
Within the most recent federal ruling, families are regarded as decision-makers, and states are required to support families so that they can “make important decisions for their child” (Early Hearing Detection and Intervention Act of 2017). This decision-making power goes beyond selecting intervention services. Families are gatekeepers for their children. They determine what professionals have the opportunity to engage and facilitate if there is to be any ongoing care. In addition, families are recognized explicitly as having their own needs, independent of the child. As such, states are also required to provide “family-to-family and deaf and hard-of-hearing consumer-to-family supports” (Early Hearing Detection and Intervention Act of 2017). Families and providers become partners in personalizing and improving services for the family as a whole (Wells, 2011).

4. Mobilize community partnerships to identify and solve health problems

Public health programs must exist within the context of the communities they serve, intending to meet relevant needs to that population. This goal can be bolstered by developing coalitions through formal and informal partnerships to promote improvement across stakeholders (CDC, 2014). In implementing EHDI, the family, different therapists, teachers, adults who are DHH, and families of children who are DHH can be sources of support (Meadow-Orlans, et al. 1997; Mikkelsen et al., 2001). The role of each of these individuals in the life of a child who is DHH has been affirmed at the state and national level (Early Hearing Detection and Intervention Act of 2017; JCIH, 2007; 2019).

Parent-to-parent support groups and dialogues with other families have been one of the most effective support methods for families (Jackson, 2011; Matloff &
Zimmerman, 1996; Mikkelson et al., 2001). These groups and interactions foster emotional support to families (Matloff & Zimmerman, 1996; Moores et al., 2001). A group of stakeholders may also be organized into a medical home for children and families. In the medical home, care is centralized, and a teemed approach to healthcare is enacted in an environment that is accessible, continuous, family-centered, culturally effective, and compassionate (Asarnow, et al., 2017; Nageswaran & Farel, 2007; Nickel, et al., 2003).

5. Develop policies and rules that support individual and community health efforts

The universal nature of EHDI is the biproduct of only approximately 50% of children who are born D/deaf or hard of hearing eligible to be called on for risk-based screening programs (JCIH, 2000). One way of looking at how policies can address potential barriers to meeting EHDI goals of screening, identification, and intervention is to consider how the SDOH interact with EHDI. Pursuing research on the impacts of SDOH in EHDI was explicitly called for by the JCIH (2019). Assessing EHDI policy against SDOH is a platform for looking at how policies can better support individuals in their hearing healthcare efforts and how innovation and change can support the reshaping of community-level challenges. The SDOH are the components of the human experience, and the environments we exist within can impact health. These factors, economic stability, neighborhood and built environment, education, health and healthcare, and social and community context, are broken out for discussion, but should be seen through the lens of intersectionality.

**Economic stability**
Under the umbrella term of economic stability are employment, food insecurity, housing instability, and poverty (Healthy People 2020, 2019). Without the financial resources, securing food and housing may be difficult. Given the definition of poverty as implemented in support program eligibility requirements, these concerns may be further complicated with poverty. An example of this would be that eligibility for programs that provide support in these areas, such as the Supplemental Nutrition Assistance Program, the Housing Choice Voucher program, and Medicaid, are related to income. The yardstick used for qualification in programs varies and does not include all people who experience the impacts of economic instability (Connecticut Department of Social Services, 2019; Connecticut Department of Housing, 2019). Within EHDI, research has brought attention to the impact of socioeconomic status on adherence to screening and follow-up recommendations (Liu, et al., 2008). From the perspective of SDOH, it is required that policymakers look past the label ascribed to an individual based on income and consider the underlying implication of that label and the functional implications it has in terms of access to care and perception of care.

While research has highlighted a connection between maternal public insurance and increased risk of LFUD, it is inappropriate to conclude that the type of insurance their mother has is the driving factor behind why children are at a higher risk of being lost to follow-up (Lui et al., 2008; Scheepers, Swanepoel, & le Roux, 2014). Instead, considering the impact of economic stability as a whole is warranted here. The type of and coverage provided by insurance may not be the driving factor behind this connection. Instead, the relationship between insurance type and income may be the
root of the correlation between insurance type and LFUD. Demographic variables around economic stability are proxies for root needs.

**Neighborhood and built environment**

Neighborhood and built environment refer to topics such as crime and violence, environmental conditions, quality of housing, and access to nutritious food (Healthy People 2020, 2019). The built environment is the physical context of a community. Examples that may be important for individuals who are DHH include the number of audiology clinics in the area or what locations are looped for telecoil usage. The built environment, or lack of specific built environment components, may play a part in care access. Rurality of the home has been noted as a demographic variable that is associated with higher lost to follow-up rates in EHDI and a topic that warrants further research (JCIH, 2019; Liu et al., 2008). Living in a rural environment may limit access to providers who can perform follow-up services due to distance to providers, which providers are covered by insurance, or the hours of operation for a given provider. Depending on the unique physical setup of a state, municipality, or region, the underlying impact of the neighborhood and built environment must be considered. Based on a location, specific interventions can be arranged, such as information on gas card or bus card programs for traveling to appointments, contact information for a clinic with various hours of operations or mobile service provision, and coordination of appointments to limit travel needs (Hunter et al., 2016). Since COVID-19, the utility and practical application of telehealth have also been at the forefront of clinical service provision and may serve to meet this accessibility need as well.
Education

Within SDOH, education refers to early childhood education and development, enrollment in higher education, high school graduation, language, and literacy (Healthy People 2020, 2019). For this discussion, these parameters should also be expanded to conceptual knowledge of EHDI and EI. Through these programs, early childhood education and development, language, and literacy can be targeted in a way conducive to education, not being a determinant that creates barriers to health.

Maternal education level has an inverse relationship with LFUD rates where increased maternal education is associated with a decrease in LFUD (Cunningham, et al., 2018; Liu et al., 2008). We must ask what about maternal education impacts EHDI. Is an increasing amount of education associated with more knowledge about EHDI? Alternatively, is maternal education serving as a proxy for income or other economic root needs? In the current literature base, explicitly controlling for maternal income has not been implemented. This does not take into account the impact of disposable income or how different jobs, employment contracts, or benefits such as insurance and paid time off have on this. One barrier to this may be that this type of information is not expressly collected on the birth record. It is a common method for this type of data to be collected at the population level.

Of specific note here is the role of health literacy. Health literacy is the composite skill impacted by the SDOH of education and health. In short, it is the skill of taking in, processing, and understanding health-related content such as information and needed services (American Speech-Language-Hearing Association, n.d.a). It has been noted in the literature that providers, audiologists included, tend to speak at a level of complexity
that is not accessible or is vastly different from what an individual or family may be able to understand (Donald & Kelly-Campbell, 2016; Nair & Cienkowski, 2010). Health literacy is already a concern across the medical arena, and EHDI-based information is not exempt from this weakness or the need for a global overhaul (Sax, et al., 2019). Print materials can be augmented to meet or exceed guidelines from the American Speech-Language-Hearing Association (n.d.a) by using short sentences, active voice, little jargon, and bulleted lists, among other recommendations.

**Health and healthcare**

Access to healthcare, primary care, and health literacy are all components of the health and healthcare determinate (Healthy People 2020, 2019). The EHDI system is the combined effort of birth hospitals, primary care providers, and specialists such as audiologists, speech-language pathologists, and other necessary specialties (JCIH, 2019). Having access to all these providers can be complicated by any of the SDOH, with challenges stemming from affording the cost of care, transport to providers or not having a provider in your area, understanding the need to see providers, and overcoming social barriers such as discrimination or isolation. These may be further complicated when the challenge in accessing care starts with not having a primary care provider (PCP) who serves as a medical home and follows through with the principles of comprehensive care by generating referrals and support (Hing, et al., 2017). Guidelines that reinforce the role of the P.C.P. and support the ability for families to access care across all SDOH may be an avenue for further policy development.
Social and community context

Social and community context refers to civic participation, discrimination, incarceration, and social cohesion (Healthy People 2020, 2019). Hearing is related to accessing spoken language and can be a component of Deaf Culture. There is a social element to identifying hearing differences for the individual and communication partners (Madell & Flexer, 2014; Padden & Humphreys 2006). Concurrently, it is also vital to recognize the role of hearing levels and identification for families within the social context. Non-cyclical grief following the identification of a child as DHH may coincide with follow-up appointments (Kurtzer-White & Luterman, 2003). This grief assumes the family was not expecting or hoping for a child who is DHH. This presupposition can impact family and provider perceptions of services.

The non-cyclical experience of grief that some families may bring with them following screening referral or identification and potential stigma related to hearing may impact social cohesion and participation. Participation barriers for individuals who are DHH and their families have been noted across the continuum of communication approaches and may exacerbate challenges to EHDI (Emond & Sutherland, 2015; Johnson, 2012; Steinberg, et al., 2002). In a community not established and structured to support accommodations for individuals who are DHH and their families, accessibility challenges may be present. Pre-existing strains on cohesion, such as discrimination due to disability, ethnicity, or other demographic characteristics, may further complicate needs. Parental refusal is one of the most commonly reported reasons for not accessing EI within the EHDI system (CDC, 2018e; 2018f; 2018g). This finding may be due to a lack of understanding of the need for EI during this period of increased stress.
Educational supports centered around meeting the social and community-based needs of a family and overcoming barriers through EI may be a viable option, along with a referral to other professionals (JCIH, 2019).

6. Enforce laws and regulations that protect health and ensure safety

Hearing screenings in the newborn population was not universally accepted and implemented in one legislative session. The start of what would become EHDI is seen in the 1990s with the culmination of usable technology for screening purposes and the implementation of some state-level universal screening programs, the first of which being Rhode Island in 1993 (National Center for Hearing Assessment and Management NCHAM, 2016; 2018; White, 2019). The current federal legislation reaffirms goals from the Early Hearing Detection Act of 2010 for universal screening. It provides the foundation for developing and monitoring state programs in meeting the standards of care outlines such as referral to EI and an updated focus on the development and execution of EHDI programs and serves to direct children, not only newborns, who are DHH into EI. (Early Hearing Detection Act of 2017; NCHAM, 2018; n.d.b). States are charged with developing legislation around EHDI as well as designing and maintaining state-level programs to support the screening, evaluation, identification, and application of EI to children who are DHH. However, the NCHAM (n.d.a) notes that the state legislation does not mandate all components of a successful system. These state guidelines tend to align with the recommendations published in the 2007, 2013, and 2019 JCIH position statements and may go beyond what is mandated at the state and federal levels.
7. Link people to needed services and assure the provision of healthcare

The acts of screening, identifying, and providing intervention around pediatric hearing levels required that newborns be connected with screeners, those who refer on the screening are seen by a pediatric audiologist, and those identified as DHH can access EI that are consistent with family goals. Across all three of these populations, EHDI programs are connecting people to the services they need. These connections to care, and their challenges, can be observed and assessed.

The first point of contact between families, children, and the EHDI system is with the initial screening. In 2016, 94.8% of the 3,852,497 children reported to Vital Records as being born in the United States received a hearing screening by one month of age (CDC, 2018d). Outside of the recommended one month of age parameter, another 2.7% of children were screened, resulting in 97.5% of all newborns receiving a hearing screening in 2016 (CDC, 2018a; JCIH, 2019). The most commonly reported reason why the screening did not occur was “unknown” (CDC, 2018g). This group harkens back to the first and second essential public health services concerning monitoring and investigating why some individuals do not pursue newborn screening.

Following the screening, 65,156 children “did not pass” their screening and thus required diagnostic evaluation (CDC, 2018c). Diagnostic results were reported for 40,835 of these children, consistent with over 62% of children who should be referred for further testing receiving a diagnostic evaluation at some point (CDC, 2018c). However, only 47.5% of children are seen and have their hearing levels documented by three months of age, as recommended by the JCIH (2007; CDC, 2018c).
In 2016, over half of the 6,337 children identified as DHH were enrolled in EI programs in line with this milestone (CDC, 2018c). The children enrolling in EI are reinforcing the goal of EHDI (JCIH, 2019). EI access is critical for supporting language development, regardless of modality (Mayberry, 2010; Muñoz, et al., 2011; Yoshinaga-Itano, 1999, 2003, 2013). However, the systemic drop-off before enrolling in EI of over 30% of the children, who have been identified as DHH, is inconsistent with the universal goals of EHDI (CDC, 2018b). When looking at the data, we are faced with a lack of systemic information as to why infants and families are not enrolled in EI. Over 38% of children, who are not enrolled in EI after being identified as DHH, have unknown reasons for not enrolling in EI (CDC, 2018f). This unknown breakdown combined with the familial declination of EI accounts for over 65% of non-enrollment in EI in children identified through EHDI (CDC, 2018f).

Currently, there are breakdowns across the EHDI system in connecting families to care. Of the reported reasons for why children did not progress through the EHDI system, the most common non-medical (mortality or medical reason) and non-logistical (could not contact, family contacted but unresponsive) is the family decline services (CDC, 2018e; 2018f; 2018g). This breakdown is inconsistent with the evidence-based-foundation of EHDI in developmental, audiological, and speech-language research that called for family-centered care and intervention services to mitigate communication challenges and the positive impact of EI on children and families (NCHAM, 2019a; Yoshinaga-Itano, 1999, 2003, 2013). While families have the right to decline services, the reasoning behind this decision has not been investigated thoroughly. Instead, the
social determinates of health bring into question if this declination is true refusal of services of a declination of engagement with the current system.

8. Assure a competent public health and personal healthcare workforce

The critical stakeholders within the EHDI system are broad. Each individual within the system has mandated education or experience that they must follow by virtue of their job description or, in the case of families, the role they fill. The federal legislation directing states in their implementations calls on families as decision-makers (Early Hearing Detection and Intervention Act of 2017). A key example of this status as decision-makers is exemplified by the ability of families to refuse services (CDC, 2018f). This mandate goes further than supporting the family’s participation in decision-making. The family’s role in directing care is codified in federal law and thus, the family becomes part of the healthcare workforce (Early Hearing Detection and Intervention Act of 2017). Yet, there is a multitude of studies that highlight the information around EHDI that families are still searching for or can benefit from more explicit instruction on, including information on screening (Krishnan, Van Hyfte, & Richards, 2019), EI (Haddad, et al., 2019; Khoza-Shangase, 2019; Larsen, et al., 2012; Pendersen & Olthoff, 2019), hearing aids and technology (Haddad et al., 2019; Van der Spuy & Pottas, 2008) financial supports (Haddad et al., 2019), family support services (Haddad et al., 2019; Van der Spuy & Pottas, 2008), and hearing levels in general (Donald & Kelly-Campbell, 2016; Sax et al., 2019). Family education on EHDI is consistent with the goal of ensuring those involved with public health programs are competent and can provide vital services.
9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services

Across the essential services, the role of families has been ever-present as the family determines if health data can be collected through screening, what appointments they attend for a diagnostic label, and if they pursue EIs. With this in mind, as a population, interventions focused on families can support all of the essential services of public health within EHDI. It is vital to investigate current literature on how families are being educated around their role in EHDI. A small base in the research includes empirically evaluated family-based interventions around EHDI topics such as LFUD is broken down based on its approach to care (Cockfield et al., 2012; Hunter et al., 2016; Yarbrough et al., 2018).

System-level intervention to support care coordination

Hunter et al. (2016) implemented a two-year LFUD reduction program based on the integration of EHDI with the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). The WIC program is federally funded and supports mothers and children accessing healthy and nutritious foods (Hunter et al., 2016). In this intervention, children referred on their initial screening in the birthing hospital and from families who were receiving or planned on receiving WIC benefits were eligible for enrollment could have their hearing rescreening services and WIC supports in the same office. This study highlighted the power of service coordination with the families that enrolled in the intervention. The baseline LFUD rate of 33% was reduced to 9.6% across both years of the study. While this form of intervention excels at connecting individuals with non-hearing related supports in a way that is consistent with addressing
economic stability and neighborhood as SDOH, integrating these two services is fiscally impossible as presented unless additional funding is procured (Hunter et al. 2016). Hunter et al. (2016) do not have an explicit mechanism for imparting hearing-based knowledge to families. There is no direct intervention at the level of families, as is consistent with the essential services that have been presented above.

**System-level intervention to integrate family-driven practices into EHDI**

Yarbrough et al. (2018) reported on their Virginia-based intervention program, a system-navigational approach that implemented family educators. Here, families of children who had moved through the EHDI system, Family Educators, were employed to connect with hospitals and audiologists providing screening services. Family educators were connected with families who requested social and emotional support around having a child who referred on their hearing screening (Yarbrough et al., 2018). In the year that the family educators were connected with the staff at hospitals and families directly for emotional support, LFUD rates at these specific locations were reduced by 4.4%. As well, the average age at rescreening following the intervention was lowered by one month. While hospitals and organizations received information and training on how to decrease LFUD that could be applied to all individuals, the educational component of the early Guide By Your Side was not universally applied or targeted to disengaged families. No statistical analysis was conducted. Individuals who participated in the direct family-level education and support services had to elect to enroll. This approach does not address families who are disengaged, are struggling to connect, or have not been engaged with the EHDI system as of yet.

**Birth parent-level intervention to infuse education into the screening**
Cockfield et al. (2012) is the only identified birth parent-level education study aimed at LFUD reduction, yet did not provide information on statistical impact. This intervention was implemented at two hospitals where, following the hearing screening results, the audiology assistant that performed the screening would alert a nurse practitioner. The nurse practitioner then obtained consent and provided the mother with a standardized lesson on the EHDI program. Content included reviewing the Georgia Newborn Hearing Screening program with a brochure and presenting content on the benchmarks that are important for timely follow-up on their results. The birthing parent was also provided with the information for the child’s next audiology appointment.

**Research summary**

The next step in furthering family-based education interventions for EHDI is to ensure adherence to the principles of public health, early intervention, and family education. Examples of this are ensuring materials are created with family education in mind, services are delivered in a manner that is consistent with public health programs, interventions are implemented within a pre-existing structure of services to reduce the impact of SDOHs, and data is being collected past three months of age/diagnostic assessment.

**10. Research for new insights and innovative solutions to health problems:**

**Family education**

Families occupy a unique space within child development in that they are responsible for many decisions during the early years of a child’s life. This position has been reaffirmed at the state and local levels regarding EHDI (Early Hearing Detection and Intervention Act of 2017). A family education approach to LFUD is different from
other methods of engagement that have been implemented. Unlike the above approaches, family education for children identified through EHDI is motivated by the third essential service of public health, informing, educating, and empowering people about health. The behavior change associated with taking a child in for further testing, identifying hearing levels, or enrollment in EI is intrinsically linked to the National Extension Parent Education Model broken out into the acts of understanding, guide and nurture, and advocate (Smith, et al., 1994).

**Understanding**

By following through with EHDI services, families may have access to the information they need to understand their child’s specific development and how hearing may impact their environment and relationships within the family. Hearing levels, when left unaddressed, can diminish the quality of communicative experiences (Carrigan & Coppola, 2017; Lederberg & Everhart, 1998). Feelings of grief have been associated with families observing and experiencing their child struggling to communicate and the social ramifications and stress of communicative isolation if these results are not expected or hoped for by the family (Feher-Prout, 1996; Kurtzer-White & Luterman, 2003). Without the knowledge of hearing differences, these struggles may be seen as without cause and negatively impact parental anxiety (JCIH, 2007).

The literature on parenting and families also provides supporting data on why recommendations stress avoiding delays in care, starting with a poignant statement from Russell and Guite (2019) that asserts “parents are critical pragmatic facilitators of their children’s care...”. By beginning to acknowledge that families are formal, in terms of consent, and informal, in terms of deciding when to ask questions, seek providers, or
sustain intervention services, gatekeepers to a child, it is pragmatic to meet the needs of families emotionally when working within EHDI. Sampling from various pediatric diagnoses, the long-term impacts of stress stemming from the identification of a child with a disability include depression, physical illness, and stress disorders that need to be met with appropriate professional referral (Brehaut et al., 2011; Zajicek-Farber, 2013). These familial experiences of isolation and grief will color how they contribute and shape the child's environment and have their own merits when avoiding this type of strife (Smith et al., 1994; Steinberg, 2001).

**Guide and nurture**

For individuals without access to language, spoken or visual, there are no shared conventionalized means of communicating meaning to support the goals of nurturing or the act of guiding. With little communication, Smith et al. (1994)'s goals of setting limits, allowing choice, and expressing emotion are challenged. For children who do not have access to language due to hearing levels, non-identification or lack of intervention services to support language in any modality can lead to a reduction in the communicative understanding in the parent-child dyad. Without this type of communication, it may be challenging to share many of the goals for a nurturing family, even when there is a gesture system in the home (Carrigan & Coppola, 2017; Lederberg & Everhart, 1998). Not pursuing the identification of hearing levels and interventions services can be perceived as a risk to the child's health and safety, given the essential nature of early language access for later language and cognitive development (Mayberry, 2010). Knowledge of hearing levels allows families to take
Advocate

The act of advocacy is a domain of the National Extension Parent Education Model and a potential goal for all family education programs. It is also integrated into the third essential service of public health, given that to advocate means to be empowered in the decision-making process. When a child is LFUD, the family and the child may not access the information necessary to advocate. While the informal and communication-based services are still accessible, formal care environments with specific intervention goals are another component of EHDI that are designed to support the family as a whole in conjunction with informal supports. Undocumented hearing levels, or a lack of education on what hearing levels mean, strip the families of the knowledge they need to find appropriate resources and build relationships with and for their child in the community. Without this information, a family cannot develop advocacy skills. Being stripped of this knowledge precludes families from pursuing attitudinal and behavioral changes in their parenting to meet their child’s needs better. Education in newborn hearing screening, specifically through family education, lays a foundation for parenting skills such as communication and advocacy.

Conclusion

Assessing EHDI through the ten essential services of public health highlights areas of strength and the potential for family involvement to improve this system. Now it is time for policies around EHDI to capitalize on the current body of work around risk factors for lost to follow up. Concurrently, addressing SDOH should also be considered.
as a way to affect environmental change to support healthy living (Healthy People 2020, 2019). With policies built on SDOH principles and sufficient flexibility to allow states to meet the needs of their families, the true goal of EHDI can be attained and more children will have access to the services that will benefit them. Currently, the drop-off in EI enrollment is not being addressed in a manner consistent with SDOHs and family-centered care (CDC, 2018b). One way to meet this need is to restructure how families are perceived within the EHDI system and embrace the Early Hearing Detection and Intervention Act of 2017, where families are a part of the public health workforce. Currently, families shape LFUD, are present in every public health service as it functions with EHDI, and may contribute to one of the most common reasons for not accessing services (CDC, 2018b). They require education on their new roles as a family of a child who is DHH. These families must be educated to meet the essential service of assuring a competent workforce through dedicated public health programs.
Figure 1. The ten essential services of public health and their broadened applications to the implementation of Early Hearing Detection and Intervention. Adapted from CDC (2014).
Acknowledgements

This manuscript was derived from Torri Ann Woodruff’s Comprehensive Examination for PhD candidacy at the University of Connecticut. This manuscript would not have been possible without the insight and support of her major advisor, Dr. Kathleen Cienkowski and committee members both past and present, Drs. Beth R. Russell, Mary Beth Bruder, Bernard Grela, Jill Raney, Sarah Woulfin, and Kim Gans.

The idea for this manuscript and Torri Ann Woodruff’s future work is the result of involvement in the Leadership Education in Neurodevelopmental and related Disabilities (LEND) program hosted at the A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research, and Service and courses with Dr. Tara Lutz in the department of Public Health at UConn Health.
Works Cited


https://doi.org/10.1177/108835760301800106
Chapter 5
Variability in Part C Eligibility for Children who are Deaf and Hard of Hearing

Torri Ann Woodruff, PhD and Kathleen M. Cienkowski, PhD
Department of Speech, Language and Hearing Sciences, University of Connecticut, Storrs, Connecticut

Abstract

This paper aims to investigate the variability in Part C Early Intervention eligibility criteria for children who are D/deaf and hard of hearing (DHH). State agencies were contacted to determine Part C eligibility criteria for children who are DHH. State criteria were reviewed and classified by two reviewers based on eligibility parameters. Four broad categories of eligibility criteria were identified: 1) no written policy; 2) eligibility based on hearing thresholds equal to or less than 25dB HL or "any level"; 3) eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency; 4) hearing thresholds exceeding 30dB HL including those with additional requirements in terms of laterality. The directory developed in this study of eligibility criteria for children who are DHH serves as a requested tool for states to compare their current operationalized policies in detail to other states, clinicians to support the families they work with, and researchers in understanding this highly pragmatic component to early intervention access.

Keywords: EHDI, Part C Eligibility, Hearing, Deaf
Introduction

For infants who are born D/deaf and/or hard of hearing (DHH), Early Hearing Detection and Intervention (EHDI) services provide a specific mechanism for support (Early Hearing Detection and Intervention Act of 2017). EHDI is a national system that funds and organizes state programs to screen newborn hearing, evaluate children who refer for further testing on their hearing screening to identify if they are DHH, and help children and families access early intervention services after identification of hearing outside of the typical range (Early Hearing Detection and Intervention Act of 2017). The federal government provides funding and general recommendations on how to run these programs, but states have the flexibility to develop their own mechanisms to ensure access to care. While EHDI applies to infants and young children, there is a focus in the legislation and research on the impact that EHDI has on newborn infants.

At the federal level, state EHDI programs report their activities to the Centers for Disease Control and Prevention (CDC) and this state-level data is released to the public (CDC, 2020a). Within the United States, over 97.5% of children born in 2018 had their hearing levels screened at birth (CDC, 2020c). This process led to the diagnosis of 6,432 children as DHH (CDC, 2020a). Children identified by EHDI systems should be enrolled in developmental support services, yet in 2018, over 33% of these children did not enroll in early intervention (EI) services (Joint Committee on Infant Hearing, 2019; CDC, 2020d).

Identifying children early as DHH but not intervening and providing support is counter to the goals of EHDI and the benefits of early identification. Early intervention services have been shown to benefit development for children identified as DHH and
can be accessed through private care providers by the family individually or through a state system that is managed at the state and federal level under Part C of the Individuals with Disability Education Act (IDEA) of 2004 (Yoshinaga-Itano, 1999; 2003; 2013). Given this overlap in population served, understanding the interaction between diagnostic services in EHDI and early intervention services delivered as part of Part C is critical to seeing the mechanism and potential barriers to care access.

The EHDI system is predicated on the Joint Committee on Infant Hearing’s (2007; 2013; 2019) recommendation for EI services to be provided by at least six months of age or sooner. The critical role of EI is founded on the idea that prompt access to supports that promote language access and language acquisition has monumental impacts on adult outcomes in cognitive and linguistic realms (Joint Committee on Infant Hearing, 2019; Yoshinaga-Itano, 1999; 2003; 2013). Individuals who do not have language access are at risk of language deprivation. Language deprivation leads to challenges in language learning and mental health concerns (Hall, 2017). This risk is especially present in the over 35% of all children identified by EHDI programs in 2018 reported not to have accessed any forms of EI (Joint Committee on Infant Hearing, 2019; CDC, 2020e).

Part C Early Intervention (Part C EI) is the most common way that families of children who are DHH access early intervention services (CDC, 2010a; 2010b; 2012a; 2012b; 2013; 2014; 2016a; 2016b; 2018a; 2018b; 2019; 2020f; n.d.a.; n.d.b.; Individuals with Disabilities Education Act of 2004). Part C EI is outlined in IDEA as a federally mandated state-organized developmental support for children and families. Services that can be provided as a part of Part C EI are selected and specialized to meet the
individual family’s goals and needs (Individuals with Disabilities Education Act of 2004). These can include a range of services such as family-based training and counseling, speech-language pathology and audiology services, sign and cued language instruction, and more (Individuals with Disabilities Education Act of 2004). Early intervention services and providers work collectively to support the family and the child as they meet individualized goals. Part C EI services are outlined and overseen at the federal and state levels. This organization is designed with the goal of minimizing the impact of developmental delays, reduction of educational costs, eventual support of independent living skills, and development of capacities for families, states, and local agencies to meet the needs of these children (Individuals with Disabilities Education Act of 2004). Sharing principles with the Early Hearing Detection and Intervention Act of 2017, families are at the center of Part C services with the Individualized Family Service Plan (IFSP; Individuals with Disabilities Education Act of 2004). An IFSP is the outline of the services that will be provided as a part of Part C and includes sections on (Individuals with Disabilities Education Act of 2004):

- The child’s current developmental status across physical, cognitive, communication, social/emotional, and adaptive development
- Information on the family in terms of resources, priorities, and developmental concerns
- The measurable results service providers will use as a metric for assessment
- The early intervention services to be provided include the logistics of implementing the services including length, duration, frequency, intensity, and mode of delivery
Other services the child will receive that may or may not be funded under Part C

When the services will start

Who will provide service coordination for the family

How the child will transition out of Part C care

What post-Part C services will look like

This document must be initiated within 45 days of a child being deemed eligible for Part C and should be reviewed at least every six months, with additional reviews schedule if conditions/needs warrant or the family requests it. A formal and accessible evaluation of the IFSP must occur yearly with the family. Families are encouraged to be active members in this process and should be supported through the use of flexible scheduling, interpreters, accessible content, and access to due process filing if unsatisfied with services. In Part C EI, federal funding is provided to states to develop their own “comprehensive, coordinated, multidisciplinary, interagency system” that aligns with the requirements of the IDEA (Individuals with Disabilities Education Act of 2004). Additionally, for EHDI, state programs are mandated to report their screening, identification, and intervention data to the CDC (Early Hearing Detection and Intervention Act of 2017). At the federal level, a child is considered eligible for Part C EI if they are under the age of three years and are “experiencing developmental delays” or “has a diagnosed physical or mentation condition that has a high probability of resulting in developmental delay” (Individuals with Disabilities Education Act of 2004). States also have the option of providing services to additional children who are “at-risk” (Individuals with Disabilities Education Act of 2004). Hearing differences are considered under the second type of eligibility based on the concern that their hearing thresholds have “a high
probability of resulting in developmental delays” as delays may not be present at birth but are possible later in life (Individuals with Disabilities Education Act of 2004). In section 1435 of Part C in the IDEA, it is highlighted that each state delineates the specific criteria for what a developmental delay is, and thus the requisite hearing levels “in order to appropriately identify infants and toddlers with disabilities that are in need of services.” In the case of children who are DHH, hearing thresholds outside of the typical range are considered a high probability indicator of future delays.

Understanding how eligibility criteria interact with EI enrollment for children who are DHH is the first step to understanding what drives enrollment in Part C EI. Past research has investigated general Part C eligibility criteria across states and how more “restrictive” eligibility criteria in terms of the degree of developmental delay have been associated with decreases in EI enrollment (McManus, et al., 2009; Elbaum, et al., 2017). However, hearing levels are not regarded or addressed in the same way, as their category for coverage under Part C is not related to a documented delay. National Center for Hearing Assessment and Management (2015) categorized operationalized eligibility definitions for children ages 3-5, as covered by Part B section 619 of the IDEA. Now it is time to conduct a similar assessment for children under the age of three years who are covered by Part C of the IDEA.

Currently, there is no current comprehensive listing of the operationalized hearing-specific eligibility criteria that include thresholds requirements in all relevant states for Part C EI in each state easily accessible by professionals or parents through academic search tools or Google (Early Childhood Technical Assistance Center, 2015;
n.d.; Laurent Clerc National Deaf Education Center, 2003). This study seeks to use publicly accessible data to identify the Part C EI eligibility criteria of each state.

Methods

This study was determined to be non-human subjects work and exempted from review by the University of Connecticut Institutional Review Board. Analyses were completed exclusively on publicly accessible data from individual state Part C EI offices and the CDC.

The criteria used to determine if a child is eligible for Part C EI are not universally represented on individual state webpages. With that, each of the 50 states and the District of Columbia were contacted to ascertain eligibility criteria for children who are DHH and seeking Part C EI. Each point of contact was reached out to up to two times, one initial point of contact and one follow-up two weeks later. If no response was received two weeks after the follow-up, the next point of contact was reached out to. The procedure for identifying points of contact was as follows:

1. All web pages associated with Part C EI were collected from the CDC (2020b) and searched for a contact email address. Contact information was collected through the CDC as it is a major repository for EHDI program data and intrinsic connection to data management and dissemination. While collecting data on Part C, it was thought that these contacts within EHDI programs connected to the CDC required data reporting would have more direct and immediate access to our population of interest (children identified as D/deaf or hard of hearing) than other resources such as the Department of Education (CDC, 2021). When multiple email addresses were located, a hierarchy of relevancy was used to identify which to contact first.
(individuals associated with Part C EI enrollment specifically, Part C EI coordinators or department heads, general question contacts, points of referral).

2. EHDI coordinator(s) were contacted via the National Center for Hearing Assessment and Management (2018)’s Contacts for Early Hearing Detection and Intervention.

3. State webpages were reviewed for contact phone numbers. These phone numbers were called, and a message was left inquiring about this topic.

Up to 10 attempts (five initial contacts and five follow-ups), or until all contact avenues were exhausted, were conducted to ascertain these criteria. Once contact was made and initial questions were answered, additional follow-up questions were asked as needed. Respondents who did not provide operationalized definitions were provided with a summary of their responses and asked to correct any misunderstandings or ambiguities with up to two follow-ups for clarification. Once the state contact reported the eligibility criteria, it was copied verbatim into an Excel spreadsheet. Criteria was broken down into key components and requirement categories (pure tone average or threshold in dB requirements, etiologic requirements, laterality requirements, permanency requirements) and if the criteria explicitly noted the eligibility of individuals identified with auditory neuropathy/dyssynchrony or recurrent otitis media.

States were then grouped based on individual constellations of requirements to be found eligible for services. Four broad categories of state policies were identified: 1) no written policy; 2) eligibility based on hearing thresholds equal to or less than 25dB HL or “any level”; 3) eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency; 4) hearing
thresholds must exceed 30dB HL (including states with requirements of thresholds above 30dB HL) including two states with additional requirements in terms of laterality. These groups highlight differences in the approach states take when determining eligibility for Part C EI with children who are DHH in terms of approaching hearing as a quantitative variable in terms of threshold, that of a dichotomous variable that is absent or present, or a nominal variable with parameters such as laterality, type, and permanency. Each state was assigned to one of these groups based on reported criteria. A research assistant cross-checked all data entry to ensure accurate presentations of individual state requirements as they were broken down and grouped. Any disagreement between the first author and research assistant was discussed and debated until consensus was reached.

The last successful point of contact for each state was reached out to up to twice more, over 12 months after initial contact, to ascertain the most up-to-date eligibility information for 2022. In these follow-ups, the contact was asked to confirm if the policy identified above was accurate for 2022. Any revisions to wording, policy, or weblink were updated based on responses to this request. States that did not respond within two weeks of the second point of contact were assumed to not have made any changes to their policy.

Results

Of the fifty states and the District of Columbia that responded to requests for information, combining all assessment years, 50 usable responses were received. State reported criteria is broken down into two-year increments starting in 2018. This is to show the instances of eligibility policy change across time.
In the 2018 data analysis, one state reported that their eligibility criteria actively changed mid-year in 2018 from “hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency” to “hearing thresholds equal to or less than 25dB HL” or “any level.” This resulted in the final policies in 2018 to include three states that had no written policy; 23 states that determined eligibility based on hearing thresholds equal to or less than 25dB HL or “any level”; 19 states that determined eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency; and four states that determined eligibility based on hearing thresholds that must exceed 30dB HL (including states with requirements of thresholds above 30dB HL and those with additional requirements in terms of laterality).

In 2020 the current policies for eligibility were reported as, three states had no written policy; 24 states that determined eligibility based on hearing thresholds equal to or less than 25dB HL or “any level”; 18 states that determined eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency; and four states that determined eligibility based on hearing thresholds must exceed 30dB HL (including states with requirements of thresholds above 30dB HL and those with additional requirements in terms of laterality). Between 2018 and 2020 one state moved to eligibility based on hearing thresholds equal to or less than 25dB HL and additional components related to laterality, type, or permanency from eligibility based on hearing thresholds must exceed 30dB HL.
(including states with requirements of thresholds above 30dB HL and those with additional requirements in terms of laterality)

2022

The data collection process for this analysis created a unique tool that combines the hearing-related eligibility requirements of various locations (Table 1). This table houses the operationalized eligibility criteria specifically for children who are DHH as it relates to Part C EI as of data collection in 2022. Of the 41 states and districts that responded (80.39% of those contacted), none reported a change in their eligibility criteria. The most change between 2020 and 2022 for these eligibility policies were the updated of reference links provided in Table 1.

Discussion

The Appendix of this study includes a functional tool to support those within the Part C EI system in ensuring engagement with the system. This type of information has not been aggregated in the past and represents the major contribution of this study. When looking at EHDI, the intervention element of the system is predicated on early intervention access such as through Part C (Early Hearing Detection and Intervention Act of 2017).

Insight into the critical connection between EHDI and Part C

Both Part C of the IDEA and the Early Hearing Detection and Intervention Act of 2017 service the same population, children who have been identified as DHH, and call for each other within the legislation. When children are identified as DHH, there is a developmental need that has been identified and Part C services are the most common way of meeting those needs during the critical developmental period of early childhood.
(CDC, 2010a; 2010b; 2012a; 2012b; 2013; 2014; 2016a; 2016b; 2018a; 2018b; 2019; 2020; 2021; n.d.a.; n.d.b). With this, a discussion of what the Part C system does when interacting with these children and families is warranted. Both of these systems impact family outcomes and should be working in conjunction to ensure access. The first step of accessing this joint impact is looking at how Part C manifestations of eligibility interact with the various diagnostic labels that EHDI provides and the needs these labels highlight.

**Insight into interstate moves**

The table of this manuscript lists eligibility criteria as of data collection in 2022. Challenges in collecting this data also highlight logistical barriers for interested parties when learning about Part C EI that are primed for future evaluation. For those who responded to this inquiry, one to ten points of contact (emails and/or phone calls) were needed to clarify and operationalize the Part C EI eligibility criteria. This can pose a challenge to providers working with families across state lines or those who are preparing for interstate moves. The aggregation of this 2022 data in Table 1 helps ameliorate the pressure on providers and families to ascertain this information. Also, this variability in state-level criteria creates the potential for region/state specific disparities in access to care. This inequitable access to services is inconsistent with the goals of the JCIH (2019) and foundation of early intervention access being universal (IDEA).

**Insight into eligibility trends**

Generally, a majority of the Part C systems in the United States are broadly inclusive of the diversity that makes up the population of children who are DHH.
Tracking eligibility trends for children who are DHH and seeking Part C Early Intervention services across six years in three timepoints provides a snapshot of not only how children and families access services, but how these eligibility requirement trends are shifting over time very slowly. For Part C services, there is a movement towards states implementing more broad eligibility requirements, but this is not widespread. Across the six years and three time points discussed, two states changed their eligibility criteria to a broader definition. A broader definition of eligibility for Part C services creates more opportunities for children to receive these services and is more in keeping with the JCIH (2019) guidance. This appears to be a transition within policies that were reported in this study to view hearing as a categorical variable, rather than a nominal. The categorical approach to hearing increases access to care and work to acknowledge that all hearing level differences require specialized support to ensure access to language and development.

Table 1 provides a directory of all states criteria as of 2022 and can be used to inform future legislative changes to Part C eligibility as it denotes the precedent for service provision across the country and outlines the variety of program implementations possible. States considering revising Part C eligibility criteria for children who are DHH may benefit from examples of other states with various other structures for eligibility and EHDI specific contacts within Part C for each state. This finding is a new addition to the literature base with Findlen et al. (2022) calling for the collection of this type of data to provide more insight into the barriers to access that families experience in the EHDI system (Findlen et al., 2022). Having a comprehensive
list of all state eligibility criteria will allow future work to interpret national aggregate data on EHDI service utilization.

Limitations

This study benefited from high response rates and clarifications from states about public policies. However, not every state responded to attempts to contact and it is important to note that decisions to support enrollment in early intervention may be made on a case-by-case basis using professional opinion and this might lead to variability in the application of the noted policies. At the same time, this study investigates Part C EI. Private EI services are an option that is available instead of or in tandem with Part C EI. These services are not governed by the IDEA and were not evaluated in this study. Future assessments of the EI system for children who are DHH, and their families must acknowledge the role of non-Part C EI in children and family life. A lingering question in this discussion is the drivers of eligibility criteria on EI enrollment for children who are DHH. It is possible that some states with more restrictive criteria serve more children, but it was beyond the scope of this study to address this question given the nature of data collection.

Future Directions

As an initial introduction to the variability in Part C service access for children who are DHH, this paper sets the foundation for the various eligibility criteria across states. Now that the categorical elements of eligibility have been documented, it is time to assess the impact that these parameters have on actual enrollment in Part C services. The structure of the data currently reported by the CDC on state-level intervention enrollment for children who are DHH does not lend itself to traditional
ANOVA analysis to answer this question. In order to address this question, further work is needed to work with individual states on collecting data on enrollment, inclusive of potential determinates outside of eligibility criteria such as the social determinants of health and drivers behind why states select these different criteria.

**Conclusion**

Part C systems provide a critical line to early intervention services for children who are DHH and their families. At the federal level, the IDEA endows states with the ability to structure their Part C systems, including eligibility criteria, in a manner that best meets the needs and unique situation of that state. Table 1 serves as a 2022 directory for professionals, families, policy makers, and researchers to use as they work to ensure care and support for children and families. Each of these stakeholder groups will use this information differently, some for clinical service provision, some for legislative change, and others to better understand data sets. This table is the foundation for future work in a number of areas.
References


https://www.cdc.gov/ncbddd/hearingloss/2014-
data/2014_ehdi_hsfs_summary_h.pdf


https://www.cdc.gov/ncbddd/hearingloss/2017-data/01-data-summary.html

Retrieved from https://www.cdc.gov/ncbddd/hearingloss/ehdi-data.html

CDC. (2020b). Information by state. Retrieved from
https://www.cdc.gov/ncbddd/actearly/parents/state-text.html


CDC. (2020e). 2018 Summary of infants identified with permanent hearing loss enrolled in early intervention (EI) before 6 months of age. Retrieved from
CDC. (2020f). 2018 Summary of national CDC EHDI data. Retrieved from

CDC. (n.d.a.). Summary of 2007 national CDC EHDI data. Retrieved from

CDC. (n.d.b.). Summary of 2008 national CDC EHDI data. Retrieved from

Early Childhood Technical Assistance Center. (2015). States’ and territories’ definitions
of/criteria for IDEA Part C eligibility. Retrieved from
https://ectacenter.org/~pdfs/topics/earlyid/partc_elig_table.pdf

Early Childhood Technical Assistance Center. (n.d.) State and Jurisdictional Eligibility
Definitions for Infants and Toddlers with Disabilities Under IDEA Part C.

1219, 1220, 1221, 1222 and 1223, codified as amended at title 42 USC §§ 280g
and 280g-1

Barriers to and Facilitators of EHDI: Learning from Our Past for a Better Future.
[Conference session]. Early Hearing Detection and Intervention Annual
Conference, virtual.
https://ehdiconference.org/Schedule/griddetails.cfm?aid=14942


<table>
<thead>
<tr>
<th>State</th>
<th>Policy group</th>
<th>Criteria</th>
<th>State Web Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="https://www.rehab.alabama.gov/services/early-intervention/ei">https://www.rehab.alabama.gov/services/early-intervention/ei</a></td>
</tr>
<tr>
<td>Alaska</td>
<td>4</td>
<td>A diagnosis of hearing loss of 40dB or greater bilaterally; or chronic otitis media lasting at least 6 months with documented fluctuations in hearing. Individuals who do not meet this criterion may be deemed eligible based on informed clinical opinion.</td>
<td><a href="http://dhss.alaska.gov/ddsp/Pages/infantlearning/contacts/default.aspx">http://dhss.alaska.gov/ddsp/Pages/infantlearning/contacts/default.aspx</a></td>
</tr>
<tr>
<td>Arizona</td>
<td>1</td>
<td>No specified criteria based on hearing loss alone. Children can become eligible for early intervention based on one of three reasons: 1. An established condition 2. A significant developmental delay in at least one area 3. Informed clinical opinion No dB threshold required in the policy nor has the program issued guidance issued around a dB threshold. There is the expectation that providers base their eligibility decisions on scientifically based research, to the extent practicable. Providers also use Informed clinical opinion (ICO) as a part of every eligibility decision and ICO may be used to establish a child’s eligibility for AzEIP even when other instruments do not establish eligibility.</td>
<td><a href="https://des.az.gov/services/disabilities/developmental-infant">https://des.az.gov/services/disabilities/developmental-infant</a></td>
</tr>
<tr>
<td>Arkansas</td>
<td>2</td>
<td>Infants/toddlers who have a diagnosis of hearing loss or a condition that is likely to result in developmental delays are eligible for early intervention. Program policy does not indicate specific levels, etiology, or laterality.</td>
<td><a href="https://dhs.arkansas.gov/dds/firstconnectionsweb/#fc-contact">https://dhs.arkansas.gov/dds/firstconnectionsweb/#fc-contact</a></td>
</tr>
<tr>
<td>California</td>
<td>4</td>
<td>A diagnosis of hearing loss of 30 dB or greater in at least one ear.</td>
<td><a href="https://www.dds.ca.gov/services/early-start/">https://www.dds.ca.gov/services/early-start/</a></td>
</tr>
<tr>
<td>Colorado</td>
<td>3</td>
<td>A diagnosis of any degree of bilateral hearing loss is eligible for services. Individuals who do not meet this criteria may be eligible if they present with a 25% or greater delay in one of the developmental domains.</td>
<td><a href="http://coloradoofficeofearlychildhood.force.com/eicolorado/EI_QuickLinks?p=Home&amp;s=Contact-Us-EI&amp;lang=en">http://coloradoofficeofearlychildhood.force.com/eicolorado/EI_QuickLinks?p=Home&amp;s=Contact-Us-EI&amp;lang=en</a></td>
</tr>
<tr>
<td>Connecticut</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="https://www.birth23.org/contact-2-2/">https://www.birth23.org/contact-2-2/</a></td>
</tr>
<tr>
<td>State</td>
<td>Code</td>
<td>Eligibility Criteria</td>
<td>Additional Resources</td>
</tr>
<tr>
<td>----------</td>
<td>------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Florida</td>
<td>3</td>
<td>Must meet one or more of the following:</td>
<td><a href="http://www.cms-kids.com/home/resources/es_policy/Attachments/3_Hearing_Loss_Criteria.pdf">http://www.cms-kids.com/home/resources/es_policy/Attachments/3_Hearing_Loss_Criteria.pdf</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1. A diagnosis of permanent hearing loss of:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>a. 25 dB or greater based on pure tone average of 500, 1000, and 2000 Hz unaided in at least one ear (air-bone gap not exceeding 10 dB HL unless there is evidence of anatomic malformation of the outer and/or middle ear)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>b. Air conduction thresholds, unaided in the better ear greater than 25 dB HL at two or more of the following frequencies: 2000, 3000, 4000, 6000 Hz in both ears (air-bone gap not exceeding 10 dB HL)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Evidence of auditory neuropathy spectrum disorder in one or both ears</td>
<td></td>
</tr>
<tr>
<td>Idaho</td>
<td>2</td>
<td>A diagnosis of hearing loss of 20 dB or greater in at least one ear</td>
<td><a href="https://healthhandwelfare.idaho.gov/Portals/0/Children/InfantToddlerProgram/Eligibility/ITPEligibilityCriteria.pdf">https://healthhandwelfare.idaho.gov/Portals/0/Children/InfantToddlerProgram/Eligibility/ITPEligibilityCriteria.pdf</a></td>
</tr>
<tr>
<td>Illinois</td>
<td>4</td>
<td>A diagnosis of hearing loss in at least one ear which meets the following criteria:</td>
<td><a href="http://www.dhs.state.il.us/page.aspx?item=30321">http://www.dhs.state.il.us/page.aspx?item=30321</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1. Hearing loss of 30 dB or greater at any two of the following frequencies: 500, 1000, 2000, 4000, 8000 Hz.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Hearing loss of 35 dB or greater at any one of the following frequencies: 500, 1000, 2000 Hz.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>If a birth to three child is referred and doesn’t meet the above criteria, there are more general developmental criteria.</td>
<td></td>
</tr>
<tr>
<td>State</td>
<td>Credits</td>
<td>Eligibility Criteria</td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>---------</td>
<td>----------------------</td>
<td></td>
</tr>
<tr>
<td>Indiana</td>
<td>3</td>
<td>A diagnosis of any degree of permanent hearing loss in at least one ear. <a href="https://www.in.gov/fssa/4655.htm">Link</a></td>
<td></td>
</tr>
<tr>
<td>Iowa</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear. <a href="https://www.iafamilysupportnetwork.org/early-access-iowa">Link</a></td>
<td></td>
</tr>
<tr>
<td>Kansas</td>
<td>3</td>
<td>A diagnosis of any degree of permanent hearing loss in at least one ear. <a href="https://www.kdhe.ks.gov/DocumentCenter/View/5923/Eligibility-PDF">Link</a></td>
<td></td>
</tr>
<tr>
<td>Kentucky</td>
<td>2</td>
<td>A diagnosis of hearing loss of 25 dB or greater in the better ear. <a href="https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/firststeps.aspx">Link</a></td>
<td></td>
</tr>
<tr>
<td>Louisiana</td>
<td>3</td>
<td>A diagnosis of permanent hearing loss of 25 dB or greater in at least one ear <a href="http://ldh.la.gov/index.cfm/page/139/n/139">Link</a></td>
<td></td>
</tr>
</tbody>
</table>
| Maine  | 3       | Must meet one of the following:  
1. A diagnosis of sensorineural hearing loss in at least one ear, consistent with one of the following unaided thresholds:  
a. Hearing loss of 25 dB HL or greater, based on pure tone average of 500, 1000, and 2000 Hz  
b. Hearing loss of 25 dB HL at two or more of the following frequencies: 2000, 3000, 4000, 6000 Hz (air-bone gaps not exceeding 10 dB HL)  
2. Evidence of an anatomical malformation of the outer and/or middle ear in conjunction with a hearing loss > or = the pure tone average of 500, 1000, or 2000 Hz  
3. Chronically unresolved or recurring conductive hearing loss of 25 dB or greater in at least one ear based on a pure tone average of 500, 1000, and 2000 Hz in conjunction with at least two of the following:  
a. 4 or more episodes of otitis media within a 12-month period and/or a single episode of otitis media (w/ or w/o effusion) lasting longer than 3 months  
b. Caregiver or physician concern over speech and/or language development related to hearing loss.  
c. Documented fluctuating hearing loss of 20 dB or greater (this includes conductive loss). Caregiver concerns related to limited response to spoken direction and/or environmental sounds. [Link](https://www.maine.gov/doe/learning/cds) |
<table>
<thead>
<tr>
<th>State</th>
<th>Grade</th>
<th>Eligibility</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maryland</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="http://marylandpublicschools.org/programs/Pages/Special-Education/MITP/about/index.aspx">http://marylandpublicschools.org/programs/Pages/Special-Education/MITP/about/index.aspx</a></td>
</tr>
<tr>
<td>Massachusetts</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="https://www.mass.gov/lists/early-intervention-policies">https://www.mass.gov/lists/early-intervention-policies</a></td>
</tr>
<tr>
<td>Michigan</td>
<td>3</td>
<td>A diagnosis of hearing loss of 25 dB or greater in at least one ear at least two frequencies between 500-4000 Hz. If hearing loss is conductive, it must be permanent. Auditory neuropathy is a qualifying condition.</td>
<td><a href="https://1800earlyon.org/contact.php">https://1800earlyon.org/contact.php</a></td>
</tr>
<tr>
<td>Mississippi</td>
<td>3</td>
<td>A diagnosis of any degree of permanent hearing loss in at least one ear.</td>
<td><a href="http://www.msdh.state.ms.us/msdhsite/index.cfm/41,0,74,html">http://www.msdh.state.ms.us/msdhsite/index.cfm/41,0,74,html</a></td>
</tr>
<tr>
<td>Missouri</td>
<td>3</td>
<td>A diagnosis of any degree of permanent hearing loss in at least one ear.</td>
<td><a href="https://dese.mo.gov/specialeducation/first-steps/eligibility">https://dese.mo.gov/specialeducation/first-steps/eligibility</a></td>
</tr>
<tr>
<td>Nebraska</td>
<td>1</td>
<td>No specified state-level criteria; each school district sets their own criteria.</td>
<td><a href="http://edn.ne.gov/cms/contact-us">http://edn.ne.gov/cms/contact-us</a></td>
</tr>
<tr>
<td>State</td>
<td>Level</td>
<td>Eligibility Criteria</td>
<td>Website Link</td>
</tr>
<tr>
<td>---------------</td>
<td>-------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Nevada</td>
<td>4</td>
<td>A diagnosis of permanent hearing loss of 40 dB or greater for at least one frequency in at least one ear.</td>
<td><a href="http://dhhs.nv.gov/Programs/IDEA/Early_Intervention_Programs/">http://dhhs.nv.gov/Programs/IDEA/Early_Intervention_Programs/</a></td>
</tr>
<tr>
<td>New Hampshire</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="https://www.dhhs.nh.gov/dcbcs/bds/earlysupport/index.htm">https://www.dhhs.nh.gov/dcbcs/bds/earlysupport/index.htm</a></td>
</tr>
<tr>
<td>New Jersey</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="https://nj.gov/health/fhs/earlyneed/for-families/when/">https://nj.gov/health/fhs/earlyneed/for-families/when/</a></td>
</tr>
<tr>
<td>New Mexico</td>
<td>3</td>
<td>A diagnosis of any degree of permanent hearing loss in at least one ear.</td>
<td><a href="https://www.earlylearningnm.org/fit-program---early-intervention">https://www.earlylearningnm.org/fit-program---early-intervention</a></td>
</tr>
<tr>
<td>New York</td>
<td>3</td>
<td>A diagnosis of any degree of hearing loss in at least one ear, with the primary focus on permanent bilateral sensorineural hearing loss.</td>
<td><a href="https://www.health.ny.gov/community/infants_children/early_intervention/">https://www.health.ny.gov/community/infants_children/early_intervention/</a></td>
</tr>
<tr>
<td>North Carolina</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="https://beearly.nc.gov/index.php/">https://beearly.nc.gov/index.php/</a></td>
</tr>
<tr>
<td>Ohio</td>
<td>2</td>
<td>A diagnosis of any degree of sensorineural hearing loss in at least one ear.</td>
<td><a href="https://ohioearlyintervention.org/">https://ohioearlyintervention.org/</a></td>
</tr>
<tr>
<td>Oklahoma</td>
<td>3</td>
<td>A diagnosis of permanent hearing loss of 25 dB or greater in at least one ear.</td>
<td><a href="https://sde.ok.gov/sooners/start">https://sde.ok.gov/sooners/start</a></td>
</tr>
<tr>
<td>Oregon</td>
<td>2</td>
<td>Must meet one of the following criteria:</td>
<td><a href="https://www.oregon.gov/ode/students-and-family/SpecialEducation/earlyintervention/Pages/default.aspx">https://www.oregon.gov/ode/students-and-family/SpecialEducation/earlyintervention/Pages/default.aspx</a></td>
</tr>
</tbody>
</table>

- Nevada: [http://dhhs.nv.gov/Programs/IDEA/Early_Intervention_Programs/](http://dhhs.nv.gov/Programs/IDEA/Early_Intervention_Programs/)
- New Jersey: [https://nj.gov/health/fhs/earlyneed/for-families/when/](https://nj.gov/health/fhs/earlyneed/for-families/when/)
- New Mexico: [https://www.earlylearningnm.org/fit-program---early-intervention](https://www.earlylearningnm.org/fit-program---early-intervention)
- Ohio: [https://ohioearlyintervention.org/](https://ohioearlyintervention.org/)
- Oklahoma: [https://sde.ok.gov/sooners/start](https://sde.ok.gov/sooners/start)
- Oregon: [https://www.oregon.gov/ode/students-and-family/SpecialEducation/earlyintervention/Pages/default.aspx](https://www.oregon.gov/ode/students-and-family/SpecialEducation/earlyintervention/Pages/default.aspx)
<table>
<thead>
<tr>
<th>State</th>
<th>Code</th>
<th>Diagnosis</th>
<th>Additional Info</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rhode Island</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear. Preferred language at the state level is “impaired hearing in one or both ears.”</td>
<td><a href="http://www.eohhs.ri.gov/Consumer/FamilieswithChildren/EarlyIntervention.aspx">http://www.eohhs.ri.gov/Consumer/FamilieswithChildren/EarlyIntervention.aspx</a></td>
</tr>
<tr>
<td>South Carolina</td>
<td>3</td>
<td>A diagnosis of bilateral hearing loss of 20 dB or greater. If the child has unilateral hearing loss, it must be related to a particular diagnosis.</td>
<td><a href="https://msp.scdhhs.gov/babynet/">https://msp.scdhhs.gov/babynet/</a></td>
</tr>
<tr>
<td>South Dakota</td>
<td>2</td>
<td>No specified threshold required. A child is eligible if by a medical diagnosis or an informed clinical opinion there is detected hearing loss.</td>
<td><a href="https://doe.sd.gov/birthto3/">https://doe.sd.gov/birthto3/</a></td>
</tr>
<tr>
<td>Tennessee</td>
<td>2</td>
<td>A diagnosis of any degree of permanent hearing loss in at least one ear that is not attributed to another cause. Confirmation of hearing-related diagnosis is required.</td>
<td><a href="https://www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis.html">https://www.tn.gov/didd/for-consumers/tennessee-early-intervention-system-teis.html</a></td>
</tr>
<tr>
<td>Texas</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="https://hhs.texas.gov/services/disability/early-childhood-intervention-services">https://hhs.texas.gov/services/disability/early-childhood-intervention-services</a></td>
</tr>
</tbody>
</table>
| Utah           | 2    | A documented sensorineural or conductive hearing loss in either or both ears (any hearing level, mild included); Inconsistency in test results including Otoacoustic Emission (OAE), Auditory Brainstem Response and/or booth testing; A documented Auditory Neuropathy Spectrum Disorder diagnosis; Failed Otoacoustic Emission tests under the following conditions: Two (2) failed OAEs, if the child is enrolled in the BWEIP with the delays in the area of communication; or Three or more documented ear infections or episodes of middle ear fluid within a three- to six-month period. | [https://health.utah.gov/cshcn/contact/](https://health.utah.gov/cshcn/contact/) }
<table>
<thead>
<tr>
<th>State</th>
<th>Level</th>
<th>Eligibility Criteria</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vermont</td>
<td>1</td>
<td>No specified criteria based on hearing loss alone. Early Intervention is based on an observable and measurable delay in development.</td>
<td><a href="https://dcf.vermont.gov/child-development/cis/IDEA_part_C">https://dcf.vermont.gov/child-development/cis/IDEA_part_C</a></td>
</tr>
<tr>
<td>Virginia</td>
<td>2</td>
<td>A diagnosis of any degree of hearing loss in at least one ear.</td>
<td><a href="http://www.infantva.org/">http://www.infantva.org/</a></td>
</tr>
<tr>
<td>Wisconsin</td>
<td>3</td>
<td>A diagnosis of any degree of permanent hearing loss in at least one ear.</td>
<td><a href="https://www.dhs.wisconsin.gov/birthto3/family/qualify.htm">https://www.dhs.wisconsin.gov/birthto3/family/qualify.htm</a></td>
</tr>
</tbody>
</table>

*Table 1. State Part C Eligibility Criteria for Children Identified as D/deaf or Hard of Hearing in 2022*
Chapter 6
Modeling Lost to Intervention in Early Hearing Detection and Intervention:
A modified eDelphi study

Torri Ann Woodruff, MS & Kathleen M. Cienkowski, PhD
Department of Speech, Language and Hearing Sciences,
University of Connecticut, Storrs, Connecticut

Corresponding Author: Torri Ann Woodruff, MS
2 Alethia Drive U-1085
Storrs, CT 06269
(860)420-2161
Torri.woodruff@uconn.edu

Conflict of Interest Statement
The authors have no relevant conflicts to disclose. Following the completion of this study, it was awarded the Student Research Award from the Educational Audiology Association.
Abstract

Purpose: The purpose of this study was to develop a functional model of the drivers behind why a family may refuse early intervention services following the identification of a child as D/deaf or hard of hearing.

Method: This model was developed using a modified eDelphi method. Invited experts (n=155) were provided proposed models of why a family may refuse early intervention services in accordance with current literature. In the first phase of feedback, participants (n=23) provided changes they would make to the model to be more in line with their perceptions of lost to intervention. These changes were implemented and a second phase of feedback with participants (n=25) moved to accept the model as presented.

Results: Agreement was reached on five main barriers to early intervention access for children who have been identified as D/deaf or hard of hearing (Family Experience, Family Culture, Perceived Vulnerability, Perceived Benefits, Perceived Barriers). Each of these main barriers has associated examples of how they may manifest across different early intervention programs and situations.

Conclusion: This is the first theoretical model of why loss to intervention happens within Early Hearing Detection and Intervention. Having a model provides the opportunity for future work to implement novel approaches to support a family during the early intervention enrollment process.
Introduction

Lost to intervention

Early Hearing Detection and Intervention (EHDI) systems across the United States report data to the Centers for Disease Control (CDC) yearly regarding the number of children who have their hearing screened, receive diagnostic evaluations, the results of those evaluations, and how many children enroll in early intervention services. The minimum expectations are that children should have their hearing screened by one month of age, for those who refer on that screening a diagnostic evaluation of hearing should be conducted by three months of age, and early intervention for children who are identified as D/deaf and hard of hearing should be started by six months of age (Joint Committee on Infant Hearing, 2019). Programs meeting these age-specific benchmarks are encouraged to have diagnostic evaluations by two months of age and early intervention by three months of age (Joint Committee on Infant Hearing, 2019).

If a child does not make it to the next clinically indicated step at any point in this progression, they are deemed lost to follow-up/documentation (LTFUD). In this study, the term LTFUD is broken down into children who do not receive a screening (lost to screening), children who do not receive diagnostic evaluations after referring on their screening (lost to identification), and children who do not enroll in early intervention services after identification as D/deaf and hard of hearing (lost to intervention, LTI). Specifically for children who are LTI, they have a diagnosis that may put them at an increased risk of developmental challenges without appropriate support. Children and their family being LTFUD at any point is counter to EHDI goals, not supportive of age-
appropriate development, and may put these children at risk of language deprivation (Hall, 2017; Yoshinaga-Itano, 1999; 2003; 2013).

Unaddressed childhood hearing differences and an associated lack of linguistic access has profound impacts on child development and is known to have downstream impacts on the individual themselves in terms of difficulty accessing education, lower literacy rates than typically hearing peers, challenges in social settings, and impaired executive functioning (LeClair & Saunders, 2019). As the individual transitions from childhood to adulthood, these challenges create ripple effects throughout the person’s life and community impacting productivity of an individual and increasing the cost of care in the public sector (World Health Organization, 2021). Outside of the individual, unaddressed differences in hearing have been associated with increasing costs for public education that is exacerbated by delayed intervention and the existence of social stigma (Grosse, 2007; Hearing Industries Association, 2004; LeClaire & Saunders, 2019). The World Health Organization (2021) advocates for early intervention and work to address hearing differences as soon as possible to mitigate these challenges.

In 2019, over 38% of the children reported to the CDC by EHDI programs as D/deaf or hard of hearing did not receive early intervention services and are LTI (Centers for Disease Control and Prevention, 2021c). Historically, CDC EHDI data available (2005-2019) demonstrates there is consistently over 20% of those identified that are not enrolling in early intervention services (Centers for Disease Control and Prevention, 2021c; 2020; 2019a; 2019b; 2019c; 2016a; 2016b; 2014; 2013; 2012; 2011; 2010a; 2010b; 2010c; 2010d). The most common known reason children identified as D/deaf and hard of hearing do not receive services is that their family refused (Centers
for Disease Control and Prevention, 2021c). While each family has its own strengths, needs, and preferences of early intervention services, the Individual Family Service Plan (IFSP) that structures the services provided is structured to meet expressed needs and preferences (Individuals with Disabilities Education Act of 2004). With this individualization in the IFSP and the wide range of services available to children and their family, the consideration of preferences for how services are provided also allows for refusal of any services (Individuals with Disabilities Education Act of 2004).

Need for a model

The goal of this study was to develop a model to describe what factors impact a family’s decision not to enroll in early intervention services. While each state has the flexibility to determine its own path to rescreening and diagnostic services, current discussions around children who are LTFUD tend to focus on the need for rescreening and diagnostic services. The works of Hunter et al. (2016) and Yarbrough et al. (2018) both discuss programs aimed at supporting children and their family when a follow-up rescreening is needed. Cockfield et al. (2012) took a slightly different approach looking at parent education to support access to diagnostic services. All three of these exemplars addressed logistical barriers to care, such as access to services, care coordination/support, and knowledge on diagnostic evaluations. While these studies did not highlight all the work done by state and national EHDI groups, they represent a trend in the published research to conceptualize LTFUD as something that happens before diagnostic services.

Children who are LTI make up a population where all members have been identified as D/deaf and hard of hearing yet are not accessing services. In this
population, compared to children lost before diagnostic services, all the children who are LTI are D/deaf or hard of hearing and presented with hearing level differences. Thus, the ratio of children who are D/deaf or hard of hearing who are at risk of language deprivation after being LTI is higher than for children who are LTFUD before diagnostic services, as the majority of these individuals who are LTFUD before identification are not expected to have hearing thresholds outside of the typical range.

At the same time, the drivers for what leads to LTI are theorized to be markedly different from those of other forms of LTFUD that trend towards logistical barriers (Liu, et al., 2008; Scheepers, et al., 2014). The incidence of personally driven disengagement with services (the ratio of families who actively refuse early intervention services) compared to logistical barriers to care (families could not be contacted, families were unresponsive, families moved out of jurisdiction, etc.) is higher in LTI compared to lost to screening or identification (Centers for Disease Control and Prevention, 2021a; 2021b; 2021c). In LTI, families are actively refusing services for some reason that is not explained in current national data sets (Centers for Disease Control and Prevention, 2021a). The drivers for this refusal are not captured in questions about logistical barriers, such as eligibility for services or ineffective contact measures. Thus, when considering LTFUD, it is critical to consider LTI as a separate subgroup from that of children who are LTFUD before diagnostic services. This acknowledgment is the first step towards developing programs and support specifically aimed at children who have been identified as D/deaf and hard of hearing and their family. This investigation was developed to help researchers, program developers, and implementers better understand the needs of each family they serve and have a theoretical and empirically
developed basis to use in working to address LTI and the above-described adverse sequelae of language deprivation and lack of linguistic access in children who are D/deaf and hard of hearing.

**Methods**

**Delphi methods**

A Delphi study engages expert stakeholders in iterative cycles of individual judgment and reflection (Okoli & Pawlowski, 2004; McPherson, Reese, & Wendler, 2018; Skulmoski, et al., 2007). The goal is to develop a panel that promotes an anonymous and balanced viewpoint where, through input aggregation, a consensus is found (McPherson, Reese, & Wendler, 2018). Delphi studies implement qualitative and quantitative components and have been used in healthcare and inquiry in audiology to understand clinician training, core competencies, and the development of models for care (Henderson, et al., 2016; Nickbakht, et al., 2022; McPherson, et al., 2018; Meibos, et al., 2019; Xue, et al., 2017). This study used a modified eDelphi approach where a panel of experts engaged in two phases of feedback on a proposed model of why LTI happens. Through these phases of feedback, participants reached consensus, but did not determine validity (Xue, et al., 2017). The experts drove the model's movement towards determinants that they perceive as impacting LTI. The Delphi approach is uniquely well suited for this investigation because of the focus on encouraging the engagement of diverse stakeholders when creating the expert panel. As implemented in this study, the Delphi method created a space to engage a large number of stakeholders who have knowledge of LTI but are not LTI themselves. While connecting with families who have refused early intervention services would be ideal,
due to the nature of LTI and a lack of contact, contacting a large population of these specific families is not feasible. Also, recruiting solely from one population, such as families who are LTI, may not represent insight into the structural causes of LTI that can be seen by those who work within the EHDI system.

Stakeholders in the EHDI system range from clinical care providers, legislators, families, self-advocates, and many more. Members of these different stakeholder groups were identified and invited to join our panel of experts for this study using the protocol by Okowi and Pawlowski (2004) discussed below. The questions posed to participants addressed the specific lived experiences that each of these populations have within the EHDI system and work to use these experiences to garner a deeper understanding of the social, personal, and cultural impacts on LTI that are not currently grasped in the national CDC data sets on EHDI. The engagement of these stakeholders is explicitly called for in federal legislation and many state implementations. With this, to embody the spirit of EHDI within this investigation qualitative methods, specifically the Delphi method, engaged those who drive the EHDI system. This study moved forward as an “eDelphi” due to the COVID-19 pandemic. The use of electronic data collection also cut down on the use of physical mail and the noted strains on participant time in mailing results using the US Mail Service.

**Initial model development**

Given this is a modified eDelphi, the panel of experts was presented with a preliminary model rather than providing general recommendations without this structure (appendix A). In this study, the initial model was developed through a review of the current literature on LFUD in general. This search included research that pointed to factors
associated with lost to screening and lost to identification. The elements that were found within the literature base were then crossed with the Health Belief Model (HBM) to provide preliminary structure to the information present within the literature base. The HMB is a commonly used framework to explain health behaviors and organize interventions to change such behaviors (Bartholomew Eldridge, et al. 2016; Champion & Skinner, 2008). In short, this model posits that perceived susceptibility to a condition being avoided, perceived severity of the condition if it develops, perceived benefits of engaging in the healthy behavior, perceived barriers to the healthy behavior, perceived self-efficacy in performing the healthy behavior, and outside cues to remind them to do the behavior all impact health decisions (Bartholomew Eldridge, et al., 2016; Champion & Skinner, 2008).

Since EHDI is a public health service governed by the Early Hearing Detection and Intervention Act of 2017, a public health law, a public health theory like the HMB was drawn upon for organizational purposes with the conceptualization that early intervention services is a health behavior that a family can engage in to address a child’s access to language. As a behavior change model, the HBM has been applied to adult amplification uptake and other public health initiatives such as reproductive education and risk behavior reduction (Saunders, et al., 2012; Bartholomew Eldridge et al., 2016). A challenge for families within EHDI (and an intervention target) is a lack of information about hearing and related topics. Given the HBM’s success in health education programs for other infant care needs such as maternal gestational nutrition (Khoramabadi et al., 2016), breast milk secretion (Liu, et al., 2018), and caring behaviors with pre-term infants (Ghomi, et al., 2019), this suggests it may be well suited
to meet this need in early intervention education. While starting with the HBM, this procedure allowed participants to highlight what determinants, from any source, impact LTI. The final model represented experts’ experiences and is not directly tied to the HMB.

**Recruitment**

To account for attrition in the expert panel of stakeholders, 155 invitations to participate were distributed with the goal of at least 10 participants in all phases from each of the following categories: those employed within EHDI or direct service providers to families involved with EHDI, noted researchers and academics, and family members/self-advocates. Hearing status was not a parameter that was explicitly used to invite participants but was noted when an individual publicly endorsed their status as an individual who was D/deaf or hard of hearing.

The protocol for inviting experts into this study was similar to that set by Okowi and Pawlowski (2004), with an emphasis on creating panels of participants who represent the invited groups and are not limited by the social network of the research team. Steps 1-5 were completed by two research team members independently and were then compared with disagreement met with discussion until agreement was reached.

1. Lists of relevant EHDI, early intervention, family support, and advocacy groups, organizations, and conferences were created.

2. Then individual names of potential experts from the identified groups, organizations, conferences, and such in step 1 were collected.

3. Individuals identified had their online accessible biographies and information reviewed to confirm the expert status and describe the type of involvement with LTI. Experts
included anyone in management, advocacy, family outreach, those who have presented on LTI or early intervention content to professional or community groups, or those endorsed as experts by previously identified participants. This variety in what constitutes expert status highlights the value of engagement from multiple perspectives and lends credence to the need for research of families to explicitly include family voice and honor the experience and expertise in raising a child who is D/deaf or hard of hearing while navigating the EHDI system. If, upon further review, an individual who had been previously identified as a potential participant did not meet these criteria in some way, they were excluded from further inclusion.

4. Individual information was reviewed again to determine the stakeholder group the individuals were a part of for our purposes. Invitees who represented more than one stakeholder group were categorized as a part of the category that had the least representation during that phase.

5. From here, invitees were rank ordered to determine who would be invited to participate first. However, it should be noted that all 155 participants identified through this process were invited to participate and the time of participation was not considered to be a factor that influenced the weighting of different qualitative comments.

6. For phase 1, 10 invitations to a new set of invitees in each stakeholder group were sent once a week until 10 participants endorsed that category on the survey or there were no further participants invited.

7. In phase two, all invitations for all participants were sent at the same time regardless of rank.
There was a specific effort to represent various states with both the highest (less than 50% enrollment in early intervention) and lowest (over 90% enrollment in early intervention) rates of LTI in the country during 2019, as EHDI is a national program. All communication modes (services, supports, and group enforcing a variety of uni- and multimodal forms of language) were also targeted, as there is a wide range of communication options and services available to individuals. The list of invited participants was developed using an iterative and premeditated outreach plan to capture professionals inside and outside the research team’s network (Okoli & Pawlowski, 2004). This process systematically reviews all possible sources of experts with whom members of the research team may not have previously had a working relationship. By encouraging new connections, the panel of experts are thought to better represent the global perspective on a topic that represents the variability in state implementations of EHDI, rather than that of an echo chamber for the research team. Each invited participant received a personalized email detailing this study's goals, why they were selected, the time commitment, and a link to participate.

**Phase One**

When members of the panel clicked on the link in their invitation email sent in over the course Fall/Winter 2020, after the consent process, they were provided information on the modified HBM (Appendix A). This modified HMB was developed based on a collection of works on EHDI, the HBM, and early intervention enrollment and serves as the initial model shown to participants in phase one. Below the information on the modified HBM was a series of Likert scale questions where they indicated the clinical utility of each determinant. Free response space was also available on the same
Phase Two

Phase two of this study aimed to develop a consensus around the appropriate drivers and organization within the model and LTI. Based on phase one, the revised modified model was shared with the participants via email link in Spring 2021. Once this link was opened, participants were shown the revised modified model (Appendix B). Their feedback was solicited in open response blocks on the overall fit of this model to the problem of LTI. Participants again saw Likert-like scales to indicate the degree of clinical utility of each presented concept. These questions also served to bolster qualitative comments by prompting thought on these concepts. Similarly to member checking, conformity to the intended comment from phase one. The qualitative comments from this phase were again subjected to the thematic coding described in
phase one. The final question on the page was a culminating dichotomous yes/no question about if they agree with this as a model to describe LTI. If a majority consensus of 66% on the model was not reached after this second phase, qualitative feedback was to be analyzed again, and a final third phase of distribution completed via an emailed link. However, this was not the case and consensus was met after two phases of feedback.

Results

Recruitment

The final pool of experts invited to participate included 155 individuals. It was curated to include individuals from various language backgrounds and those who represent multiple communities involved in providing support to children who are D/deaf and hard of hearing and their family. Participants in the survey were given the opportunity to provide fine-grain distinctions of their specific role (Service provider, EHDI administrator, Family, Self-advocate, Research/Academic, or Other) that were subsequently collapsed into three major categories (Professionals, Family and Self-advocates, and Researchers and Academics).

Some participants represented multiple stakeholder categories. In these instances, participants were assigned to the category that had the fewest identified experts. This procedure led to the group being comprised of 25% family members and self-advocates, 20% researchers and academics, and 55% professionals (Figure 1). While professionals working in various disciplines within EHDI make up the largest population invited, a quarter of all participants invited to participate were those who were identified as families of individuals served by EHDI or self-advocates. Hearing
status was not a parameter that was explicitly used to invite participants. In collecting publicly accessible information to determine stakeholder category and expert status (Professionals, Family and Self-advocates, and Researchers and Academics), approximately 10% of invited participants noted they were D/deaf or hard of hearing themselves.

**Phase One**

During phase one, 23 participants entered the survey and completed varying components resulting in a 14.8% response rate. The stakeholder identities, Figure 1, were separated into Family (n=8), Research/Academic (n=7), and Professional/Service Provider (n=8). Appendix A displays the model iteration shown to participants. Comments on this model were then collected and aggregated by stakeholder category in Table 1. These comments were reviewed and turned into action items. Action items, listed in Table 2, were functional steps taken to address comments and themes from participants and create the model shown in Appendix B. Table 1 shows the breakdown of comments by stakeholder group so that the action items in Table 2 can be linked back to each stakeholder group to ensure all points of view are represented in Appendix B.

Comparing Appendix A and B provides the most insight into the specific changes that were made based on the action steps presented in Table 2 as derived from the qualitative coding. The overarching directives from this phase of the Delphi included the addition of two new categories, family experience and family culture to highlight the impact of past experiences, biases, and culture in decision making, combination of perceived severity and perceived vulnerability to better reflect how participants
conceptualized these concepts, the removal of cues and self-efficacy as separate categories so that these concepts could be redistributed into other categories, the addition of explicit examples into each category such as a call out to unilateral hearing differences in perceived vulnerability, and an overhaul of the language used in the model to be more strengths based.

Table 3 shows the breakdown of the Likert like data and bolsters qualitative comments and calls for the removal/reorganization of concepts presented as part of Cues and Self-Efficacy with the least favorable scores in terms of utility and quality of description represented by more positive scores.

**Phase Two**

Participants in phase 2 were contacted using the same list and methods as phase one. Twenty-five participants responded to the phase two model, Figure 1, and represented Family/Self-advocate (n=5), Research/Academic (n=7), and Professional/Service Provider (n=13). As participation was anonymous, the individuals who returned to do the second phase were not explicitly tracked and those who did not respond to requests to participate in phase one were allowed to participate in phase two. Of the phase two participants, 24% (n=6) endorsed that they had been participants in phase one and an additional 32% (n=8) reported that they may have participated in phase one. The iteration of the model that participants were shown is presented in Appendix B. Comments on this iteration were coded and again sorted into Table 4.

Unique to this phase, participants were asked to respond to a dichotomous statement about their agreement with the model as presented. With majority acceptance of the current iteration of the model, by the 19 of 22 participants who responded to this
question (86.3%), the criteria for acceptance set forth (>66%) was met. With this, only respondent-provided edits for clarity were implemented into the final model, as there was not to be another phase to allow for content changes. Following the implementation of the clarity edits, the final model, Figure 2, was completed. This version of the model includes all information provided by participants, including sub examples.

Discussion

Though qualitative methods, a model of the determinants that contribute to why the family of a child who is D/deaf or hard of hearing may refuse early intervention services was developed. The action items described above were distilled from the qualitative coding process and resulted in Figure 2. This model provides a theoretical foundation for understanding why LTI exists within EHDI. The components presented (Family Culture, Family Experience, Perceived Vulnerability, Perceived Benefit, and Perceived Barriers) highlight key components of what drives LTI based on research, professional experience, and the insight from family and self-advocates. While this model is the first of its kind and probes the novel question of why there are a population of children who are LTI due to family refusal of services, the social determinants of health provide one way of considering why these specific factors were selected by participants as drivers in the decision to not access early intervention services.

Broadly, the social determinants of health are the parts of our world where we live, work, and play (U.S. Department of Health and Human Services, n.d.e). The five social determinants are economic stability, education access and quality, healthcare access and quality, neighborhood and built environment, and social and community context (U.S. Department of Health and Human Services, n.d.f.) These components can
be seen across the five categories of the final model, however the model developed in this study organizes the manifestations of each determinant based on how it presents in the community. This sets up future investigations to view these manifestations of determinants as actionable areas of change that are amenable to interpersonal, environmental, or policy interventions at the public health level and provides a foundation for understanding the social determinants of health may be the drivers behind why these factors impact enrollment in early intervention. Each social determinant can be discussed and illustrated with elements from the final model (figure 2) with connections to Healthy People 2030 (n.d.f.), a program within the U.S. Department of Health and Human Services that creates goals and metrics for addressing health disparities rooted in the social determinants of health.

**Economic Stability**

The social determinant of economic stability is broadly centered around the Healthy People 2030 goal of helping people earn steady incomes that allow them the meet their needs, specifically healthcare needs (U.S. Department of Health and Human Services, n.d.a). Conversely, economic instability and the inability to afford various healthcare needs detrimentally impacts the health of individuals and their communities. In LTI, the concept is ever present in the perceived barriers related to concerns about the cost of accessing early intervention services. The endorsed statement of “Depending on the state and financial situation/economic background of the family, some early intervention services will come with direct costs for enrollment and tangential costs, such as that of transport, that limit accessibility of services” hits at this concept and overlays of how economics, such as the direct cost of various devices and indirect costs such as taking
time off work or using fuel, can compound with other challenges, like limited access to transportation.

**Education Access and Quality**

Health People 2030 focuses on increasing educational opportunities for children and adolescents to address this determinant (U.S. Department of Health and Human Services, n.d.b). When looking at the decision-making process in families who refuse early intervention for children who are D/deaf and hard of hearing, these children who are not accessing intervention services may have challenges in accessing language and education later in life. When applying this determinant to a family who refuses early intervention services, the implications of not having access to educational opportunities, both in the past and in the moment, are to be considered. For example, with the expressed comment of “There is a need for more accessible information on intervention, family support services, hearing-specific intervention services, and language acquisition to support families in understanding the benefits of early intervention for their child, and the psychosocial functioning of the family” may point to a lack of background education or literacy in terms of accessing written or presented materials about early intervention stemming from the types of educational opportunities the family was provided during their own development. At the same, the need for increased educational opportunities for family is called for with the statement “Multiple approaches are needed, as are attempts, to share information on and connect individuals to interventions and various service providers.”
Healthcare Access and Quality

Increasing access to comprehensive and high-quality healthcare is the driver used to understand how this determinant can be used to improve community health and, in the case of this study, how access to early intervention can be supported when a child is identified as D/deaf or hard of hearing (U.S. Department of Health and Human Services, n.d.c). Given that early intervention is a healthcare service, this determinant is present through the model. The primary manifestations of this determinant in the model are as a call for more accessible content in terms of understand and culture. The first two statements under Family Culture where the disconnect between families served and providers is highlighted and calls for improvement in provider-patient/family communication are made both in general and specifically when language used in the home is not English. Of note is that access to early intervention services is a benchmark of Health People 2030 in terms of addressing this determinant (U.S. Department of Health and Human Services, n.d.c).

Neighborhood and Built Environment

The determinant of Neighborhood and Built Environment is addressed through the creation of neighborhoods and environments that promote health and safety (U.S. Department of Health and Human Services, n.d.d). Many of the challenges related to physical location are tied to forms of lost to follow up that occur before intervention services are indicated. While not heavily represented in this model, due to the type of lost to follow up under investigation, it is critical to remember that this determinant can work with other determinants, such as economic instability, and rurality, which further compound the changes or require creative family-centered problem solving to address.
Social and Community Context

The determinant of social and community context is focused on how support and empowerment is transmitted within a community (U.S. Department of Health and Human Services, n.d.e). To address this, Healthy People 2030 has the goal of increasing social and community support, similarly to all the concepts endorsed as elements of family experiences in this study. How individual families and communities view early intervention services shapes involvement and how comfortable families are reaching out to state services for intervention. This in turn impacts the the ease families have finding social supports that are called for to address barriers present in family conceptualizations of perceived benefit. This concept is outlined by point two of this section “There is a need for more accessible information on intervention, family support services, hearing-specific intervention services, and language acquisition to support families in understanding the benefits of early intervention for their child, and the psychosocial functioning of the family.”

The components in this model reinforce that the challenges associated with LTI are unique from those of lost to screening and lost to identification and the current logistical focus on care coordination does not address all factors in play. Instead, the focus for LTI intervention must be family-centered with attention paid to the lens in which a family exists (culture and experience), and their perception of services and needs related to hearing.

The Abridged Model

An abridged version of the model was also developed based on the results of phase two. This model, Figure 3, includes the major categories and definitions only. The
sub examples are not included to allow for a more straight-forward presentation of the key components. The removal of sub examples in this abridged version of the model may provide states, agencies, and individual providers the flexibility to apply this model while keeping with a family-centered and individualized approach to supporting decision-making on early intervention enrollment. By retaining only the key components and descriptors, Figure 2 can be used as a starting point for future works looking to tailor this model to specific populations.

**Future directions**

This model is poised for use in creating, implementing, and evaluating programs that support children and their family during the start of their early intervention journey. By understanding the drivers of what leads to LTI, and specifically focusing on why a family may decline services, interventions to support these individuals can be developed. This model will serve as the foundation for developing Woodruff et al.’s (in preparation) “Swaddling Ear to Ear,” a research-based, family-focused, data-driven parent education module to support early intervention enrollment.

As the focus on supporting each family through the entire EHDI system continues to grow, the focus on LTI interventions will increase. Future work should consider the impact of each factor in the model to determine the relative effect of each discrete component. This future direction will provide a further strengthened foundation for future efforts to address model components and support early intervention enrollment.

Within the EHDI system, each state can structure its program to fit the needs and laws of that state. However, the population recruited for this study was from the national level. Moving forward, states can create their own focus groups or capitalize on task
forces and boards already involved in EHDI to help refine the model to meet the circumstances in their state, specifically in terms of the EHDI system and noted challenges. As with any work, this model is a consensus of our identified experts and will benefit from cultural tailoring and family-centered implementation.

**Conclusions**

Having a model of LTI that highlights the intrinsic differences between the various forms of lost to follow up in EHDI is critical for understanding the unique situation and positionality of every family. This model is a step towards family-centered care and responsive interventions to meet each family where they are within EHDI, be that screening, identification, or intervention. This study joins the growing collection of research in speech, language, and hearing sciences that implement the Delphi method. The Delphi method’s qualitative applications provide space for stakeholders in the EHDI system (parents, self-advocates, care providers, care coordinators, and program implementers) to provide meaningful feedback and genuinely engage in systems change work as intended within the Early Hearing Detection and Hearing Act of 2017.

**Acknowledgements**

This work was completed as part of Torri Ann Woodruff’s bound dissertation. Her committee, Dr Bernard Grela, Dr. Beth S. Russell, Dr. Kim Gans, Dr. Sarah Woulfin, Dr. Mary Beth Bruder, and her Major Advisor Dr. Kathleen Cienkowski provided vital feedback and support over the course of this and many other projects. Dr. Melissa Karp was a critical resource and aid in the development of the sample, analysis of the data, and interpretation of results.
Data Accessibility Statement

Due to the nature of this research and the small pool of experts, the risk of participant identification has been deemed the primary risk, thus supporting data is not available.


Individuals with Disabilities Education Act, 20 USC. § 1400 (2004)


https://doi.org/10.26077/19hq-4048

https://doi.org/10.1097/AUD. 0000000000000915


https://doi.org/10.1016/j.ijporl.2019.07.009


https://doi.org/10.1080/14992027.2017.1406156


Figure 1
Representation of Various Stakeholder Groups

- Professionals
- Researchers and academics
- Family members and self-advocates
Figure 2
Final Model

**Family Culture:** The intersection of an individual or family’s cultural identity along with the decision to enroll in early intervention services.

- The current make-up of the profession and common materials do not match the cultural, linguistic, and educational diversity that is represented by the families eligible for early intervention.
- Providers may not exhibit cultural understanding of each family’s unique situation.
- There is a need for the inclusion of all forms of communication (visual, auditory, and tactile) as opportunities that are not mutually exclusive.

**Family Experiences:** The unique experiences and feelings that families bring into their decisions about medical care and enrolling in early intervention services.

- Parents/caregivers and families who are D/deaf and hard of hearing themselves comprise a population that is under-represented in the research. These individuals may bring their own experiences that shape their early intervention enrollment decisions.
- Families may be uncomfortable or distrusting of involving themselves with state-run services, or with providers they perceive as inadequately skilled in providing services to children who are D/deaf and hard of hearing.
- Families may experience a range of emotions during the process of early identification and intervention. This range may include the expression of stress, grief, happiness, denial, guilt with accessing services in the place of others, and concerns about labeling a child at such a young age.

**Perceived Vulnerability:** The perceived risk and seriousness of not ensuring access to language following identification combine to form the perceived vulnerability of a family to adverse outcomes.

- Results of testing and information, specifically about how sensorineural hearing levels are typically permanent, are not presented in a way that can be understood by families.
- When referrals are made, or information about how hearing levels of any degree or laterality can impact the developmental trajectory for a child is presented, it is not done so in a way that families understand. Conversely, providers in early intervention systems and physicians may not be responding to the severity and critical nature of accessing support.
- There are few natural components to the environment to remind families when a child is identified as D/deaf or hard of hearing that early intervention may benefit them, since many families and individuals do not have any experience with hearing differences.
- Families of children with unilateral hearing differences may focus on the ear with auditory access and not see the need for services to support the child.

**Perceived Benefit:** The possibility to address adverse impacts of reduced access to language and perceptions about the feasibility of achieving those positive outcomes.

- Families may not understand their role in early intervention as a way of supporting their child’s development.
- There is a need for more accessible information on intervention, family support services, hearing-specific intervention services, and language acquisition to support families in understanding the benefits of early intervention for their child, and the psychosocial functioning of the family.
- Families have concerns about the ability of providers to meet their child’s needs and produce benefit especially when faced with other perceived health risks.

**Perceived Barriers:** The elements of enrolling in early intervention that make accessing early intervention more challenging or is perceived as a negative of enrolling.

- Current educational materials for families and early intervention system structures may not be comprehensible to families. There is a need for more information on early intervention topics presented in formats that are accessible.
- Depending on the state and financial situation/economic background of the family, some early intervention services will come with direct costs for enrollment and tangential costs, such as that of transport, that limit accessibility of services.
- The presence of medical complexity, risk factors, and additional disabilities complicate the process of accessing services, and those who are a part of the DeafPLUS community may feel like a separate population.
- The structure of state-level early intervention and EHDI systems may impact how enrollment referrals are made and how families are tracked.
- Multiple approaches are needed, as are attempts, to share information on and connect individuals to interventions and various service providers.
Figure 3
Abridged Model

Family Culture
The intersection of an individual or family’s cultural identity along with the decision to enroll in early intervention services.

Perceived Barriers
The elements of enrolling in early intervention that make accessing early intervention more challenging or is perceived as a negative of enrolling.

Perceived Benefit
The possibility to address adverse impacts of reduced access to language and perceptions about the feasibility of achieving those positive outcomes.

Perceived Vulnerability
The perceived risk and seriousness of not ensuring access to language following identification combine to form the perceived vulnerability of a family to adverse outcomes.

Family Experiences
The unique experiences and feelings that families bring into their decisions about medical care and enrolling in early intervention services.
<table>
<thead>
<tr>
<th>Barrier</th>
<th>Cues</th>
<th>Self-efficacy</th>
<th>Benefits</th>
<th>Seriousness</th>
<th>Susceptibility</th>
<th>Culture</th>
<th>Special Populations</th>
<th>Wording</th>
<th>Survey logistics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>noted researchers/academics</strong></td>
<td>Failure to make referral Lack of trust in systems, government, professional Privacy concerns Immigration status</td>
<td>Unclear concept Rename to follow up support Children may not provide behavioral cues to hearing Cues are location dependent - only some states have this challenge</td>
<td>Separate readiness from self-efficacy Father comment is unclear Second parental readiness comment is redundant with other sections</td>
<td>Address parents who are DHH and don’t do EI Stronger representation of perceived importance and motivation Parents do not understand their role in EI Not true that parents don’t see that value in EI</td>
<td>Does not make note of the variation in training for those doing diagnostics</td>
<td>Statements should be under seriousness</td>
<td>Lack of diverse providers Lack of diverse materials Lack of materials in home language Lack of cultural understanding</td>
<td>Model has negative tone Use of word parents</td>
<td>Participant hearing status and language Likert sections too similar across pages Not options to select more than one</td>
</tr>
<tr>
<td><strong>those employed within EHDI</strong></td>
<td>Families concealing preferences and home behaviors to not jeopardize services</td>
<td></td>
<td>Need to focus on language and the brain</td>
<td></td>
<td>Focus on amplification Spoken language and ASL are not mutually exclusive</td>
<td>Thank you for including DeafPlus DeafPlus as a different topic</td>
<td></td>
<td>Not option to select more than one</td>
<td></td>
</tr>
<tr>
<td><strong>family members/self-advocates</strong></td>
<td>Transient families are hard to track Providers not perceived as having needed skills Cues is unclear Move second cues to barriers Need for coordination This is an overwhelming time for families Parents need to see benefits</td>
<td></td>
<td>Where families get support (parent to parent, deaf mentor) First cues to seriousness</td>
<td>Unclear Statements should be under seriousness Explicit inclusion of visual language</td>
<td></td>
<td>Unilateral hearing (focus on good ear, not see impact of other ear)</td>
<td>Model has negative tone Wording is confusing</td>
<td>Not option to select more than one</td>
<td></td>
</tr>
<tr>
<td>Need for multiple attempts to educate on EI</td>
<td>Need for increased accessibility with other services</td>
<td>Need for connection with medical home</td>
<td>Father comment is unclear</td>
<td>Benefits are psychosocial as well Need for hearing specific services Covid and remote services do not feel effective</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2
Action Steps Developed in Phase One

<table>
<thead>
<tr>
<th>Perceived Barrier</th>
<th>Perceived Cues</th>
<th>Perceived Self-efficacy</th>
<th>Perceived Benefits</th>
<th>Perceived Seriousness</th>
<th>Perceived Susceptibility</th>
<th>Culture</th>
<th>Special Populations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Failure to make referral/data management</td>
<td>Unclear concept</td>
<td>Feedback that needs to be added</td>
<td>Address parents who are DHH and don't do EI</td>
<td>Feedback that needs to be added</td>
<td>Unclear concept – &quot;statements should be under seriousness&quot;</td>
<td>Feedback that needs to be added</td>
<td>Feedback that needs to be added</td>
</tr>
<tr>
<td>• Transient families are hard to track</td>
<td>• Children may not provide behavioral cues to hearing</td>
<td>• This is an overwhelmin g time for families</td>
<td>• Additional research on this population and move to new &quot;Family experience&quot;</td>
<td>• Doe s not make note of the variation in training for those doing diagnostics</td>
<td>• La ck of diverse providers</td>
<td>• Thank you for including DeafPlus</td>
<td></td>
</tr>
<tr>
<td>• Lack of trust in systems, government, professional</td>
<td>• Rename to follow up support</td>
<td>• Parents need to see benefits</td>
<td>• Stronger representation of perceived importance and motivation</td>
<td>• First cues to seriousness</td>
<td>• La ck of diverse materials</td>
<td>• DeafPlus as a different topic</td>
<td></td>
</tr>
<tr>
<td>• Privacy concerns</td>
<td>• Going forward, we will also have definitions of each category</td>
<td>• Cues are location depended 9 only some states have this challenge</td>
<td>• Additional research on this concept and emphasize this in the descriptions.</td>
<td>• Reframe here about how the structure might start with minimization</td>
<td>• La ck of materials in home language</td>
<td>• Move this to new topic</td>
<td></td>
</tr>
<tr>
<td>• Immigration status</td>
<td>All components moved to other columns and this was removed. The use of the words cues was misleading.</td>
<td>• Parents need to see benefits</td>
<td>• Not true that parents don't see that value in EI</td>
<td>• First cues to seriousness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Families concealing preferences and home behaviors to not jeopardize services</td>
<td>• Cues are location depended 9 only some states have this challenge</td>
<td>• Separate readiness from self-efficacy</td>
<td>• Remove and reframe according to point below</td>
<td>• Reframe to get at this point</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individuals and families may be uncomfortable or distrusting of involving themselves in state-run services</td>
<td>• Ren ame concept &quot;Family Experience&quot;</td>
<td>• Father comment is unclear</td>
<td>• Parents do not understand their role in EI</td>
<td>• Need to focus on language and the brain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Need for multiple attempts to educate on EI</td>
<td>• Removal concept &quot;Family Experience&quot;</td>
<td>• Removal concept &quot;Family Experience&quot;</td>
<td>• Reframe to get at this point</td>
<td>• Add to what needs to be more accessible</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multiple approaches and attempts are needed to share information on and</td>
<td>• Move second cues to barriers</td>
<td>• Second parental readiness is redundant with other sections</td>
<td>• Need to focus on language and the brain</td>
<td>• Benefits are psychosocial as well</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Need for coordination with other services</td>
<td>• Moved to barriers</td>
<td>• Delete</td>
<td>• More research on this</td>
<td>• Where families get support (parent to parent, deaf mentor)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Need for connection with medical home</td>
<td>• Moved to barriers</td>
<td></td>
<td></td>
<td>• Fold in with above point</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Moved to barriers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This will not become a component as the comments here are folded in elsewhere
<table>
<thead>
<tr>
<th>Wording</th>
<th>Survey logistics</th>
</tr>
</thead>
</table>
| connect individuals to interventions  
• Need for increased accessibility | Covid and remote services do not feel effective |

| This is a new component that has been added |

<table>
<thead>
<tr>
<th>Structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wording</td>
</tr>
</tbody>
</table>
| Model has negative tone  
• Reframe Use of word parents  
• Move to families where possible, where not parents/caregivers Wording is confusing Review each | Participant hearing status and language  
• Too much that might reduce anonymity. Also, recruitment looks to create diversity in this specifically so will not change Likert sections too similar across pages  
• Reformate so that the difference key words are bolded. Not options to select more than one Fix that |
Table 3  
*Likert Data from Phase One*

<table>
<thead>
<tr>
<th></th>
<th>Clinical Utility</th>
<th>Quality of Description</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Standard Deviation</td>
</tr>
<tr>
<td>Perceived Seriousness</td>
<td>-1.96</td>
<td>.9</td>
</tr>
<tr>
<td>Perceived Susceptibility</td>
<td>-2.24</td>
<td>.8</td>
</tr>
<tr>
<td>Perceived Benefit</td>
<td>-2.46</td>
<td>.6</td>
</tr>
<tr>
<td>Perceived Barriers</td>
<td>-2.12</td>
<td>.8</td>
</tr>
<tr>
<td>Cues</td>
<td>-1.56</td>
<td>1.3</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>-1.74</td>
<td>1.1</td>
</tr>
</tbody>
</table>
## Table 4
Comments from Phase Two (n=25)

<table>
<thead>
<tr>
<th>Noted researchers/academics</th>
<th>Copy Edit</th>
<th>Add specific example of existing idea</th>
<th>Clarify present idea</th>
<th>Remove specific examples of existing ideas</th>
<th>Linguistic choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Idea parents have that child not have needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concern that the child is taking services from others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concerns about labeling a child so young</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concerns with skills of providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providers lacking specialized training</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training for professionals on equity, diversity, and inclusion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of understanding of parental benefit of EI</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unclear comments about parents of children who are D/deaf and hard of hearing themselves</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Define “adequate” in concerns about providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More clarity with feelings mentioned post diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Second bullet sounds like screening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Impact of unilateral needs to be more clear</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separate ideas in second bullet of benefits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concerns if statement on the cost is true</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Edit section of DeafPlus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Removed EHDI from list of places where info is needed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remove COVID reference (this is transient)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical home does not fit in this discussion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deaf Gain language</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Those employed within EHDI</th>
<th>Copy Edit</th>
<th>Add specific example of existing idea</th>
<th>Clarify present idea</th>
<th>Remove specific examples of existing ideas</th>
<th>Linguistic choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concerns with skills of providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physicians not responding to severity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents think costs are higher than they are</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What if the parents don’t have access to peers?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents don’t see a benefit of the service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental denial</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More open to all communication modes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remove the word deprivation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family members/self-advocates</th>
<th>Copy Edit</th>
<th>Add specific example of existing idea</th>
<th>Clarify present idea</th>
<th>Remove specific examples of existing ideas</th>
<th>Linguistic choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational Background</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Economic background</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accessibility of communication for parents</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial Access</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost of transport</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Idea parents have that child not have needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concerns with skills of providers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EI providers not responding to severity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal systematic barriers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providers lacking specialized training</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The statement of utility of unilateral and mild are true</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statements don’t always fit with groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived health risks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remove COVID reference (this is transient)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More open to all communication modes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Did not indicate</th>
<th>Can’t read Copy Edit</th>
<th>Add specific example of existing idea</th>
<th>Clarify present idea</th>
<th>Remove specific examples of existing ideas</th>
<th>Linguistic choice</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

141
Appendix A
ModelShown in Phase One

Perceived Seriousness
- Results of testing and information about how sensorineural hearing levels are typically permanent are not understood by parents
- When referrals to other services are made, parents may not understand

Perceived Susceptibility
- Information about how hearing levels of any degree or laterality can impact the developmental trajectory for a child is not understood

Perceived Benefits
- Parents do not recognize early intervention services as a way of supporting their child’s development
- There is a need for more accessible information on intervention, parent support services, and EHDI

Perceived Barriers
- Current educational materials for parents and intervention system structures may not be comprehensible to parents of children and there is a need for more accessible information on hearing aids and technology
- Depending on the state and financial situation of the family, some services will come at a cost to families
- The social, physical, and accessibility of the environment that these children and families are in can pose specific challenges
- The presence of medical complexity, risk factors, and additional disabilities complicate the process of accessing services

Cues
- There are few cues to remind families when a child is diagnosed that they need services since many families and individuals do not have any experience with EHDI or hearing
- Providers and informational sources are not making the referral to EI/other services in a manner that highlights its importance

Parental readiness for change/Self-efficacy
- Early identification may lead to the experience of shock/stress along with grief if this is not a hoped for finding
- Parents see themselves as not having enough information on topics like early intervention
- Fathers parenting self-efficacy is positively associated with being involved with interventions

### Model Shown in Phase Two

#### Family Culture
- The intersection of an individual or family's cultural identity along with the decision to enroll in early intervention (EI) services
  - The current make-up of the profession and our materials do not match the cultural and linguistic diversity that is represented by the families that are eligible for early intervention.
  - Providers may not exhibit cultural understanding of each family's unique situation.
  - There is a need for the explicit inclusion and integration of visual language into EI that includes it and spoken language as not mutually exclusive options.

#### Family Experiences
- The unique experiences and feelings that families bring into their decisions about medical care and enrolling in EI services
  - Parents/caregivers and families who are D/deaf and hard of hearing themselves represent a population that is under-represented in the research. These individuals may bring their own experiences that shape their EI enrollment decisions.
  - Families may be uncomfortable or distrusting of involving themselves in state-run services or with providers not perceived as adequate.
  - Early identification may lead to the experience of shock/stress along with grief if this is not a hoped for finding. This can be an overwhelming time for families and this may impact their ability to begin the EI process.

#### Perceived Vulnerability
- The perceived risk and seriousness of not ensuring access to language following identification combine to form the perceived vulnerability of a family to adverse outcomes
  - Results of testing and information about how sensorineural hearing levels are typically permanent are not presented in a way that can be understood by families.
  - When referrals are made, or information about how hearing levels of any degree or laterality can impact the developmental trajectory for a child is presented, it is not done so in a way that families understand. Conversely, because of the variability in who counsels on screening results, the importance of this may not be highlighted.
  - There are few natural components to the environment to remind families when a child is identified that that early intervention may benefit them since many families and individuals do not have any experience with hearing.
  - Families of children with unilateral hearing differences may focus on the ear with access and not see the impact of decreased access.

#### Perceived Benefit
- The possibility to address adverse impacts of language deprivation and perceptions about the feasibility of achieving those positive outcomes
  - Families may not recognize their role in EI services as a way of supporting their child’s development.
  - There is a need for more accessible information on intervention, family support services, EHDI, hearing specific intervention services, and language in the brain to support families in understanding the benefits of EI for their child and the psychosocial functioning of the family.
  - Families have concerns about the ability of providers to meet their child’s needs and benefit, especially in the time of COVID-19.

#### Perceived Barriers
- The elements of enrolling in early intervention that make accessing early intervention more challenging or is perceived as a negative of enrolling
  - Current educational materials for families and intervention system structures may not be comprehensible to families of children and there is a need for more accessible information on early intervention topics.
  - Depending on the state and financial situation of the family, some EI services will come at a cost.
  - The presence of medical complexity, risk factors, and additional disabilities complicate the process of accessing services and those who are a part of the DeaPLUS community may feel like a separate population.
  - The structure of state-level EI and EHDI systems may impact how enrollment referrals are made and how families are tracked.
  - There is a need for multiple approaches and attempts are needed to share information on and connect individuals to interventions, various service providers, and medical homes.
Chapter 7

Application of Intervention Mapping to address Lost to Intervention in Early Hearing Detection and Intervention

Torri Ann Woodruff, M.S. and Kathleen M. Cienkowski, Ph.D.

Department of Speech, Language and Hearing Sciences

University of Connecticut

Storrs, CT 06268

Acknowledgments: We would like to thank the entirety of Torri Ann Woodruff’s dissertation committee (Drs. Kim Gans, Beth Russell, Mary Beth Bruder, Bernard Grela, and Sarah Woulfin) for their service on the committee and feedback during the development stages of the program described in this manuscript. Emily LaSpada provided critical insight as the trained implementor for this program. The authors declare they have no conflicts of interest. This research did not receive any specific grant from funding agencies in the public, commercial, or not for profit sectors.

Correspondence concerning this article should be addressed to: Torri Ann Woodruff, MS, 2 Alethia Drive, U-1085, Storrs, CT 06269. Email: torri.woodruff@uconn.edu; Phone: 860-420-2161.
Abstract

Purpose: Detail the application of intervention mapping as a protocol for developing a novel way to address lost to intervention within the early hearing detection and intervention systems.

Design: Intervention mapping (IM) is an approach to behavior change that is typically utilized in public health initiatives. This six-step process walks health program developers, researchers, and policy makers through a rigorous research and community-based approach to understanding why a health concern or problem is present in a community and to create an intervention to change it. While using IM to address lost to intervention in Early Hearing Detection and Intervention programs, the focus is on why families, after identification of their child as D/deaf or hard of hearing, choose to not enroll in early intervention services covered by part C of the Individuals with Disabilities Education Act of 2004.

Results: This process culminated in the development of “Swaddling Ear to Ear” as a novel approach to the implementation of behavior change theory and early intervention access.

Conclusion: Intervention Mapping is poised to support policy makers, care providers, and families with the requisite tools to navigate early intervention services and begin a systemic line of research working to access inequalities in barriers to care and access for newborns identified via Early Hearing Detection and Intervention programs across the United States.
Introduction

What is EHDI?

Early Hearing Detection and Intervention (EHDI) programs work to screen the hearing of all newborns, identify children who are D/deaf or hard of hearing, and support access to early intervention services with families (Early Hearing Detection and Intervention Act of 2022). These programs typically fall in line with the recommendations of the Joint Committee on Infant Hearing (JCIH, 2019) to screen the hearing of all newborns before they are one month of age, ensure that all children who refer on this screening receive a diagnostic evaluation by three months of age, and those identified as D/deaf and hard of hearing receive early intervention services by six months of age. Early intervention services include a wide range of supports tailored to meet the family's needs and can include the support of audiologists, speech language pathologists, sign language instructors, Deaf mentors, Teachers of the Deaf, and many more (Individuals with Disabilities Education Act of 2004). These services can be provided by various state agencies under Part C of the Individuals with Disabilities Education Act or those procured privately by families from community providers (CDC, 2021; Individuals with Disabilities Education Act of 2004). While EHDI programs are called for and funded at the national level as a part of public health law, within required components, each state can build its program to meet the specific needs of its community (Individuals with Disabilities Education Act of 2004).

While the success of EHDI programs in the United States during 2019 resulted in the screening of over 97% of births and the identification of 5,934 children as D/deaf or hard of hearing, only 3,662 (less than 2/3 of those identified) are reported to have
accessed early intervention services (CDC, 2021). This creates a critical population of those who were lost to intervention (LTI). The LTI population is comprised of individuals and families that have been identified as having a potential developmental risk factor and are not accessing the supports to ensure linguistic and emotional development. From a philosophical standpoint, LTI is in direct conflict with the intervention goals of EHDI and negates the success of screening and diagnostic efforts for those who are LTI. The value in screening and identification of children who are D/deaf and hard of hearing is tied to the positive impact that timely identification has on intervention services and supporting the linguistic and emotional development of the child and their families (Yoshinaga-Itano, 1999; 2003; 2013). When children are LTI they have been successfully screened and identified, but that information does not transition into actionable steps and supports. The screening and diagnostic information loses much of its potential impact and value.

With this conflict within the EHDI system, those who are LTI represent a critical breakdown in the support and facilitation of accessible information for children who are D/deaf or hard of hearing and their families. Current quality improvement programs in EHDI trend towards the increase of screenings and diagnostic evaluations. Recent work on LTI has highlighted that online information for families preparing to enter early intervention (those on the verge of being LTI) is not written in a manner that is linguistically accessible or in alignment with federal readability guidance (Woodruff & Cienkowski, 2021). Inaccessible information about early intervention compounds with these highly personal decisions across five main domains: family culture, family experience, perceived barriers, perceived benefits, and perceived vulnerability to
exacerbate misinformation and misinformation that prevents service access (Woodruff & Cienkowski, in review). There is now a critical need to address the challenge of LTI by infusing new research on this population with existing information about the successful implementation of public health programs (CDC, 2021).

**What is intervention mapping?**

Intervention Mapping (IM) is a protocol that walks through program development to support community-centered, research-driven, and theory-based interventions (Bartholomew Eldridge, Markham, Ruiter, Fernandez, Kok, & Parcel, 2016). This step-by-step protocol has a history in public health as a means of designing and evaluating intervention to change health behaviors and environments to improve health outcomes such as preventative medicine, cardiovascular health, and cancer (Majid, Kim, Cako, & Garliardi, 2018). The six steps (Figure 1) that make up IM are a means of making sure that research questions and approaches are consistent with behavior change theory, as well as what clinical providers need and families deserve (Bartholomew Eldridge et al., 2016). This function-driven education makes the use of IM more applicable and supports the use of manuscripts, like this one, detailing the application of the IM approach within the realm of EHDI.

**Purpose**

Walking through the discrete steps to apply IM to LTI within EHDI chronicles the novel, yet merited use, of this procedure. Documenting the multiple components to the application of IM within this area also serves to delineate the level of rigor inherent in this type of work. Future works looking to capitalize on the literature about behavior change in public health may use this manuscript as a formula for the application of IM to
topics with the realm of supporting children who are D/deaf or hard of hearing and their families. This manuscript will further the conceptualization of EHDI as an interdisciplinary service, specifically inclusive of public health services and theory.

**Intervention Mapping Steps**

**Step 1**

Step one of IM explicitly calls for the development of a working group of stakeholders to come together to determine the goals of the program (Bartholomew Eldridge et al., 2016). The working group should include individuals from a range of stakeholder groups and specialties that are primed to address the health concern in question (Bartholomew Eldridge et al., 2016). The working group for this study included experts in the following areas: IM, early intervention in speech language pathology, aural rehabilitation, qualitative research methods, developmental disabilities, and parent education. Additional consultations through this process were made by a culturally Deaf adult who identifies as a racial and linguistic minority and the parent of a child who is under the age of three.

Working group members were educated on the problem of LTI by Author Woodruff through multiple meetings, written documents, and a culminating dissertation prospectus and grant application. To support understanding of LTI and begin the theory driven process of IM, a logic model of the problem for LTI was developed based on the framework from Bartholomew Eldridge et al. (2016; Figure 2) and Woodruff & Cienkowski (in revision). A logic model is a visual representation of the behaviors and environmental factors that lead to a health problem, LTI, the larger quality of life concern
this health problem leads to, language deprivation and the determinants of these behaviors and environmental factors.

This logic model highlights the environmental determinants of a child’s family that are relevant to LTI and reinforces that there is a causal relationship between family culture, family experiences, perceived vulnerability, perceived benefit, and perceived barriers of EI and seeking help and the experience of language deprivation by children and families, a quality of life outcome, who do not get the support they are entitled to as a part of EI (Woodruff & Cienkowski, in review). Members provided feedback on the approach to modeling during group meetings as well as individually in some cases. As such, the goal of this implementation of IM is families electing to be a part of EI.

**Step 2**

With the logic model of the problem and the outcome established, the focus of IM moves to discrete steps outlined by Bartholomew Eldridge et al. (2016), rather than overarching topics and challenges. The next product is a matrix of performance and change objectives. Performance objectives are produced by crossing the determinants that shape the behavior with steps to engaging in the intended behavior (Bartholomew Eldridge et al., 2016). Some examples are shown in Table 1, column A. Each one of these performance objectives is then crossed with the determinants that were identified in Figure 2. Crossing the performance objectives with each determinant creates a cell in Table 1 where a change objective can be created. Change objectives are the outcomes from the intervention that work to move through the performance objectives while systematically addressing the determinates (columns B and C of Table 1). The goal of combining performance objectives with determinants to develop change objectives is to

150
outline the steps that participants will take within the intervention to create the desired outcome and ensure a systematic approach to addressing all facets of the health problem.

**Step 3**

Once the discrete expectations for each participant across all determinants and performance objectives have been identified, the mechanisms to engage each of these change objectives must be selected (Bartholomew Eldridge et al., 2016). Step three represents a critical shift in how IM pushes LTI interventions compared to that of current scripting or programs to address lost to screening or identification, given the interactive component with parents and the focus on theory-driven topics (National Center for Hearing Assessment and Management, 2010). The intervention materials created are focus on transitioning the participant from an educational setting to a point of critical thinking and empowerment to ensure the coordination of services to support access. This interaction addresses parental disengagement directly by developing an environment where engagement in the educational module is expected and creates an opportunity to practice engagement skills, consistent with the foundational practices of early intervention and the parental behaviors required to enroll in intervention services.

Each activity to elicit the completion of the change objective is derived from behavior change theory as it relates to the determinant being addressed. Table 2 shows the linkage of a few change objectives and the research-backed approach to changing that at the cognitive level (Bartholomew Eldridge et al., 2016). The decision on what activities to engage in during the module were focused on those that have been implemented in other behavior change interventions. Specifically, the approaches
implemented were those that work to change initial determinates related to perception of health. Specific emphasis was placed on those behaviors that could be implemented a strengths-based and errorless learning approach such as role play, guided practice, personalized risk, and implementation planning. Thus, the environment that a child grows up in (family) will have the perception of EI altered to be more in line with engagement in the intended health outcome of accessing EI.

**Step 4**

In step four of IM, the planning moves from theory-based to physical production (Bartholomew Eldridge et al., 2016) of the intervention. Here the method of intervention delivery was selected to be online. With COVID-19 at the top of many Americans minds and the continued variability in safety for gathering and physical contact, online delivery methods are accessible regardless of current public health guidance. Also, building an online resource to move in tandem with the educational program increases the reach of the intervention. The website itself was built in Google to have compatibility with a variety of web enabled devices, including cellphones. With over 91% of the United States population having access to the internet through their cellphone, this confounding barrier is limited (Statista, 2022).

With the selection of the online mode, a color scheme and simple branding for “Swaddling Ear to Ear” (Figure 3) were selected to support participants in associating the key components of enrolling in early intervention with their daily lives. The four steps to enrolling in early intervention (knowing your eligibility based on hearing test results, connecting with the service, making relevant appointments, and staying engaged) were each assigned their own graphic and color that permeated the webpage and represent
broad groupings of performance objectives. This consistency and repetition in message are consistent with behavior change work as a whole (Bartholomew Eldridge et al., 2016) and specifically with regards to barriers to early intervention access in EHDI (Woodruff & Cienkowski, in review). Once the general structure of the four steps were selected, each step had its own webpage created that featured a graphic organizer at the top of the page with key points and the associated symbol. Below this graphic organizer was prompting questions to help families navigate through the functional steps of addressing these key points.

In line with national recommendations, each of the pages was reviewed for readability to ensure it was written at a 6th grade or below reading level (Safeer & Keenan, 2005; Sax et al., 2019; U.S. Department of Health and Human Services, n.d.; Weiss, 2006; Woodruff & Cienkowski, 2021). An online accessibility expert was brought on to review all pages on the site for screen reader compatibility and visual contrast acceptability. The videos included in the module have accurate captioning and image descriptions. Consultations with the parent of a child under the age of three, a culturally Deaf adult with experience in social services for children who are D/deaf and hard of hearing, an IM expert, skilled providers of early intervention services for children who are D/deaf and hard of hearing (audiology, speech-language pathologist, teacher of the deaf), and an individual working at the state-level to implement EHDI provide assurance of accuracy of module information. Given that the intervention will first be tested in a pilot study, it is anticipated that following the completion of this study, materials will be further refined by future users.
Steps 5 and 6

Steps five and six of IM focus on taking the program that is developed in step four and ensuring that it is applicable to the population of interest (Bartholomew Eldridge et al., 2016). Given the unique position of EHDI as a system called for at the federal level but devised to be responsive at the state level, the processes of step five and six should be developed in conjunction with the individual EHDI program and community that the program will be implemented with. These steps are covered by Woodruff et al. (in preparation).

*Step five is the development of an implementation plan for the adaptors, implementers, and maintainers of the program* (Bartholomew Eldridge et al., 2016). The goal is to ensure that once ready, the intervention will be agreeable to those who will use it. Doing this requires developing a list of all potential users (implementers who will deliver the messaging, adaptors who will create the community’s structure for the program, and maintainers who will keep the program running over time). These individuals may need their own outcome and performance objectives along with change objectives for the use of the program.

*Step six of the IM protocol is evaluation* (Figure 4; Bartholomew Eldridge et al., 2016). The outcomes for each IM program will be different. For Swaddling Ear to Ear, as a novel behavior change program focused on changing perceptions of early intervention to support engagement for children who are D/deaf and hard of hearing, the evaluation must look at outcomes in terms of behavior (enrolling in early intervention) and changes in participant perceptions of determinants. Process evaluation, including fidelity and dose of intervention implementation, the management of the implementers (who
they are, the training of the implementers, and implementer oversight) is critical to ensure consistency of the program and the control of outside variables.

**Swaddling Ear to Ear: Addressing LTI in EHDI**

Swaddling Ear to Ear represents the first time that IM has been used to address LTI in EHDI. As a program, Swaddling Ear to Ear is delivered on a one-on-one basis in virtual format with a trained implementer using a family-facing webpage to organize and visually reinforce content. A link to the family-facing website that accompanies this educational session can be found at https://sites.google.com/uconn.edu/early-intervention-swaddling/home?authuser=1. This website includes primarily the educational materials used in the session with the implementer leading the hands-on sessions. The program’s four main components (knowing your eligibility based on hearing test results, connecting with the service, making relevant appointments, and staying engaged) are modular and can be treated as individual mini-modules. The content in the current development is specific to EI in Connecticut, however these elements (phone numbers, names of services, eligibility criteria) can be modified without changing the theoretical drivers behind how the program is built.

The implementer trained in the program leads a hands-on practice session covering skills related to advocacy. Families are able to practice reading an audiogram, discussing personalized risks in terms of access to language based on home language and hearing levels, and engage in intention planning to prepare for the various intermediary steps in navigating EI. The semi-structured script used by the implementer is in the appendix. An abbreviated example of what one of the hands-on sessions looks like can be found at https://kaltura.uconn.edu/media/Swaddling+Ear+to+Ear/1_yyfzlz64.
Conclusion

Intervention Mapping exists to bridge the translational gap between behavior change theory, research on behavior change interventions, and public health initiatives (Bartholomew Eldridge et al., 2016). Within EHDI, there is a need to translate what research tells us about the benefits of early intervention into a program that is useable by parents and providers when making enrollment decisions. At the same time, IM represents the use of public health theory and evidence-based practice to develop a program that changes the environment that children who are identified as D/deaf and hard of hearing in to address the determinants that lead to LTI. Tapping into IM’s history in public health, the application of this process to EHDI reaffirms that since EHDI is governed by public health law, it can and should be viewed as an interdisciplinary concept inclusive of public health principles. The inherent connection between IM and public health uniquely poises it to capitalize on the strong tradition of and legislative push for parent, advocate, and professional input on program development in EHDI (Early Hearing Detection and Intervention Act of 2017).

Not extensively represented in this manuscript is the evaluation component, step 6, of IM (Woodruff & Cienkowski, in development). It is critical that programs that are developed through IM be subjected to evaluations with qualitative and qualitative rigor to assure the feasibility, fidelity, and utility of these programs. Evaluation procedures provide EHDI programs with publishable data that may be useful for other state programs that are looking to better embody the goals of EHDI while addressing LTI. While underrepresented in the literature, these evaluations are critical to ensuring the
credibility of IM and further evidence-based work in EHDI to support children and families in Woodruff & Cienkowski (in prep).
References


https://doi.org/10.15142/fptk-b748


https://doi.org/10.1016/j.ijporl.2019.07.009


Figure 1. The six steps of intervention mapping (Bartholomew Eldridge et al., 2016)
Figure 2. Logic model of the problem of lost to intervention (Woodruff & Cienkowski, in review)
<table>
<thead>
<tr>
<th>A: Performance objective</th>
<th>B: Family Culture</th>
<th>C: Family Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respond/Answer attempts to connect from CT EI before the child is six months of age</td>
<td>Explain the language used in the home and describe how to request interpretation services</td>
<td>Express confidence in ability to discuss child’s development, needs, recommendations and current concerns of families and providers.</td>
</tr>
<tr>
<td></td>
<td>Describe the unique role of each person in the family as it relates to the EI process</td>
<td>List the different ways that EI may contact the families.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Add the state hotline for EI referral to phone or address book</td>
</tr>
</tbody>
</table>

Table 1. Example matrix of change objectives
<table>
<thead>
<tr>
<th>Change Objective</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Add the state hotline for EI referral to phone or address book</td>
<td>Guided Practice/Implementation intention</td>
</tr>
<tr>
<td>Connect experiences with strengths-based observations provided from other families</td>
<td>Cultural Similarity</td>
</tr>
<tr>
<td>Demonstrate record keeping by retaining notes from the call with EI and appointments in a dedicated handbook.</td>
<td>Chunking/Advanced Org/Imagery/Guided Practice/Implementation intention</td>
</tr>
<tr>
<td>Demonstrate the ability to interpret their child’s audiogram including type, configuration, and recommendations</td>
<td>Direct Experience/Guided Practice</td>
</tr>
<tr>
<td>Describe the unique role of each person in the family as it relates to the EI process</td>
<td>Implementation intention</td>
</tr>
<tr>
<td>Diagram the number of different steps of EI referral.</td>
<td>Direct Exposure</td>
</tr>
<tr>
<td>Explain the importance of developmental needs and the impact of delayed intervention/language deprivation.</td>
<td>Fear Arousal/Personalized Risk</td>
</tr>
<tr>
<td>Express confidence in ability to discuss child’s development, needs, recommendations and current concerns of family and providers.</td>
<td>Role Play</td>
</tr>
<tr>
<td>Identify what logistical supports will be needed to meet needs</td>
<td>Implementation intention/Guided Practice/Discussion</td>
</tr>
<tr>
<td>List local family support services available in their town or county.</td>
<td>Implementation intention</td>
</tr>
<tr>
<td>List the benefits of EI compared to not accessing services.</td>
<td>Personalized risk</td>
</tr>
<tr>
<td>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</td>
<td>Direct Exp/Personalized Risk/Verbal Persuasion</td>
</tr>
<tr>
<td>State that EI will only contact them/provide services if they provide consent</td>
<td>Discussion</td>
</tr>
<tr>
<td>State that the family is the most important component of the EI system while working to ensure that children who are D/deaf or hard of hearing do not experience language deprivation.</td>
<td>Repeated Exposure</td>
</tr>
</tbody>
</table>

Table 2. Change objectives and research-based methods to address needs.
Figure 3. Branding used for program.
Figure 4. Evaluation plan for program.
Appendix

Semi-structured Script for Implementer

Thank you so much for signing up for today! Today we will be using this website and the pages you sent earlier like these. Do you have any questions before we start?

I will tell you a little about me, you can ask me questions, and then I want to know your family.

Name

Student at UConn

Working with Torri

Today we are going to be talking about early intervention for your baby. What is important to know is that everyone you meet on your journey wants to and has to make themselves easy to understand. That can mean getting an interpreter, repeating things, or asking for something to be written down with drawings or handouts. We will be going to this website and I am also sending you a workbook with everything we talked about so that you can look at things again later if you have questions or bring them to your audiologist to use when talking.

Tell how to get to website

HEARING TESTS

Tell how to navigate to this page

Hearing differences are not common at birth. Many people may have never met someone with hearing different than themselves.

What experiences does your family have with hearing?

Probe looking to see if they have experience - if yes
What were those interactions/experiences like?

Looking to create either positive associations (telling good stories) Or create cognitive dissonance between the negative experiences they report and the positive things they plan to do with their baby

What do you think contributed to that?

If no - normalize that many people do not and that this gives them the opportunity to learn more about hearing

We asked these types of questions to some people who are similar to you or know people like you. And the things you are feeling are normal.

There has been a lot going on in your life since your baby joined the family! Who have you met related to your baby’s hearing?

IF having trouble - Some people you might have met are

Audiologists
Pediatricians
Hearing Screeners

Each of these people has different but related jobs.

You have seen a lot of people at this point and know different names or phone numbers. If you have any papers, please grab those too! We will add everyone to your phone and figure out what they do for you and your family.

Add each person they already met to their phones.

The next thing I want to chat about is your hearing test and the form they filled out for you. This is called an audiogram and is how your baby’s hearing is shown. I think Melissa does a nice job reminding us what an audiogram is.
VIDEO

This is a lot to remember! You can watch this video whenever you want. Audiologists go to school for 8 years to be able to do this! I have this handout for you with a link to that video to review it if you want to later.

What does that mean for when they are learning to communicate?

Go through the audiogram - For a language that uses speech, if they don't have access to high frequencies they might not use 's or mispronounce words. If they don't have access then they might not develop spoken language

This isn't going to be the only audiogram your baby gets. As your baby gets older, you will need them less often, but for the next few months, you are going to be with your audiologist a lot. What makes it easier or harder for you to get to these appointments?

For each concern, the family brings up nod, tell them it makes sense, and offer a solution/support from the central 211 line

Also we have that list in their download

A lot of the things you mentioned are challenges many families face. You have a newborn! Some big concerns from other families are

Getting to appointments - There are programs that will pay you back for the miles you drive

Getting time off of work - Appointments are made around your schedule! People can come to your home or the child's daycare

Finding child care for siblings - At-home appointments can be done with your whole family there, it is encouraged! We will also work to build a community around you to help with these types of challenges
**Affording this** - In Connecticut, early intervention from the state is free. There are also groups that can help you learn sign language, get hearing devices, and much more for no or less cost.

**Not understanding what people say** - You are the most important person in your child's life. Ask questions. Get hand-outs. Ask for interpreters. All of these are things that you are entitled to. There are also parent organizations who are here to help you understand everything that is going on.

**Not feeling ready or sure** - This can be a confusing time. All you want to do is love on your new baby. Everyone you are meeting wants to help you and your baby grow. Share what you are feeling with those around you. There are ways to connect with parents who have taken this journey and learn from them.

**CONNECT**

**Tell how to navigate to this page**

You might hear the term language deprivation to describe when someone does not have language access. This does not mean that you are taking anything from your child! All it means is there isn't language access.

Early Intervention services can mean a lot of things when supporting language, and it all depends on what you as a family WANT for the baby. You might also hear it called EI or Birth to Three. These are all the same thing and you can get them for free in Connecticut because of your baby’s audiogram.

Some common things that families ask for to meet goals are

Hearing Evaluations

Speech and Language Therapy
Sign Language Instruction
Hearing Aids/Cochlear Implants
Family Support Groups
and anything else that the child needs to grow
What are some of your goals for the baby?

List 3 to start - encourage them

If you go back into your phone - scroll back to the first contact we put in NAME, and let's write down what goal they can help you with as a note in that contact.
As you open up each contact you can also “link” them to the other providers you know.

Now that we know what early intervention is, it is time to talk about getting it! There is a process for getting early intervention, and everyone involved wants to give your family what you need.

This picture shows how to get early intervention. Since you are in control of early intervention, I thought we could run through how it might go. Who in the family will be in charge of making the appointments and contacting early intervention? Do you have 211 saved on your phone? Great - we are going to do a practice call -
(if one person, have them take on the parent role and the facilitator will be the operator. if 2 people, the person calling is the parent and the one not calling is the 211 operator with the list of questions to ask as seen in the diagram).
What is important to know is that you are in charge of every step. No one will contact you if you don’t agree, and you can ask for as much or as little help as possible.
Early intervention and the phone numbers that you have saved are not the only people here to support you. Who in your family and friends do you feel comfortable talking with or asking for help?

**Congratulate for naming people and probe what they think might be the most helpful to ask each person to do**

**Talk about family supports**

**APPOINTMENTS**

**Tell how to navigate to this page**

Once you have contacted early intervention that first time, things will move very quickly! You will need to answer your phone when people call – even if you do not know the number. The goal will be to make sure that your family is getting all of the services you want, by the time your baby is 6 months old.

**DESCRIBE DIAGRAM and congratulate that they are already ⅔ of the way done**

If we look back on your goals for the baby, each one of those will have a meeting and provider connected to it. We can use this to walk through all the steps, who you will contact, and what that process will be like.

**Discuss each point - this is planning intention and key**

**For when - have them set reminders on their phone**

That can be hard to do when you are trying to learn all this information and take care of your baby. With that, I thought we could do a practice of what that might look like. You can ask me a specific question about what we have covered, a goal you have, or a question you want to answer, and I will explain in a "not so clear" way. You should stop
me to ask questions, get additional materials, or take notes. This will help you hear the
information again and get you used to advocating for your baby!

KEEP GROWING

Tell how to navigate to this page

Once you are in early intervention, everything is set up to get you where you want to be.
With that, you will have to advocate for your baby.
That is a pretty big task. To help wrap your head around that, I want to go over how you
advocate. To get that started, you will see that the final page of your download is a
"family plan of care" This will be able to go into the front of your planning so that you
have all the tools you need to advocate. We will go over this form together, fill it out and
consider what it would be like to start a conversation using it.

Talk through and make sure each line is understood - basically what is
your role? Then How do you ask for help? Then How do you educate? And such
Ask “How do you start a conversation when you need someone’s help?”

Congratulate any step towards advocacy

Reminder about asking for better explanations, things in writing, interpreters, and
such

A reminder that people have to give them this - it is the law

Reminder they are not alone and do not have to advocate along - parent groups
The most important thing for you to know is that you control this. Everyone you meet is
here to help you learn. If you ever think the person you are talking to is unclear, you
should ask for an interpreter, take-home materials, and follow-up questions.
We have talked about a lot today and have tried to set you up for everything. How can we get through this to do list?
Chapter 8
Swaddling Ear to Ear: A novel family-education approach to lost to intervention in Early Hearing Detection and Intervention

Introduction

In the last two decades in the United States, there has been rapid development and implementation of public health programs targeting the early identification and support of children who are born D/deaf or hard of hearing and their families. This system is currently mandated by the Early Hearing Detection and Intervention (EHDI) Act of 2017. This public health law outlines the needs for hearing screenings for all children, diagnostic services for those who refer on screenings or have risk factors, and the provision of quality early interventions services to children who are identified as D/deaf or hard of hearing (Early Hearing Detection and Intervention Act of 2017). States have the flexibility to define their own processes and requirements on how the system runs to meet the unique situation in each state (Early Hearing Detection and Intervention Act of 2017). However, the published guidance by the Joint Committee on Infant Hearing (JCIH) is typically used as a foundation for programs.

In accordance with the JCIH (2019), state and federal expectations tend to focus on the adherence to 1-3-6 where children should have a hearing screening by one month of age, those who need it should have a diagnostic assessment by three months of age, and those who are identified as D/deaf or hard of hearing should have access to early intervention services by six months of age. These milestones are the minimum expectation for service provision and recently, a 1-2-3 model has been proposed (JCIH, 2019). Nationally, over 98% of newborns had their hearing screened before one month of age, and of the 61,475 who referred on that screening 52% of those children received
a hearing assessment to confirm hearing in the typical range (32,193) or hearing outside of the typical range (5,934) with 62% of children eventually having a hearing assessment (CDC, 2021d). However, of the population made only of children who have been identified as D/deaf or hard of hearing, only 61.7% are recorded as receiving early intervention at all and fewer receiving services by 6 months (CDC, 2021a; 2021b). The drop off of services at early intervention is particularly distressing given the positive impact that early intervention has on child language development and the JCIH goals specifically calling for early intervention.

The state of Connecticut serves as an example of service drop off in children who are identified as requiring diagnostic services (461), those identified as D/deaf or hard of hearing (93) and those who eventually access services at some point (60; CDC, 2021a; 2021c). While Connecticut's screening by one month rate and access to diagnostic services before three months of age is above the national average, the percentage of children who access intervention services in a timely manner, only 43% of children who are identified have timely access to early intervention services (CDC, 2021b). There is a disconnect at the national and Connecticut state level between the identification of children as D/deaf or hard of hearing and using that information to benefit the child’s development.

The 35% of children in Connecticut and the 39.9% at the national level who are identified as D/deaf or hard of hearing but are not tracked as accessing early intervention services are lost to intervention (LTI; CDC, 2021e). While LTI impacts the smallest population within EHDI (2370), it also has the highest concentration of those who would benefit from the EHDI system as all children in this group have been
identified as D/deaf or hard of hearing, and thus have a developmental risk factor that would make early intervention services to support language development beneficial (CDC, 2021e). Yet, this population is underrepresented in the EHDI literature on program improvement and service uptake. While no population has a greater inherent need for representation and evidenced based work to address systemic barriers to service access, those who are LTI occupy a unique space in the EHDI system.

Families who are LTI have distinct needs from that of those who do not access screening or diagnostic services due to logistical reasons such financial status, rurality of the home, and provider access (CDC, 2021e; Hunter, Meinzen-Derr, Wiley, Horovath, Kothari, & Wexelblatt, 2016; Kanji & Krabbenhoft, 2018, Khoze-Shangase, 2019; Liu, Farrell, MacNeil, Stone, & Bartfield, 2008; Razak, Fard, Hubbell, Cohen, Hartman-Joshi, & Levi, 2020; Scheepers, Swanpoel, & le Roux, 2014). These logistical barriers are not represented in current data sets on EI access, as there is the potential for EI services to be provided in the home to help mitigate these concerns (CDC, 2021e, Individuals with Disabilities Education Act of 2004). Alternatively, the known reasons for LTI is dominated by family declination of services (CDC, 2021e). The most comprehensive evaluation of why families decline EI services is from Woodruff and Gautherin (in review) through combining pervious works and qualitative inquiry to focus on the personal factors, such as family culture, experiences, perceived vulnerability, perceived benefit, and then perceived barriers. While barriers to access like seen in LTD are present in LTI, they do not represent the complexity or drivers of why families are declining services and becoming LTI and thus new approaches to address LTI challenges specifically are needed.
Purpose

The goal of this study was to assess implementation of a novel behavior change program focused on teaching functional skills to support families of children who have been identified as D/deaf or hard of hearing as they navigate accessing Part C early intervention services in the state of Connecticut. As the first program of its kind, driven by recent research into the specific drivers of LTI in EHDI systems, the program highlights a critical need for support. The rigorous evaluation of the program presented through this manuscript serves to unify past works on accessibility and barriers to care within EHDI while encouraging future work done at the state and federal level to pursue publication and peer review.

Methods

Participants in this study will be exposed to Swaddling Ear to Ear, a novel behavior change method described by Woodruff and Cienkowski (in prep) and then provided feedback and follow-up on early intervention decision making/attitudes.

Implementation

Schedule

The implementation of this program was designed to take about one hour. The steps in this process and when recording was engaged are delineated below and the progression through the steps is in Table 1.

Program

This study is an evaluation of the Swaddling Ear to Ear program described in Woodruff et al. (in prep). This program is a hands-on collaborative training session where participants engage with a trained implementer to cover the process of enrolling
in early interventions for children who are D/deaf or hard of hearing. The website to accompany this program can be found at https://sites.google.com/uconn.edu/early-intervention-swaddling/home?authuser=1.

This program will be delivered via a web conferencing program, WebEx, to afford participants the flexibility to participate on their own schedule in their preferred location. The inclusion of virtual participation also serves to alleviate any ongoing COVID-19 concerns. Consent will be collected prior to the start of the program via online webform, Qualtrics, and again in verbal form following the start of the program.

**Implementer training**

The implementer is an undergraduate student with experience in Speech, Language and Hearing Sciences and ties to the local Deaf community. Undergraduate students represent a section of the population who have received training in the realm of audiology and early intervention for individuals who are D/deaf or hard of hearing yet do not have a degree in the topic. This type of educational experience without a degree is similar to what can be reproduced in the community health educator model where community members are trained in a topic area and then implement behavior change programs. In preparation for being an implementer the undergraduate engaged in a multi-week training curriculum to familiarize them with EHDI, early intervention, and the implementation of this program. Didactic training on the EHDI system within the state of Connecticut was provided along with pre-recorded academic lectures on EHDI and early intervention programs.

Following exposure to background content, the implementer was provided with the outline script from which they will base their implementation of the program on to
review and ask clarification questions on. Implementers were also provided exemplar videos of what implementations can look like with examples of reframing participant comments into strengths-based reflections and positioning themselves as process resources without crossing over into counseling. Following exposure to didactic content, recordings, and question and answer sessions, the implementer created videos of themself doing mock implementations of the programs. These videos were reviewed by the first author and individual feedback was provided in team meetings to address points where changes in the delivery were needed. This iterative feedback process was paired with a check list of all discrete tasks that each implementer had to engage in during a session to show fidelity (Appendix A). Implementers were considered fully trained in the program once a mock video recording was reviewed that addressed all implementation tasks and delivery was deemed sufficient by the first author.

Once working with participants, implementers will complete post session memos, in the qualitative tradition, to reflect on the sessions in terms of content, experience, and potential changes to make with their next session. Audio recordings of the sessions and subsequent testing with participants will also recorded and reviewed by the implementors and first author for further quality improvement.

Survey

As a part of the pre/post design for this study evaluation of attitude change, participants will complete a survey online in Qualtrics that will be shared via WebEx chat link. This survey will contain thirty Likert-like statements about their perceptions of early intervention for children who are D/deaf or hard of hearing where 0 is Completely
disagree, 5 is No opinion and 10 is Completely agree (Appendix B). Following the completion of those 30 questions, the educational program will be delivered.

Following the educational program, participants will continue the survey to complete information about their child’s hearing healthcare. While the participant will be provided this information into the online program, the implementer will leave the session and will be replaced by the first author so that the interview portion of the study can commence. Following the interview, participants will be directed back to Qualtrics and will finish responding to a series of questions and accessing resources related to the social determinates of health (SDOH). Participants will be asked to complete the thirty Likert-like questions again. The Accountable Health Communities Health-Related Social Needs Screening Tool (ACH) will be utilized as the screener for social determinates of health in this study. This measure is part of a national program that is run by the Center for Medicare and Medicaid Services to mirror Centers for Disease Control and Prevention’s (CDC) approach to SDOH (CMS, n.d.b.; .Trust for America’s Health, 2021). The ACH has been run as a trial in Connecticut with a number of references and partnerships between the Connecticut Department of Public Health and other programs (CMS, n.d.a.; Connecticut DPH, n.d.; Mercer, 2019).

**Interview**

Participants will be interviewed about their experiences in the educational program. All participant sessions (educational programs and interviews) will be recorded using the integrated WebEx recording and captioning service. Taking a phenomenological approach, the subjective experience and interpretation of that experience will be probed by the first author in a semi-structured format (Appendix C).
While the interview will be focused on the experiences of the participants within the educational program, the interviewer will have the flexibility to follow participants in their line of thought and will be encouraged to probe fully and expand on all topics that will be brought up.

**Analysis**

Analysis of programs that are developed according to intervention mapping principles are underrepresented in the research base. The analysis component of this study represents three distinct lines of questioning that highlight the flexibility of this type of intervention and the amenability of implementation across EHDI systems.

**Implementation Analysis**

For the implementation analysis a random subset of 25% of the module implementations from all educational sessions will be transcribed alongside the interviews. These transcripts will be assessed against the list of performance objectives developed by Woodruff et al. (year) during the development of the educational program. Similarly, to the process of training the program implementer, this process of transcribing and comparing the implementation of the educational module to the key objectives and steps outlined in the programs will serve as an assessment of the implementer's skills and a quality check for consistency of the implementation. This will be completed by the implementer and first author. The percentage score computed by comparing the total number of performance objectives met compared to the total called for in the module will be subjected to summary statistics.
Feasibility Analysis

The need for acceptability of this type of program by families of children who have been recently identified as D/deaf or hard of hearing drove the use of qualitative methods in this study. These transcriptions will be subjected to an iterative coding methodology using nVivo software. Following each interview, once the transcriptions are completed, word files of the transcripts will be uploaded in nVivo for processing. All transcripts are to be read twice before coding commences. Coding was an iterative process using inductive codes generated through the initial readings. The first pass of coding included broader concepts present. Second pass coding further broke down large categories of codes into discreet examples such as specific emotions or comments. This process will be repeated for each interview. After every three interviews, all codes will be reviewed for fit. At the completion of coding for all transcripts, individual codes will be collapsed into the themes present within the interviews.

Triangulation. The process of triangulation is well respected and expected within the realm of qualitative research as a means of ensuring the robustness of qualitative coding decisions and as an additional defense against bias. Since the instrument of measure in qualitative work is the coder, added scrutiny is needed to ensure the calibration of the instrument. To triangulate the codes generated two methods will be used, memoing and having a second coder.

The process of memoing empowers the researcher to reflect on their experiences and perceptions of what is happening during the interview and coding process. Following each interview and coding session, the first author will reflect on the
experience commenting on potential themes, challenges, and barriers/biases that may have presented. This reflective process supports deeper thinking on codes and accountability. Memos will be recorded in a digital logbook for evaluation.

The use of the second coder provides another layer of triangulation that extends outside of the primary coder. A randomly selected 500-word section of each interview will be reviewed and coded by the second author. The Kappa coefficient between the two coders will then calculated as a means of reflecting the robustness of coding.

Impact Analysis

The impact of this program will be evaluated in the short and long term. Short term impacts will be evaluated by means of perceptual shift as measured by the pre/post measure on the perceptions of early intervention services survey. The Likert-like questions administered before and after the educational program will be subjected to repeated measures t-tests with significance set at p<.05.

After the educational program, families or their audiologists will be contacted to ascertain early enrollment status. This data will be collected at 6 months of age, as in accordance with Joint Committee on Infant Hearing (JCIH) standards, children should be in early intervention by that point. The rate of enrollment for the study sample will be compared to Connecticut State EHDI program data on enrollment in 2022 to birth to three and early intervention programs.

Current work

We are currently recruiting with every infant diagnostic center in the state of Connecticut to identify any child under the age of 3 years who has been identified as D/deaf or hard of hearing and is not enrolled in early intervention services. Given the
incredibly small size of this population in the state of Connecticut, recruitment and this implementation evaluation is an ongoing project that embodies the next step in this programmatic line. Future work will also include the translation of this program along with culturally relevant adaptations (see next document in bound).
Works Cited


Individuals with Disabilities Education Act, 20 USC. § 1400 (2004)


https://www.doi.org/10.15142/fptk-b748


<table>
<thead>
<tr>
<th>Event</th>
<th>Implementer</th>
<th>Chat Box Content</th>
<th>Recording</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session start</td>
<td>LaSpada</td>
<td>Qualtrics link</td>
<td></td>
</tr>
<tr>
<td></td>
<td>LaSpada</td>
<td>Information sheet</td>
<td></td>
</tr>
<tr>
<td></td>
<td>LaSpada</td>
<td>Verbal consent</td>
<td></td>
</tr>
<tr>
<td>Live consent</td>
<td>LaSpada</td>
<td>Verbal consent</td>
<td>x</td>
</tr>
<tr>
<td>Pretesting</td>
<td>LaSpada</td>
<td>Initial measure</td>
<td>x</td>
</tr>
<tr>
<td>Educational Module</td>
<td>LaSpada</td>
<td>Website link</td>
<td></td>
</tr>
<tr>
<td>Post testing</td>
<td>LaSpada</td>
<td>Qualtrics link</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>LaSpada</td>
<td>Participant Code</td>
<td>x</td>
</tr>
<tr>
<td>Interview</td>
<td>Woodruff</td>
<td>Interview session</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Woodruff</td>
<td>Participant Code</td>
<td>x</td>
</tr>
<tr>
<td>End of session</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Appendix A**

**Check list of all discrete tasks in implementation**

<table>
<thead>
<tr>
<th>Task</th>
<th>Completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Add the state hotline for EI referral to phone or address book</td>
<td></td>
</tr>
<tr>
<td>Compare and contrast all language modes and their applications to the family</td>
<td></td>
</tr>
<tr>
<td>Connect experiences with strengths-based observations provided from other families</td>
<td></td>
</tr>
<tr>
<td>Demonstrate record keeping by retaining notes from the call with EI and appointments in a dedicated handbook.</td>
<td></td>
</tr>
<tr>
<td>Demonstrate the ability to interpret their child’s audiogram including type, configuration, and recommendations</td>
<td></td>
</tr>
<tr>
<td>Describe family exp with hearing - views on etiology of hearing differences and hearing status of all members of the family and with individuals who are D/deaf and hard of hearing</td>
<td></td>
</tr>
<tr>
<td>Describe the EI services that families of children who are identified as D/deaf or hard of hearing are legally entitled to through Part C of IDEA, including, clinical service provision, family support, language acquisition, and family benefits</td>
<td></td>
</tr>
<tr>
<td>Describe the unique role of each person in the family as it relates to the EI process</td>
<td></td>
</tr>
<tr>
<td>Diagram the number of different steps of EI referral.</td>
<td></td>
</tr>
<tr>
<td>Explain the importance of developmental needs and the impact of delayed intervention/language deprivation.</td>
<td></td>
</tr>
<tr>
<td>Explain the language used in the home and describe how to request interpretation services</td>
<td></td>
</tr>
<tr>
<td>Express confidence in ability to discuss child’s development, needs, recommendations and current concerns of family and providers.</td>
<td></td>
</tr>
<tr>
<td>Identify what logistical supports will be needed to meet needs - State that EI services are provided at little to no cost for families. List services to help meet needs associated with traveling to this meeting, such as gas card programs List potential funding opportunities for assistive technology. Identify funding sources to support diagnostic services (including insurance, assistance programs, payment plans, and state laws related to cost). List friends and family members that will be able to come with you to the meeting, help drive, babysit other children, or provide other supports during evaluations</td>
<td></td>
</tr>
<tr>
<td>List local family support services available in their town or county.</td>
<td></td>
</tr>
<tr>
<td>List the benefits of EI compared to not accessing services.</td>
<td></td>
</tr>
<tr>
<td>List the different ways that EI may contact the family.</td>
<td></td>
</tr>
<tr>
<td>Locate a list of EI providers in the state in the same town or county as the family.</td>
<td></td>
</tr>
<tr>
<td>Match the job title of common EI providers with their general job descriptions, roles, skills, and value of involvement</td>
<td></td>
</tr>
<tr>
<td>Request take home materials on topics covered</td>
<td></td>
</tr>
<tr>
<td>State that EI will only contact them/provide services if they provide consent</td>
<td></td>
</tr>
<tr>
<td>State that the family is the most important component of the EI system while working to ensure that children who are D/deaf or hard of hearing do not experience language deprivation.</td>
<td></td>
</tr>
<tr>
<td>State that their child is at risk for language deprivation as a result of their hearing levels, if not addressed thought intervention.</td>
<td></td>
</tr>
<tr>
<td>State that without an IFSP meeting, their child cannot enroll in EI.</td>
<td></td>
</tr>
<tr>
<td>State the EHDI guidelines for timely follow up (1-3-6)</td>
<td></td>
</tr>
<tr>
<td>State the expectation of having to make calls to follow up with EI.</td>
<td></td>
</tr>
<tr>
<td>State the expectation of having to travel to or have providers come into the home for services</td>
<td></td>
</tr>
<tr>
<td>State the expectation that all families of newborns have hectic homes and this is expected by EI staff</td>
<td></td>
</tr>
<tr>
<td>State the expectation that the families will be able to ask for specific services to support themselves and their child.</td>
<td></td>
</tr>
<tr>
<td>State the expectation that they will have questions during and after appointments</td>
<td></td>
</tr>
<tr>
<td>State the expectation that this meeting will be scheduled at a time that works for the families.</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix B
Likert-like questions

<table>
<thead>
<tr>
<th>Construct</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>GLOBAL</td>
<td>Are you interested in early intervention for your child? Yes/No/I do not know what early intervention is</td>
</tr>
<tr>
<td>Perceived VULNERABILITY</td>
<td>My child’s hearing isn’t a big deal</td>
</tr>
<tr>
<td>REVERSE</td>
<td>It is not likely that my child will have problems communicating because that does not run in my family</td>
</tr>
<tr>
<td>REVERSE</td>
<td>The advantages of getting early intervention services for my child are greater than the disadvantages</td>
</tr>
<tr>
<td>REVERSE</td>
<td>I have heard you should get early intervention for your child if they have differences in their hearing</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Getting my child early intervention services is worth the cost</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Having hearing differences limits my child’s access to communication</td>
</tr>
<tr>
<td>REVERSE</td>
<td>When children with hearing differences don’t get early intervention, they and their families suffer</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Without early intervention, my child’s development will be negatively impacted</td>
</tr>
<tr>
<td>Perceived benefits</td>
<td>The benefits of getting early intervention outweigh the costs</td>
</tr>
<tr>
<td>REVERSE</td>
<td>I would worry if my child could not communicate because of their hearing</td>
</tr>
<tr>
<td>REVERSE</td>
<td>I don’t have trouble communicating with my child, so not having early intervention would not be a big problem for me</td>
</tr>
<tr>
<td>REVERSE</td>
<td>I worry about my child missing out on their childhood because of their hearing</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Spending time learning about hearing and early intervention would be valuable to me</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Early intervention is only focused on my child, so I do not need to be involved</td>
</tr>
<tr>
<td>REVERSE</td>
<td>It isn’t likely professionals would know how to benefit my child.</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Once your child has a hearing difference there’s not much you can do about it</td>
</tr>
<tr>
<td>Perceived barriers</td>
<td>It would be uncomfortable for my child to get early intervention</td>
</tr>
<tr>
<td>REVERSE</td>
<td>It is too much trouble to get early intervention</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Most people say early intervention does not work well</td>
</tr>
<tr>
<td>REVERSE</td>
<td>If my child had a hearing difference, I would do everything I could to avoid getting early intervention</td>
</tr>
<tr>
<td>REVERSE</td>
<td>I understand what I hear and read about the benefits of early intervention</td>
</tr>
<tr>
<td>REVERSE</td>
<td>The costs of early intervention are too high for me</td>
</tr>
<tr>
<td>REVERSE</td>
<td>It is too difficult for me to get early intervention for my child because of their other needs, even when I know they need it</td>
</tr>
<tr>
<td>REVERSE</td>
<td>It is difficult for me to enroll in early intervention in my state</td>
</tr>
<tr>
<td>Family Culture</td>
<td>My lifestyle choices make it difficult for me to get early intervention for my child because I don’t think they will understand me</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Care providers do not look, sound, or act like me so I don’t think they will understand my family</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Family Experiences</strong></td>
<td>My personal history with hearing tells me everything I need to know about early intervention</td>
</tr>
<tr>
<td>REVERSE</td>
<td>Early intervention services run by the state are there to help me and will be filled with qualified people</td>
</tr>
<tr>
<td>REVERSE</td>
<td>I have too many feelings right now and cannot think about early intervention</td>
</tr>
</tbody>
</table>
Appendix C
Format of semi-structured interview

Tell me about your experience with your child’s hearing.

What was it like to go through today’s session?
PROBE – educational value
   New information (can you tell me more about any new information from today?)
Understand old information (can you tell me more about what it was like to hear some information again?)
Change decision making based on info (can you tell me more about how today factors into your decision making?)
PROBE – emotional value
Role as an advocate (can you tell me more about how it made you feel as a parent?)
   Importance of EI (can you tell me more about how you feel about EI?)
PROBE – functionality
   Duration (How do you feel about the timing for this?)
   Content (How do you feel about what was covered?)
Online/virtual/COVID (what was it like to do this in a virtual setting?)
   Who was administering it (how was it interacting with the presenter?)

How did this session compare to your other hearing care appointments?
PROBE – utility (how do you feel about using your time to do this?)
PROBE – understandability (What do you think you got out of this conversation?)
   PROBE – comfort (how did it feel to talk in this setting?)
PROBE – impact on decision making (how do you feel about making a decision about EI?)

Is there anything you would like to tell me before we wrap up?
Chapter 9

Nearly 6,000 children were identified as D/deaf or hard of hearing via Early Hearing Detection and Intervention (EHDI) programs in the United States in 2019 (CDC, 2021c). However, over 1/3 of those children and families are not documented as having access to early intervention services and fewer receive timely access (CDC, 2021c). The most commonly known reason is that the child’s family refused services (CDC, 2021d). When looking at families who use Spanish in the home, 13% of the US population, there is a disconnect between these needs and the 3.7% of audiologists who are bilingual in English and Spanish (Caballero, Munoz, Schultz, Graham, & Meibos, 2018). This study looks at the application of a newly developed educational approach to informing families about hearing and fostering advocacy skills within the cultural values, attitudes, and approaches to medical care specific to Hispanic/Latinx communities (Caballero et al., 2018; Steinberg, 1997; 2003; 2007).

This grant application was funded by the Educational Audiology Association.

SPECIFIC OBJECTIVES

In the last two decades in the United States, there has been a growth of public health programs targeting early identification and support of children who are D/deaf or hard of hearing (DHH) and their families. This system is mandated by a public health law, the Early Hearing Detection and Intervention (EHDI) Act of 2017. State and federal guidance tend to follow Joint Committee on Infant Hearing (JCIH) recommendations of screening by one month of age, identification by three months, and enrollment in early intervention (EI) services by six months (2019).
The state of Connecticut serves as an example of service drop off in children who are identified as requiring diagnostic services (461 children), those identified as DHH (93 children) and those who eventually access services at some point (60 children; CDC, 2021c; 2021d). While Connecticut's screening by one month rate and access to diagnostic services before three months of age is above the national average, only 43% of children identified have timely access to EI services (CDC, 2021c).

While lost to intervention (LTI) impacts the smallest population within EHDI (2370 children, 39.9% identified nationally) and impacts children of Hispanic (39.7%) and non-Hispanic (42.3%) birthing parents equally, it also has the highest concentration of children in who have been identified as DHH, and thus have a developmental risk factor that would make EI services to support language development beneficial (CDC, 2021a).

Families who are LTI have distinct needs from that of those who do not access screening or diagnostic services due to logistical reasons such as finances, rurality of the home, and provider access (CDC, 2021d; Hunter, Meinzen-Derr, Wiley, Horovath, Kothari, & Wexelblatt, 2016; Kanji & Krabbenhoft, 2018, Khoze-Shangase, 2019; Liu, Farrell, MacNeil, Stone, & Bartfield, 2008; Razak, Fard, Hubbell, Cohen, Hartman-Joshi, & Levi, 2020; Scheepers, Swanpoel, & le Roux, 2014). Woodruff and Cienkowski (in review), combined previous works and qualitative inquiry to focus on family culture, experiences, perceived vulnerability, benefits, and barriers as drivers in LTI broadly. In the Hispanic/Latinx community, cultural assumptions from primarily English-speaking profession need to be evaluated (Callabero et al., 2018). Specifically, members of Hispanic/Latinx communities have highlighted challenges in advocating for their preferred language/Spanish services when working with early intervention providers.
(Steinburg, 2003), a cultural narrative about the causes and treatment of hearing differences to be rooted in religion or fatalistic concepts (Callabero et al., 2018; Steinberg, 2007; 1997), and integrating their child into the community (Callabero et al., 2018; Steinberg, 1997; 2007). With all of this and the need for family-centered care in mind, there is a need for a linguistically and culturally tailored program to support advocacy and EI access for Spanish speaking families in the US who have children identified as DHH.

O1: Adapt Woodruff et al. (in prep)’s program for families who speak Spanish.

O2: Assess the impact of this program with families of children who are DHH and use Spanish.

METHODS AND PROCEDURES

O1: Adapt Woodruff et al. (in prep)’s program for families who speak Spanish.

Participants. The Woodruff et al. (in prep) program that is being adapted in this study includes a hands-on educational module about early intervention, advocacy, and personal goal setting facilitated by a community health implementer who has been trained in the module. In this study, the implementer will be a bilingual undergraduate student who expresses cultural identity within a Hispanic and/or Latinx community and heritage or native Spanish speaker status. Up to five additional self-identified cultural liaisons will be recruited from the University and healthcare community in the state of Connecticut via word of mouth to provide feedback on the language, structure, and concepts of the program. These cultural liaisons will self-identify as members of a cultural group that is associated with Hispanic and/or Latinx culture and be heritage speakers of Spanish. The intention of including multiple liaisons along with the
implementer is to respect the fact that in the Spanish-speaking community, there is no homogeneity in culture.

**Implementer training.** The undergraduate implementer will engage in a training curriculum to familiarize themselves with EHDI, EI, and the implementation of this program through didactic lecture, team meetings, reviewing previous sessions, and mock sessions that are reviewed for feedback. After the implementer is fully trained with English, all materials will be professionally translated into Spanish at a 6th grade reading level and the adaptation process will begin.

**Adaption.** The fully trained implementer and cultural liaisons will be provided with translations of all program materials to review. They will be asked to make linguistic edits to the materials to ensure consistency of tone with the English language version and add/remove elements that are culturally relevant to the Spanish-speaking community. All direct edits suggested by liaisons will be incorporated into the program, and conceptual comments will be uploaded into nVivo for thematic analysis and inclusion in the updated program. The updated version of the program will be shared with all implementers so they can provide approval or suggest further edits. Up to three rounds of edits, or until majority acceptance of the program is attained, will be conducted.

O2: Assess the impact of this program with families of children who are DHH and use Spanish.

**Participants.** The intervention itself will be offered to parents of children identified with hearing levels outside of the typical range who use Spanish in the home. A sample of five families is being targeted. This number is slightly lower than previous pilot parent-
level interventions but is consistent with the small population in and the start of this programmatic line of research (Carlon, Carter & Stephenson, 2017; Holte Shea, Haugen, Bernsten, Gottormsen, Overby, Haraldstad, Meland, & Abindsnes, 2016; Pereira, D’Affonseca, & Williams, 2013; Sacks, Shay, Repplinger, Leffel, Sapolich, Suskind, Tannenbaum, & Suskind, 2014).

**Method.** The implementation of this program was designed to take about one hour where participants will provide consent, engage in pretesting, walk through the educational module, complete post testing, and have a qualitative interview about the program.

As a part of the pre/post design for this study evaluation of attitude change, participants will complete a survey online in Qualtrics. This survey contains thirty Likert-like statements about their perceptions of EI for children who are DHH (Table 1) that will be translated into Spanish using a trained translator providing interpretive translation. Following the completion of those questions, the educational program will be delivered. After the educational program, participants will continue the survey to complete information about their child’s hearing healthcare. While the participant inputs this information into the online program, the implementer will prepare for and then conduct the interview portion of the study in Spanish. Taking a phenomenological approach, the subjective experience and interpretation of that experience will be probed by the implementer in a semi-structured format (Table 2). While the interview focuses on the experiences of the participants within the educational program, the interviewer had the flexibility to follow participants in their line of thought and encouraged the expansion of all topics brought up. Following the interview, participants will be directed to finish
responding questions related to the social determinates of health and complete the Likert-like questions again. All participant sessions (educational programs and interviews) will be recorded and educational modules will be translated literally into English by a certified interpreter.

Analysis. The analysis component of this study represents three distinct lines of questioning that highlight the flexibility and amenability of implementation to EHDI. For the implementation analysis, a random subset of 20% of the educational programs will be assessed against the list of performance objectives developed by Woodruff and Cienkowski (in prep) during the development of the educational program. The implementation of the educational module will be compared against the key objectives and steps as an assessment of the implementer's skills and a quality check for consistency. The percentage computed by comparing the total number of performance objectives met compared to the total called for in the module will be assessed.

Feasibility analysis will include looking at the comments and feedback from participants provided in their interviews. The need for acceptability of this type of program by families of children who have been recently identified as DHH drove the use of qualitative methods in this study. All interview transcripts will be translated into English and then subjected to qualitative analysis using nVivo software. Coding in qualitative research is an iterative process using inductive labels or “codes” generated from within the data. These codes reflect the content and ideas presented in the interview and will be generated by the first author. The first phase of coding will include broader concepts present such as benefits of the program, drawbacks of the program, thoughts about early intervention, or changes that could be made to the program. Second pass coding
will further break down large categories of codes into discreet examples such as specific emotions or comments. At the completion of coding, individual codes are collapsed into larger themes.

In qualitative work, the coder/research is the instrument of measure grouping and categorizing the comments of the participants into overarching concepts for the sample. The process of triangulation is well respected and expected within the realm of qualitative research as a means of ensuring the robustness of qualitative coding decisions and as an additional defense against bias. Following each interview and coding session, the implementer will reflect on the experience commenting on potential themes, challenges, and barriers/biases that may have presented. This process is referred to as memoing in the qualitative literature. The memoing process supports deeper thinking on codes and accountability. The use of the second coder provides another layer of triangulation that extends outside of the primary coder. A randomly selected 500-word section of each interview was reviewed and coded using the above mentioned codes by the implementer after the first author. The Kappa coefficient between the two coders will then be calculated as a means of reflecting the robustness of coding.

Short term impacts were evaluated by means of perceptual shift as measured by the pre/post measure on the perceptions of EI services survey. The Likert-like questions will be subjected to repeated measures t-tests with significance set at p<.05. The EI enrollment for the study sample 6 months post participation will be compared to Connecticut EHDI program data.
FACILITIES AND OTHER RESOURCES

The applicant will incur production needs related to the development and creation of intervention materials. Part of these expenses are absorbed through the use of technology, such as using email and the internet, online data collection systems, and the implementation of WebEx as a remote access point for participants and automated transcription. Production costs that cannot be mitigated through the use of technology can commonly be addressed with resources accessible to the applicant given graduate student status, including printing services both in ink and 3D. Facilities and various pieces of equipment (computers, recording devices, qualitative and quantitative software) are found in the Aural Rehabilitation Lab, which the applicant has access to due to her status as a graduate student and research affiliate. This affiliation with the Aural Rehabilitation Lab also affords the applicant access to a wide pool of potential cultural liaisons (students and professionals), connections to recruitment sites, and skilled mentors.

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Cost per unit</th>
<th>Units needed</th>
<th>Cost of item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Website and survey interpretive translation</td>
<td>Standard conceptual interpretation of website contact via RushTranslate into Spanish</td>
<td>$0.10 per word</td>
<td>2505</td>
<td>$250.50</td>
</tr>
<tr>
<td>Certified translation of interviews</td>
<td>Certified translation of transcriptions into English</td>
<td>$24.99 per page</td>
<td>50</td>
<td>$1249.50</td>
</tr>
<tr>
<td>Payment of non-implementer cultural liaisons</td>
<td>Payment made to the cultural liaisons who are not the implementer for their time and feedback</td>
<td>$50.00 per person</td>
<td>5</td>
<td>$250.00</td>
</tr>
<tr>
<td>Bilingual student implementer</td>
<td>The student implementer will be provided with research experience rather than monetary compensation</td>
<td>$0.00</td>
<td>1</td>
<td>$0.00</td>
</tr>
</tbody>
</table>
## Payment of families

<table>
<thead>
<tr>
<th>Payment to participants in the form of an Amazon gift card to participants with information about baby and hearing related items available on Amazon</th>
<th>$50.00 per session</th>
<th>5</th>
<th>$250.00</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>$2000.00</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Month Number</th>
<th>Deliverable</th>
</tr>
</thead>
</table>
| 1 | Name of bilingual undergraduate student who completed the interview and application process  
   Completion of didactic training on EHDI, EI, and CITI with implementer |
| 2 | List individuals who may serve as cultural liaisons (as determined using KRNW processes from Okoli & Pawloski, 2004)  
   Four meeting sessions with the implementer to go over the script and goals |
| 3 | Four meeting sessions with the implementer to go over recordings of past mock sessions and discussion around outcome measures  
   Copy of website in Spanish |
| 4 | Four mock sessions with English speaking participants and self-evaluation of adherence to outcome measures  
   Linguistically edited Spanish language program based on liaison feedback  
   Qualitative analysis of thematic comments from liaisons and implemented changes  
   List of clinical sites to recruit from |
| 5 | Four mock sessions with English speaking participants and self-evaluation of adherence to outcome measures  
   Presentation of final Spanish language program |
| 6 | Recruit participants  
   Implementer transcribed interview and session  
   Certified translation of transcripts to English  
   Qualitative analysis of transcripts  
   Drafting of manuscript introduction |
| 7 | Recruit participants  
   Implementer transcribed interview and session  
   Certified translation of transcripts to English  
   Qualitative analysis of transcripts  
   Drafting of manuscript methods |
| 8 | Recruit participants  
   Implementer transcribed interview and session  
   Certified translation of transcripts to English  
   Qualitative analysis of transcripts |
<p>| 9 | Recruit participants |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>205</td>
<td>• Implementer transcribed interview and session</td>
</tr>
<tr>
<td></td>
<td>• Certified translation of transcripts to English</td>
</tr>
<tr>
<td></td>
<td>• Qualitative analysis of transcripts</td>
</tr>
<tr>
<td></td>
<td>• Drafting of EAA poster submission for Objective 1</td>
</tr>
<tr>
<td>10</td>
<td>• Recruit participants</td>
</tr>
<tr>
<td></td>
<td>• Implementer transcribed interview and session</td>
</tr>
<tr>
<td></td>
<td>• Certified translation of transcripts to English</td>
</tr>
<tr>
<td></td>
<td>• Qualitative analysis of transcripts</td>
</tr>
<tr>
<td></td>
<td>• Drafting of manuscript qualitative results</td>
</tr>
<tr>
<td>11</td>
<td>• Likert analysis – descriptive and t-test</td>
</tr>
<tr>
<td></td>
<td>• Memo analysis – descriptive and qualitative comments</td>
</tr>
<tr>
<td></td>
<td>• Kappa analysis</td>
</tr>
<tr>
<td></td>
<td>• Drafting of manuscript remaining results</td>
</tr>
<tr>
<td>12</td>
<td>• Draft manuscript</td>
</tr>
</tbody>
</table>

The research to be conducted follows the same protocols as Woodruff and Cienkowski (in prep) with the approval letter attached. The change in population (specifically targeting Spanish-speaking families with a linguistically appropriate program delivered in their preferred language) is not anticipated to impact the risk to or experiences of participants and is expected to be approved as an amendment to the approved protocol following the completion of translation for the program.
Torri Ann Woodruff, PhD candidate, benefited from a blended and inherently translational education coming from a clinically-oriented background into the research arena. Collaborations with researchers and clinicians in psychology, special education, public health, and audiology lead to a focus on supporting children who are D/deaf and hard of hearing and their families navigate care systems and access critical linguistic supports in a culturally aware manner. Focusing on the use of qualitative methods, Torri Ann highlights the insight and power of participant words and experiences to elevate the understanding of audiologic research and truly integrate person-centered care. Torri Ann will serve as the primary investigator for this program.

Emily LaSpada is a rising senior at the University of Connecticut with studies concentrated in Speech, Language, and Hearing Sciences. Experience working through both the West Hartford and Mansfield Public school systems lends to a strong educational background. Emily has a passion for working with individuals that are D/deaf and Hard of Hearing, stemming from fluency in ASL and history with the American School for the Deaf. Recent experience in the UConn Speech Processing and Language Development and Aural Rehabilitation Labs has shaped a new goal of working as a Pediatric Audiologist with possible research work. Emily will serve as a research assistant and implementation trainer.

Kristin Dilaj is the Co-Director and pediatric audiologist at the New England Center for Hearing Rehabilitation, LLC. Her areas of expertise include cochlear implant programming and pediatric aural (re)habilitation. She previously served as a co-chair and is currently a member of the Connecticut Early Hearing Detection and Intervention Task Force. She is a past president of the Academy of Rehabilitative
Audiology. Kristin’s research interests include cochlear implant programming and access for children with hearing loss in mainstream learning environments. Kristin will serve as the mentor for this project.

Lily Nieto is a coordinator for the Connecticut Birth to Three system. As a bilingual English/Spanish speaker, Lily understands how critical hearing and early intervention are to language development. This drives her in ensuring access to hearing services for all the children and families she works with across childhood. Lily will serve as a critical connection to Spanish-speaking communities and provide authentic feedback and insight into this culturally responsive project.
<table>
<thead>
<tr>
<th>Construct</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>GLOBAL</td>
<td>Are you interested in early intervention for your child? Yes/No/I do not know what early intervention is</td>
</tr>
<tr>
<td>Perceived</td>
<td>REVERSE My child’s hearing isn’t a big deal</td>
</tr>
<tr>
<td>VULNERABILITY</td>
<td>REVERSE It is not likely that my child will have problems communicating because that does not run in my family</td>
</tr>
<tr>
<td></td>
<td>The advantages of getting early intervention services for my child are greater than the disadvantages.</td>
</tr>
<tr>
<td></td>
<td>REVERSE I have heard you should get early intervention for your child if they have differences in their hearing</td>
</tr>
<tr>
<td></td>
<td>REVERSE Getting my child early intervention services is worth the cost</td>
</tr>
<tr>
<td></td>
<td>REVERSE Having hearing differences limits my child’s access to communication</td>
</tr>
<tr>
<td></td>
<td>REVERSE When children with hearing differences don’t get early intervention, they and their families suffer</td>
</tr>
<tr>
<td></td>
<td>REVERSE Without early intervention, my child’s development will be negatively impacted</td>
</tr>
<tr>
<td>Perceived</td>
<td>REVERSE The benefits of getting early intervention outweigh the costs</td>
</tr>
<tr>
<td>benefits</td>
<td>REVERSE I would worry if my child could not communicate because of their hearing</td>
</tr>
<tr>
<td></td>
<td>REVERSE I don’t have trouble communicating with my child, so not having early intervention would not be a big problem for me</td>
</tr>
<tr>
<td></td>
<td>REVERSE I worry about my child missing out on their childhood because of their hearing</td>
</tr>
<tr>
<td></td>
<td>REVERSE Spending time learning about hearing and early intervention would be valuable to me</td>
</tr>
<tr>
<td></td>
<td>REVERSE Early intervention is only focused on my child, so I do not need to be involved</td>
</tr>
<tr>
<td></td>
<td>REVERSE It isn’t likely professionals would know how to benefit my child.</td>
</tr>
<tr>
<td></td>
<td>REVERSE Once your child has a hearing difference there’s not much you can do about it</td>
</tr>
<tr>
<td>Perceived</td>
<td>REVERSE It would be uncomfortable for my child to get early intervention</td>
</tr>
<tr>
<td>barriers</td>
<td>REVERSE It is too much trouble to get early intervention</td>
</tr>
<tr>
<td></td>
<td>REVERSE Most people say early intervention does not work well</td>
</tr>
<tr>
<td></td>
<td>REVERSE If my child had a hearing difference, I would do everything I could to avoid getting early intervention</td>
</tr>
<tr>
<td>Understanding</td>
<td>REVERSE</td>
</tr>
<tr>
<td>---------------</td>
<td>---------</td>
</tr>
<tr>
<td>Early Intervention</td>
<td>The costs of early intervention are too high for me</td>
</tr>
<tr>
<td>REVERSE</td>
<td>It is too difficult for me to get early intervention for my child because of their other needs, even when I know they need it</td>
</tr>
<tr>
<td>REVERSE</td>
<td>It is difficult for me to enroll in early intervention in my state</td>
</tr>
<tr>
<td>REVERSE</td>
<td>I am confident that I know how to get early intervention</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Culture</th>
<th>REVERSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>My lifestyle choices make it difficult for me to get early intervention for my child because I don’t think they will understand me</td>
<td></td>
</tr>
<tr>
<td>Care providers do not look, sound, or act like me so I don’t think they will understand my family</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Experiences</th>
<th>REVERSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>My personal history with hearing tells me everything I need to know about early intervention</td>
<td></td>
</tr>
<tr>
<td>Early intervention services run by the state are there to help me and will be filled with qualified people</td>
<td></td>
</tr>
<tr>
<td>I have too many feelings right now and cannot think about early intervention</td>
<td></td>
</tr>
<tr>
<td>Table 2</td>
<td></td>
</tr>
<tr>
<td>------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Outline of semi-structured interview</strong></td>
<td></td>
</tr>
<tr>
<td>Tell me about your experience with your child’s hearing.</td>
<td></td>
</tr>
<tr>
<td>What was it like to go through today’s session?</td>
<td></td>
</tr>
<tr>
<td><strong>PROBE – educational value</strong></td>
<td></td>
</tr>
<tr>
<td>• New information (can you tell me more about any new information from today?)</td>
<td></td>
</tr>
<tr>
<td>• Understand old information (can you tell me more about what it was like to hear some information again?)</td>
<td></td>
</tr>
<tr>
<td>• Change decision making based on info (can you tell me more about how today factors into your decision making?)</td>
<td></td>
</tr>
<tr>
<td><strong>PROBE – emotional value</strong></td>
<td></td>
</tr>
<tr>
<td>• Role as an advocate (can you tell me more about how it made you feel as a parent?)</td>
<td></td>
</tr>
<tr>
<td>• Importance of EI (can you tell me more about how you feel about EI?)</td>
<td></td>
</tr>
<tr>
<td><strong>PROBE – functionality</strong></td>
<td></td>
</tr>
<tr>
<td>• Duration (How do you feel about the timing for this?)</td>
<td></td>
</tr>
<tr>
<td>• Content (How do you feel about what was covered?)</td>
<td></td>
</tr>
<tr>
<td>• Online/virtual/COVID (what was it like to do this in a virtual setting?)</td>
<td></td>
</tr>
<tr>
<td>• Who was administering it (how was it interacting with the presenter?)</td>
<td></td>
</tr>
<tr>
<td>How did this session compare to your other hearing care appointments?</td>
<td></td>
</tr>
<tr>
<td><strong>PROBE – utility</strong> (how do you feel about using your time to do this?)</td>
<td></td>
</tr>
<tr>
<td><strong>PROBE – understandability</strong> (What do you think you got out of this conversation?)</td>
<td></td>
</tr>
<tr>
<td><strong>PROBE – comfort</strong> (how did it feel to talk in this setting?)</td>
<td></td>
</tr>
<tr>
<td><strong>PROBE – impact on decision making</strong> (how do you feel about making a decision about EI?)</td>
<td></td>
</tr>
<tr>
<td>Is there anything you would like to tell me before we wrap up?</td>
<td></td>
</tr>
</tbody>
</table>
Works Cited


https://doi.org/10.15142/fptk-b748


