

## Understanding Barriers to Timely Enrollment of Early Intervention Services for Children who are Deaf and Hard of Hearing

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### Abstract

The Joint Committee on Infant Hearing guidelines recommend that children who are deaf and hard of hearing should begin early intervention by six months of age. However, prior work has revealed a substantial percentage of children who receive a diagnosis of hearing loss by three months of age, but do not enroll in early intervention by six months of age (Grey et al., 2022). To further understand barriers to enrollment in early intervention for these families, we completed qualitative semi-structured interviews with 10 caregivers whose children were diagnosed with hearing loss by three months of age but did not begin early intervention by six months. We recruited from participants in Grey et al. (2022). Interviews were coded using the Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006) as a guiding framework. The interviews revealed widespread barriers encountered by families of children who are deaf and hard of hearing across ecological systems, ranging from child characteristics to macro-level issues like insurance coverage. To ensure that all children who are diagnosed with hearing loss have timely access to early intervention, changes to current policy and practice are needed across multiple ecological systems.

**Keywords:** early intervention, barriers, family perspectives, qualitative design, children who are deaf and hard of hearing

**Acronyms:** DHH = deaf or hard of hearing; EHDI = early hearing detection and intervention; FCEI = family-centered early intervention; UNHS = universal newborn hearing screening

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The average age at which children who are deaf and hard of hearing (DHH) receive an audiological diagnosis and enroll in early intervention services has steadily decreased since the advent of universal newborn hearing screening (UNHS) programs. The Early Hearing Detection and Intervention (EHDI) system was created to accelerate the screening, diagnosis, and intervention process for children who are DHH. The current EHDI guidelines recommend that infants should receive a hearing screening by one month of age, be diagnosed with a hearing loss by three months of age, and enroll in early intervention by six months of age (1-3-6 guidelines; Joint Committee on Infant Hearing [JCIH], 2019).

For the past decade, various agencies and research teams have examined the percentage of children who are DHH

who have met the screening, diagnosis, and intervention timeline outlined in EHDI's 1-3-6 guidelines. Based on data collected in 2020 from 50 states and seven territories of the United States, the Center for Disease Control and Prevention (CDC) reported 98.2% of newborn babies received a UNHS before one month of age (CDC, 2020). Of the infants who failed their UNHS, only 60.0% received a diagnosis of hearing loss or no hearing loss by three months of age, and 61.4% of those diagnosed with hearing loss enrolled in early intervention services before six months of age.

Research samples are consistent with this population-based data. Despite UNHS being routine practice, it appears that timely follow up for diagnosis and intervention is not as common. Across two research samples,

Yoshinaga-Itano et al. (2017) and Grey et al. (2022) reported that only 58% and 57%, respectively, of children who are DHH met all three EHDI benchmarks. McLean et al. (2019) reported that a little more than 50% of those children diagnosed with a hearing loss began early intervention services before their six-month birthday, and Holte et al. (2012) found that 75% of children who are DHH were enrolled in early intervention by six months of age. Out of 76 children who are DHH across 31 states who were enrolled in a longitudinal study of language and literacy acquisition, Grey et al. (2022) reported that 95% received a hearing screening by one month of age, 70% were diagnosed with a hearing loss by three months of age, and only 62% of those who received a hearing loss diagnosis began intervention by six months of age.

Therefore, it appears that a substantial percentage of children who are DHH, 25–50%, do not begin early intervention services by the recommended 6 months of age. It is crucial to understand barriers encountered by families of children who are DHH after a failed newborn hearing screening. We have previously reported on barriers during the diagnosis process in Reynolds et al. (2023). The purpose of this study, therefore, was to understand families' barriers to timely enrollment in early intervention services. We approached our research questions using Bronfenbrenner's Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006) as our theoretical lens.

### **The Bioecological Model of Human Development**

The Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006) is the culminating model of the work of Urie Bronfenbrenner, who proposed the Ecological Model of Human Development originally in 1979. In this model, an individual's development is affected by a series of nested systems beginning with the individual and branching outwards into the extended community and broader culture (Bronfenbrenner, 1979). The core of the Bioecological Model is the individual and includes specific personal traits that influence the course of their development. These traits can include birth complications, diagnoses, and temperament. Working outwards, the microsystem is characterized by the relationships, environments, and communities that the developing individual has direct interactions with on a regular basis. Interactions between components in the microsystem make up the mesosystem. The mesosystem categorizes the complex interrelations that exist between the immediate communities influencing the individual. An example interaction in the mesosystem might encompass how the caregiver's work schedule relates to a child's school; for example, the work schedule might make it difficult to schedule an appointment to talk with the child's teacher or a child's ability to participate in extracurricular activities. Beyond the mesosystem, the exosystem consists of the organizations and environment outside of the immediate community that hold influence on the individual, but do not directly include the individual. Within the exosystem exists a broad range of formal and informal social structures. A caregiver's workplace, the home

and neighborhood of the child, the media a child may be exposed to, and ruling government bodies (local, state, and federal) are all considered influencing factors that fall into the exosystem. The final sphere is the macrosystem, which is characterized by overarching societal systems, including but not limited to the political, economic, educational, and healthcare systems used by the culture in which the developing individual lives.

The Bioecological Model of Human Development has been used to guide qualitative research since it was first proposed and is especially prevalent in research concerning early education and intervention (Swick & Williams, 2006; Tudge et al., 2021). The model's value lies in its holistic approach, which allows investigators to examine the impact and relationship of multiple factors on a child's development (Eriksson et al., 2018; Swick & Williams, 2006). Barriers of interest in the present study, for example, may exist across any of the systems in the Bioecological Model, some of which can be addressed by the caregiver and some of which lie out of their control (Awad et al., 2019; Holte et al., 2012; Shulman et al., 2010).

### **Prior Work on Barriers to Hearing Healthcare Services**

Recently, there has been increased attention to barriers to meeting EHDI's three-month diagnosis benchmark (Bush et al., 2015; Holte et al., 2012; Kingsbury et al., 2022; McLean et al., 2019; Richlin et al., 2023; Shulman et al., 2010). From this work, it is clear that barriers faced by families are systemic, complex, and multidimensional. These barriers can occur at multiple levels, beginning at the patient and fanning out to society at large, making the Bioecological Model of Human Development an ideal framework through which to comprehensively examine the issue. At the level of the patient, barriers to diagnosis by three months consist of birth complications, speech and language delays (perceived or documented), severity and configuration of hearing loss, and comorbidities (Awad et al., 2019; Holte et al., 2012; McLean et al., 2019). Family-level barriers include conflicting work responsibilities, transportation challenges, rural location, minimal to no insurance coverage, and lack of understanding the importance of follow up (Awad et al., 2019; Bush et al., 2015; Holte et al., 2012; McLean et al., 2019; Shulman et al., 2010). Provider barriers include a lack of knowledgeable professionals (e.g., pediatric audiologists, speech-language pathologists, early interventionists), limited early intervention and family support programs, and complex diagnostic appointments requiring multiple evaluations and lengthy wait lists (Awad et al., 2019; Holte et al., 2012; Shulman et al., 2010). Similar barriers were identified by Reynolds et al. (2023), who examined caregivers' impressions of their path to obtaining a diagnosis of hearing loss for their child. Provider barriers were the most frequently reported, with caregivers describing limited access to providers in their area and inadequate informational counseling when they were put into contact with providers. In the present study, we focus specifically on barriers to timely start of early intervention services.

## The Need to Focus on Access to Early Intervention for Children who are DHH

The EHDI benchmark of 6 months for early intervention enrollment is based on decades of research showing its benefit to spoken language outcomes (e.g., Yoshinaga-Itano et al., 2010; Yoshinaga-Itano et al., 2017). Grey et al. (2022) reported that the only unique predictor of preschool omnibus spoken language outcomes between children who met EHDI benchmarks and those who did not is enrollment in early intervention by six months of age, highlighting the importance of this final benchmark for developmental outcomes. Ideally, early screening and early diagnosis of hearing loss leads seamlessly to immediate enrollment in appropriate early intervention services. However, there is a subset of families who meet the one month hearing screening and three month diagnosis EHDI benchmarks, but do not meet the six month early intervention benchmark (Findlen et al., 2023). To be able to reduce or eliminate barriers and/or develop methods for intervening, it is necessary to understand why a large number of children who are diagnosed with hearing loss by three months of age do not begin early intervention by six months of age. The purpose of the present study was to examine the barriers that prevent individuals from meeting the final goal of the 1-3-6 EHDI recommended timeline after meeting the one-month screening and three-month diagnosis goals, and to categorize reported barriers using Bronfenbrenner's Bioecological Model of Human Development as our theoretical lens. We addressed the following research questions in this study:

1. What barriers prevent children who are DHH who met previous EHDI benchmarks from meeting the final EHDI goal of enrollment in early intervention by six months of age?
2. Which systems of the Bioecological Model of Human Development represent barriers for children who are DHH trying to enroll in early intervention?

### Method

All study procedures were approved by the University of South Carolina Institutional Review Board. All participants provided informed consent prior to participating in the interviews.

### Participants

In this study, we specifically recruited caregivers of children in Grey et al. (2022) whose children met the EHDI guideline for diagnosis of hearing loss by three months of age but did not meet the guideline for enrollment in early intervention by six months of age. We invited via email or phone call all participants whose children met these criteria, and all agreed to participate in this follow-up study. Participants included 10 caregivers whose children are deaf or hard of hearing (DHH) and use amplification and spoken English as

their primary language. Table 1 presents demographic information for each caregiver and their child who is DHH.

### Procedures

**Interview process.** Each caregiver of a child who is DHH participated in individual semi-structured interviews conducted by the third author. The interviews were conducted virtually via Zoom for Telehealth and were recorded using Zoom's internal capabilities. Eight of the interviews were with the child's mother only and two of the interviews were with the child's mother and father. The average length of interviews was 21 minutes (range: 11 to 36 minutes). The interview questions focused on barriers to enrollment in early intervention. The interview protocol was developed based on Bronfenbrenner's Bioecological Model (Bronfenbrenner & Morris, 2006) and specifically addressed barriers related to each system of the model. The interview protocol is displayed in the Appendix.

**Transcription process.** Each interview was transcribed verbatim by either the third author or a graduate student research assistant. Accuracy of interview transcription was verified by the other. Thus, final transcriptions represented consensus of the two transcribers.

**Coding process.** Analysis was completed by the first, second, and fourth authors. We used a combined deductive and inductive coding approach in this study. Deductive coding is a top-down approach to qualitative analysis in which the research team develops the initial codebook based on an established framework prior to coding interviews (Saldaña, 2021). Our framework in this study was Bronfenbrenner's Bioecological Model of Human Development. Therefore, our initial codes matched to each system in the model: Child, Microsystem, Mesosystem, Exosystem, and Macrosystem. Inductive coding is a bottom-up approach to qualitative analysis in which the research team develops codes as the dataset is analyzed (Saldaña, 2021). As the coding progressed, new codes were added to the codebook based on the data. Codes that emerged during this process were related to specific barriers experienced by families within each of the bioecological systems.

Prior to reading or listening to any interview, the first author created an a priori codebook in collaboration with the second and fourth authors, which was based on the Bioecological Model of Human Development. Then, the second and fourth authors separately coded each interview using the initial codebook and adding additional codes as they were identified from the data. They met with the first author regularly during coding to discuss disagreements and refine the codebook. The final analysis represents consensus of the coders and first author on the final codebook and themes/subthemes that were identified in the interviews. Finally, the entire research team reviewed and agreed on the final codebook and themes identified.

**Table 1**  
*Demographic Information for Participants*

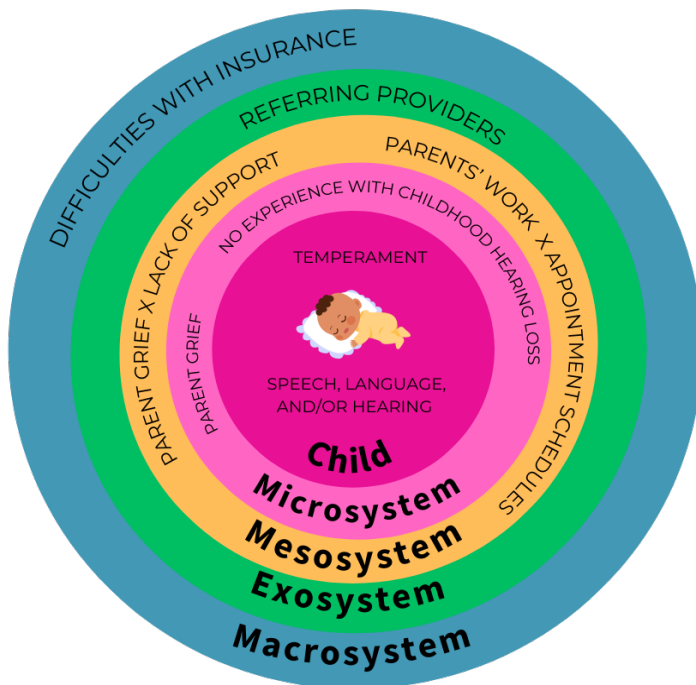
Participant Number	Caregiver(s) Interviewed	Child Amplification	Child Degree of Hearing Loss	Child Sex Assigned at Birth	Geographic Region in U.S.	Languages at Home	Race	Ethnicity	Age at Early Intervention Enrollment	Maternal Education
1	Mother + Father	Bimodal	Severe to Profound	Girl	West South Central	English 100%	White	Not Hispanic or Latino	14 months	Graduate degree
2	Mother	Bilateral Cochlear Implant	Profound	Boy	East North Central	English 75% Albanian 25%	White	Not Hispanic or Latino	9 months	Some college
3	Mother	Bilateral Cochlear Implant	Severe to Profound	Boy	Mountain West	English 100%	White	Not Hispanic or Latino	10 months	Bachelor's degree
4	Mother	Bilateral Hearing Aids	Mild to Moderate	Girl	South Atlantic	English 100%	White	Not Hispanic or Latino	7 months	Bachelor's degree
5	Mother	Bilateral Hearing Aids	Severe	Girl	South Atlantic	English 100%	Black or African American	Not Hispanic or Latino	24 months	Graduate degree
6	Mother	Bilateral Hearing Aids	Mild to Moderate	Girl	West North Central	English 100%	White	Not Hispanic or Latino	9 months	Some college
7	Mother + Father	Bilateral Hearing Aids	Moderately Severe	Boy	Pacific West	English 100%	White	Not Hispanic or Latino	50 months	Some college
8	Mother	Unilateral Hearing Aid	Moderate	Girl	West South Central	English 100%	White	Not Hispanic or Latino	17 months	Bachelor's degree
9	Mother	Bilateral Hearing Aids	Mild to Moderate	Boy	East South Central	English 100%	Native Hawaiian or Other Pacific Islander	Not Hispanic or Latino	17 months	Bachelor's degree
10	Mother	Bilateral Hearing Aids	Moderate	Boy	Pacific West	English 60% Spanish 40%	Not Reported	Hispanic or Latino	9 months	Some college

## Results

Themes identified from caregiver interviews are presented below. Overall, barriers to timely access of early intervention reported by caregivers spanned the systems of the Bioecological model, including child, microsystem, mesosystem, exosystem, and macrosystem factors (see Figure 1). Subthemes in each system are described below.

**Figure 1**

*Barriers to On-Time Enrollment in Early Intervention by System of the Bioecological Model of Human Development.*



*Note.* This figure is based on the description of nested systems in Bronfenbrenner and Morris (2006).

### Barriers Related to Child

We identified two barriers to early intervention related to child factors: child temperament and child hearing or speech/language skills. First, caregivers reported that child temperament influenced their ability to access early intervention; however, the specific temperament characteristics varied child-to-child. For example, some caregivers reported that a difficult temperament caused a delay in accessing early intervention. This temperament was seen primarily in opposition to wearing amplification devices, which influenced the speed at which caregivers sought early intervention.

Some caregivers reported that they believed that early intervention wouldn't be useful until they felt their child was well adjusted to their amplification devices. Other caregivers reported that a slow-to-warm-up temperament influenced the speed at which they enrolled in early intervention. One caregiver, for instance, reported that their child's shyness resulted in professionals being hesitant to use test results to make eligibility decisions, which delayed their enrollment in early intervention services: "A lot of the

testing that was done in that timeframe wasn't the most accurate because she ... didn't want to participate."

Additionally, several caregivers reported that their enrollment in early intervention was delayed because they were told that their child's hearing and/or speech and language did not qualify for the state program. Caregivers reported that child factors that led to being told they would not qualify included mild to moderate degrees of hearing loss, as well as speech and language development that was on target at three to six months of age. It is important to note that decisions about early intervention eligibility for children who are DHH were being made on the basis of no delay in speech or language at six months of age or younger.

### Barriers Related to Microsystem

The two main barrier categories within the microsystem were lack of caregiver experience with childhood hearing loss and caregiver grief. First, caregivers reported a lack of experience related to childhood hearing loss, expressing the idea that they did not feel equipped to make decisions about early intervention. For example, one caregiver reported that they felt pressure to "make a fairly quick decision" about their child's communication modalities after diagnosis. They reported that they thought they would just need hearing aids: "Probably just get hearing aids and he'll be fine. No one in the family really knew. I'm a physical therapist. I know about therapy in general but speech is a lot different." Many caregivers reported that they did not feel a sense of urgency in getting their child enrolled in early intervention because they had no experience with childhood hearing loss—they didn't recognize the need for intervention prior to their child beginning to talk.

Second, caregivers reported grief and a feeling of loss after their child's hearing loss diagnosis. A caregiver recalled being "kind of sad at first realizing that he wouldn't be able to have normal hearing like I've had my whole life." Another said, "I remember feeling very overwhelmed and very scared. I'm very worried about my child. What was the future going to look like for her? Cause this was something that I had not experienced before and no one in our family had hearing loss. I think as parents we all envision our children being perfect. And not that she's not perfect but I knew that with this we were going to have some obstacles and some challenges that we were gonna have to learn how to overcome in order to help her succeed." This grief encompassed feelings that their child would miss out on a normal life, as well as feelings of guilt for any potential role they had in causing the hearing loss, and fear for their child's future. Some caregivers reported being in denial, whereas others reported feeling overwhelmed without a clear picture of where to go next. Both led to delays in early intervention.

### Barriers Related to Mesosystem

Relevant to the mesosystem, two primary interactions were identified: (a) caregivers' grief and lack of support from extended family members or community members, as well as (b) caregivers' work and appointment scheduling. For some families, caregiver grief was amplified by a lack of support from extended family or

communities. Caregivers reported that without buy-in from their support systems, they questioned the need for intervention for their child. This interaction of caregiver grief and lack of support from family or community resulted in delays to enrollment in early intervention. Caregivers reported switching focus from following recommendations for early intervention to convincing others to support and participate in their decisions regarding their child's development (e.g., wearing hearing aids at grandma's house). In other cases, caregivers reported getting mixed messages from community members regarding the use of amplification and choice of communication mode and waited to enroll in early intervention while they attempted to learn more about their child's options.

Additionally, caregivers' schedules impacted the timely enrollment in early intervention for some children. Several caregivers reported that it was difficult to schedule appointments with hearing healthcare professionals and/or early intervention systems while also maintaining their work schedules and productivity. This difficulty was sometimes, but not always, related to distance from the family to a specialized service provider. Caregivers discussed their difficulty in navigating all the appointments needed for their child in light of the time away from work required; often this included substantial travel time as well as the time in appointments.

### **Barriers Related to Exosystem**

The primary barrier within the exosystem was related to referring providers. Caregivers reported a lack of communication from medical professionals, difficulty obtaining referrals for early intervention, and professionals who did not follow the EHDI 1-3-6 guidelines. In many cases, caregivers reported that providers, primarily pediatricians, did not know that they should refer their child to early intervention, and in some cases explicitly declining caregivers' requests for a referral. Provider lack of knowledge of the EHDI guidelines was widespread. Less common, but reported by some caregivers, were providers who do not believe in referring any child for early intervention prior to certain ages (in this study, some caregivers reported they were told their pediatrician never refers before 14–18 months). In hindsight, caregivers reported that had early intervention been recommended by their provider, they would have enrolled earlier. Caregivers whose providers declined to provide a referral for early intervention report they wished they had pushed the issue more or with a different professional. A caregiver said, "originally a lot of the doctors told us don't do anything cause it's single sided and she'll develop fine." Although pediatricians were the primary medical professional related to this issue, hearing healthcare professionals (encompassing multiple professions including otolaryngologists, audiologists, and speech-language pathologists) were also mentioned by a minority of caregivers for downplaying the need for early intervention for their child.

### **Barriers related to Macrosystem**

Finally, the primary barrier within the macrosystem was difficulties with insurance. Seventy percent of caregivers reported difficulties with insurance. These difficulties included their insurance declining coverage of early intervention, as well as overly complicated protocols to obtain coverage. Some caregivers reported having to change providers because of insurance changes, which led to additional delays. A caregiver details their difficulty with insurance coverage: "We fought like hell. We got out of the NICU and we had severe insurance drama go on because I was very naïve... My work's benefits advisor advised that we get the HMO... I go to call and make the doctor's appointments and they're like oh no no no. You have an HMO. You can't do anything. You have to go through all these loops and hoops and scoops to get that. So we're trying to get the insurance fixed. I was on the phone everyday fighting for two or three hours."

### **Discussion**

The purpose of this study was to understand families' barriers to timely enrollment in early intervention services for their children who are DHH. We approached our inquiry through a lens of Bioecological Model of Human Development (Bronfenbrenner & Morris, 2006). By situating our findings within this model, we were able to gain a comprehensive understanding of the multi-layered and multi-leveled barriers to early intervention for this population. Our findings suggest that barriers to timely access of early intervention for children who are DHH are numerous and span bioecological systems for the child. Child factors such as temperament that made testing difficult ranging to macrosystem factors such as difficulties with insurance coverage delayed enrollment in early intervention for the children who are DHH in this study. Increasing the percentage of children who are DHH who meet the six month EHDI early intervention guideline will require comprehensive, widespread improvements to the current hearing healthcare system.

### **Child**

First, professionals must be aware of potential child-level factors that may influence the speed at which early intervention is accessed. Many infants who are DHH initially resist wearing amplification devices (Visram et al., 2021), and caregivers have previously reported that child behavior impacts their time of hearing aid use (Muñoz et al., 2015). For families who choose a spoken language communication modality, hearing healthcare professionals should spend time explaining expectations and provide strategies to increase usage when introducing new devices. Additionally, professionals should explicitly tell families that this resistance does not prevent the child and family from accessing and benefiting from early intervention. Likewise, hearing healthcare professionals should not delay early intervention based on child temperament. Recall that our participants all received a diagnosis of hearing loss by three months of age, so temperament played a role only in their access to early intervention, not diagnosis of hearing loss. Importantly,

Sanson (1996) reported that ratings of child shyness did not stabilize until after one year of age and even then only showed moderate stabilization. Children who are diagnosed with mild degrees of hearing loss should also not be the basis of declining access to early intervention. Children with mild, unilateral, or even minimal hearing loss are likely to experience later academic difficulties, and early intervention may prevent these difficulties (e.g., Bess et al., 1998; Fitzpatrick et al., 2019; Walker et al., 2020).

### **Microsystem**

Next, professionals should be aware that most caregivers have no prior experience with childhood hearing loss. Hearing loss health literacy is extremely low even in caregivers who have more than a year of experience with their child's hearing loss (Cooper & Werfel, 2024). Therefore, it is vital that professionals provide multimodal supports, be mindful of how much information is conveyed at one time, and check caregiver understanding (Richlin et al., 2023). Richlin and colleagues' 2023 article, "Living in the Void Between Hearing Health Care Encounters: Evaluation of the Barriers Families Face" is an excellent resource for providers to read more about informational counseling with families of children diagnosed with hearing loss.

Caregivers also reported experiencing many facets of grief during the 1-3-6 timeline, including feeling shame, wondering what they could have done differently, mourning the loss of an idealized view of their child's future, and feeling paralyzed in the decision-making process. Hearing healthcare providers can help caregivers navigate their grief by providing appropriate counseling and referring families to appropriate mental health professionals. Providers should practice a client-centered model of counseling, in which the provider practices selfless listening, the parent participates in testing so the family can take ownership of their child's diagnosis from the beginning, and the provider shares information while acknowledging the family's painful feelings (for more details, see Luterman, 2021). Luterman recommends that, often, information sharing should be done in a subsequent appointment, particularly if the family exhibits behaviors consistent with grief and/or shock. Additionally, there is a need to explicitly consider how to convey information to families in multiple formats and multiple times to scaffold families in learning about their child's hearing loss and the full range of their treatment options.

### **Mesosystem**

Professionals also must be aware of key interactions that occur within family systems. Specifically, in this study we identified two interactions that served as barriers to early intervention enrollment. First, caregivers reported feelings of grief that were compounded by lack of support. This lack of support sometimes came from extended family members, such as grandparents, which highlights the need for family-centered early intervention (FCEI) approaches. FCEI approaches emphasize the need for considering multiple family members and how their needs may differ when planning early intervention services for

children (Dirks & Szarkowski, 2022). Involving extended family members and encouraging caregivers to involve them in interactions with hearing healthcare providers, including audiologists and speech-language pathologists, may provide an avenue for informational counseling with family beyond the primary caregivers to relieve some burden from the family. Other caregivers reported lack of support from their communities. Caregivers often sought support from the local DHH community but reported that they were sometimes met with hostility regarding their communication and/or amplification choices. Importantly, this reported hostility goes both ways: some caregivers reported being told their child would never learn spoken language if they used sign language, whereas others reported being told that cochlear implantation was abusive to their child. Both of these perspectives are highly emotionally charged, and there is no evidence to suggest that either is true. As providers, we must be aware of these potential support system difficulties and prepare families to navigate them. As a field, it's time to step past these extremes and be respectful of family choices.

The second interaction we identified was the interaction of caregiver work schedules and appointment scheduling. The field has long recognized the hearing healthcare disparities faced by families resulting from distance from a hearing healthcare facility (e.g., Bush et al., 2013). The caregivers in this study also highlighted the burden to families that comes from time off work, particularly in some cases immediately following parental leave. The time required for follow-up appointments and the lack of time off work to complete them is an issue the field must be aware of and help families to address; we believe this burden should fall on providers, not families. This finding also indicates the need for provider flexibility in scheduling visits as well as institutional commitments to investing in mobile service delivery. Telepractice has the potential to alleviate some of this burden, and families in rural areas are enthusiastic about its use (Bush et al., 2015).

### **Exosystem**

At the level of the exosystem, caregivers reported tremendous difficulty getting referred to early intervention by their providers. Primarily, these difficulties centered on pediatricians; however, a minority of families reported that hearing healthcare specialists downplayed the need for early intervention for their child. The majority of caregivers reported that their pediatricians lacked knowledge about the EHDI guidelines for early intervention enrollment, and some caregivers reported that their pediatricians never refer any child to early intervention prior to specific ages (e.g., 18 months), with the potential loss of a full year of early intervention progress. Our field must provide better support to front-line professionals in knowing who, when, and how to refer. Hearing healthcare providers should explore ways in which information about the need for early intervention for children who are DHH and basic knowledge of the EHDI guidelines can be better conveyed to pediatricians to enact systemic change in this area. It is also important to consider how individuals with lived experiences related to childhood hearing loss, including

deaf mentors and parents who have previously navigated the hearing healthcare system, may collaborate with hearing healthcare providers to ensure that families have appropriate support.

### Macrosystem

The prevailing theme from the macrosystem was difficulties with insurance. Consistent with prior research (Bush et al., 2015; Kingsbury et al., 2022), caregivers whose children are DHH reported dealing with overly complicated insurance protocols, minimal to no coverage for early intervention services, and forced changes in providers (e.g., in the case of enrolling their child in Medicaid) as significant barriers to enrolling in early intervention. Because insurance and Medicaid rules and regulations are largely beyond the control of families and hearing healthcare professionals, the need for change in hearing healthcare requires work to change systems via top-down, as well as bottom-up, approaches. Local advocacy efforts have been quite successful at a state level for initiatives like insurance coverage for pediatric hearing aids, and similar approaches may be appropriate for early intervention services. It is vital that hearing healthcare providers know the specific IDEA Part C eligibility rules in their states and provide this information to families via informational counseling, along with information about how families can self-refer via ChildFind.

### Conclusion

Families of children who are DHH face widespread, systemic, multi-layer barriers to enrolling in early intervention services for their child. The barriers identified herein spanned Bronfenbrenner's Bioecological Model of Human Development, from child-level factors such as temperament to macrosystem-level factors such as insurance. Hearing healthcare professionals must be aware of these barriers and take steps to ensure that all families are able to access early intervention services in a timely manner for their children who are DHH.

### References

- Awad, R., Oropeza, J., & Uhler, J. (2019). Meeting the Joint Committee on Infant Hearing standards in a large metropolitan children's hospital: Barriers and next steps. *American Journal of Audiology*, *28*, 251–259. [https://doi.org/10.1044/2019\\_AJA-18-0001](https://doi.org/10.1044/2019_AJA-18-0001)
- Bess, F., Dodd-Murphy, J., & Parker, R. (1998). Children with minimal sensorineural hearing loss: Prevalence, educational performance, and functional status. *Ear & Hearing*, *19*, 339–354. <https://doi.org/10.1097/00003446-199810000-00001>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Bronfenbrenner, U., & Morris, P. (2006). The bioecological model of human development. In R. Lerner & W. Damon (Eds.), *Handbook of Child Psychology, Vol. 1: Theoretical Models of Human Development* (6<sup>th</sup> ed., pp. 793–828). Wiley. <http://doi.org/10.1002/9780470147658.chpsy0114>
- Bush, M., Burton, M., Loan, A., & Shinn, J. (2013). Timing discrepancies of early intervention hearing services in urban and rural cochlear implant recipients. *Otology & Neurotology*, *34*, 1630–1635. <https://doi.org/10.1097/MAO.0b013e31829e83ad>
- Bush, M., Hardin, B., Rayle, C., Lester, C., Studts, C., & Shinn, J. (2015). Rural barriers to early diagnosis and treatment of infant hearing loss in Appalachia. *Otology & Neurotology*, *36*, 93–98. <https://doi.org/10.1097/MAO.0000000000000636>
- Centers for Disease Control and Prevention. (2020). 2020 CDC Early Hearing Detection and Intervention (EHDI) hearing screening & follow-up survey. <https://www.cdc.gov/ncbddd/hearingloss/2020-data/documents/2020-hsfs-explanations-508.pdf>
- Cooper, E., & Werfel, K. (2024). High general health literacy does not ensure hearing loss health literacy in mothers of children who are deaf or hard of hearing. *American Journal of Speech-Language Pathology*, *33*, 468–475. [https://doi.org/10.1044/2023\\_AJSLP-23-00110](https://doi.org/10.1044/2023_AJSLP-23-00110)
- Dirks, E., & Szarkowski, A. (2022). Family-centered early intervention (FCEI) involving fathers and mothers of children who are deaf or hard of hearing: Parental involvement and self-efficacy. *Journal of Clinical Medicine*, *11*(3), 492. <https://www.mdpi.com/2077-0383/11/3/492>
- Eriksson, M., Ghazinour, M., & Hammarström, A. (2018). Different uses of Bronfenbrenner's ecological theory in public mental health research: What is their value for guiding public mental health policy and practice? *Social Theory & Health*, *16*, 414–433. <https://doi.org/10.1057/s41285-018-0065-6>
- Findlen, U. M., Davenport, C. A., Cadieux, J., Gehred, A., Frush Holt, R., Vaughn, L. M., Houston, D., & Hunter, L. L. (2023). Barriers to and facilitators of early hearing detection and intervention in the United States: A systematic review. *Ear and Hearing*, *44*(3), 448–459. [https://journals.lww.com/ear-hearing/fulltext/2023/05000/barriers\\_to\\_and\\_facilitators\\_of\\_early\\_hearing.3.aspx](https://journals.lww.com/ear-hearing/fulltext/2023/05000/barriers_to_and_facilitators_of_early_hearing.3.aspx)
- Fitzpatrick, E., Gaboury, I., Durieux-Smith, A., Coyle, D., Whittingham, J., & Nassrallah, F. (2019). Auditory and language outcomes in children with unilateral hearing loss. *Hearing Research*, *372*, 42–51. <https://doi.org/10.1016/j.heares.2018.03.015>



- Grey, B., Deutchki, E., Lund, E., & Werfel, K. (2022). Impact of meeting early hearing detection and intervention benchmarks on spoken language. *Journal of Early Intervention, 44*, 235–251. <https://doi.org/10.1177/10538151211025210>
- Holte, L., Walker, E., Oleson, J., Spratford, M., Moeller, M. P., Rousch, P., Tomblin, J. B., & Ou, H. (2012). Factors influencing follow-up to newborn hearing screening for infants who are hard-of-hearing. *American Journal of Audiology, 21*, 163–174. [https://doi.org/10.1044/1059-0889\(2012/12-0016\)](https://doi.org/10.1044/1059-0889(2012/12-0016))
- Joint Committee on Infant Hearing. (2019). Year 2019 position statement: Principles and guidelines for early hearing detection and intervention programs. *Journal of Early Hearing Detection and Intervention, 4*(2), 1–44. <https://doi.org/10.15142/fptk-b748>
- Kingsbury, S., Khvalabov, N., Stirn, J., Held, C., Fleckenstein, S., Hendrickson, K., & Walker, E. (2022). Barriers to equity in pediatric hearing health care: A review of the evidence. *Perspectives of the ASHA Special Interest Groups, 7*, 1060–1071. [https://doi.org/10.1044/2021\\_persp-21-00188](https://doi.org/10.1044/2021_persp-21-00188)
- Luterman, D. (2021). Counseling parents at the time of diagnosis: Moving toward client-centered practice. *American Journal of Audiology, 30*(1), 226–230. [https://doi.org/doi:10.1044/2020\\_AJA-20-00122](https://doi.org/doi:10.1044/2020_AJA-20-00122)
- McLean, T., Ware, R., Heussler, H., Harris, S., & Beswick, R. (2019). Barriers to engagement in early intervention services by children with permanent hearing loss. *Deafness & Education International, 21*, 25–39. <https://doi.org/10.1080/14643154.2018.1528745>
- Muñoz, K., Olson, W., Twohig, M., Preston, E., Blaiser, K., & White, K. (2015). Pediatric hearing aid use: Parent-reported challenges. *Ear & Hearing, 36*, 279–287. <https://doi.org/10.1097/AUD.0000000000000111>
- Reynolds, G., Werfel, K., Vachio, M., & Lund, E. (2023). Early experiences of parents of children who are deaf or hard of hearing: Navigating through identification, intervention, and beyond. *Journal of Early Hearing Detection and Intervention, 8*, 56–68. <https://doi.org/10.26077/6d9d-06f3>
- Richlin, B., Blaiser, K., & Bush, M. (2023). Living in the void between hearing health care encounters: Evaluation of the barriers families face. *Perspectives of the ASHA Special Interest Groups*. [https://doi.org/10.1044/2023\\_PERSP-23-00038](https://doi.org/10.1044/2023_PERSP-23-00038)
- Saldaña, J. (2021). *The Coding Manual for Qualitative Researchers* (4th ed.) SAGE Publications.
- Sanson, A. (1996). Shyness ratings: Stability and correlates in early childhood. *International Journal of Behavioral Development, 19*, 705–724. <https://doi.org/10.1080/016502596385532>
- Shulman, S., Besculides, M., Saltzman, A., Ireys, H., White, K., & Forsman, I. (2010). Evaluation of the universal newborn hearing screening and intervention program. *Pediatrics, 126*, S19–S27. <https://doi.org/10.1542/peds.2010-0354F>
- Swick, K., & Williams, R. (2006). An analysis of Bronfenbrenner's bioecological perspective for early childhood educators: Implications for working with families experiencing stress. *Early Childhood Education Journal, 33*, 371–378. <https://doi.org/10.1007/s10643-006-0078-y>
- Tudge, J., Navarro, J., Merçon-Vargas, E., & Payir, A. (2021). The promise and the practice of early childhood educare in the writings of Urie Bronfenbrenner. *Early Child Development and Care, 191*, 1079–1088. <https://doi.org/10.1080/03004430.2020.1844193>
- Visram, A., Roughley, A., Hudson, C., Purdy, S., & Munro, K. (2021). Longitudinal changes in hearing aid use and hearing aid management challenges in infants. *Ear & Hearing, 42*, 961–972. <https://doi.org/10.1097/AUD.0000000000000986>
- Walker, E., Sapp, C., Dallapiazza, M., Spratford, M., McCreery, R., & Oleson, J. (2020). Language and reading outcomes in fourth-grade children with mild hearing loss compared to age-matched peers. *Language, Speech, & Hearing Services in Schools, 51*, 17–28. [https://doi.org/10.1044/2019\\_LSHSS-OCHL-19-0015](https://doi.org/10.1044/2019_LSHSS-OCHL-19-0015)
- Yoshinaga-Itano, C., Baca, R. L., & Sedey, A. L. (2010). Describing the trajectory of language development in the presence of severe-to-profound hearing loss: A closer look at children with cochlear implants versus hearing aids. *Otology & Neurotology, 31*(8), 1268–1274. <https://doi.org/10.1097/MAO.0b013e3181f1ce07>
- Yoshinaga-Itano, C., Sedey, A., Wiggan, M., & Chung, W. (2017). Early hearing detection and vocabulary of children with hearing loss. *Pediatrics, 140*, e20162964. <https://doi.org/10.1542/peds.2016-2964>

## Appendix

### Interview Protocol

1. How did you feel or what was your initial reaction to the hearing loss diagnosis?
2. Had you had any experience with hearing loss prior to your child's diagnosis?
3. Did you encounter any difficulties with your child receiving hearing aids after diagnosis? If so, what were they?
4. What were you told was the next step after being diagnosed and fitted with hearing aids?
5. How did you find your early intervention (EI) provider? Who helped you?
6. What went well about the process of finding an EI provider and starting services?
7. What was the main difficulty that you encountered when trying to find an EI provider and begin services?
8. First, can you talk about experiences in beginning EI that might have been related to your child?
9. Next, can you talk about experiences in beginning EI that might have been related to your family?
10. Next, can you talk about experiences in beginning EI that might have been related to your community?
11. Next, can you talk about experiences in beginning EI that might have been related to your healthcare providers?
12. Last, can you talk about experiences in beginning EI that might have been related to society and culture?

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*Note.* EI = early intervention.