



# **Public Input 2018 Survey Findings: Impacts of Early Hearing Detection and Intervention on Deaf and Hard of Hearing Children**

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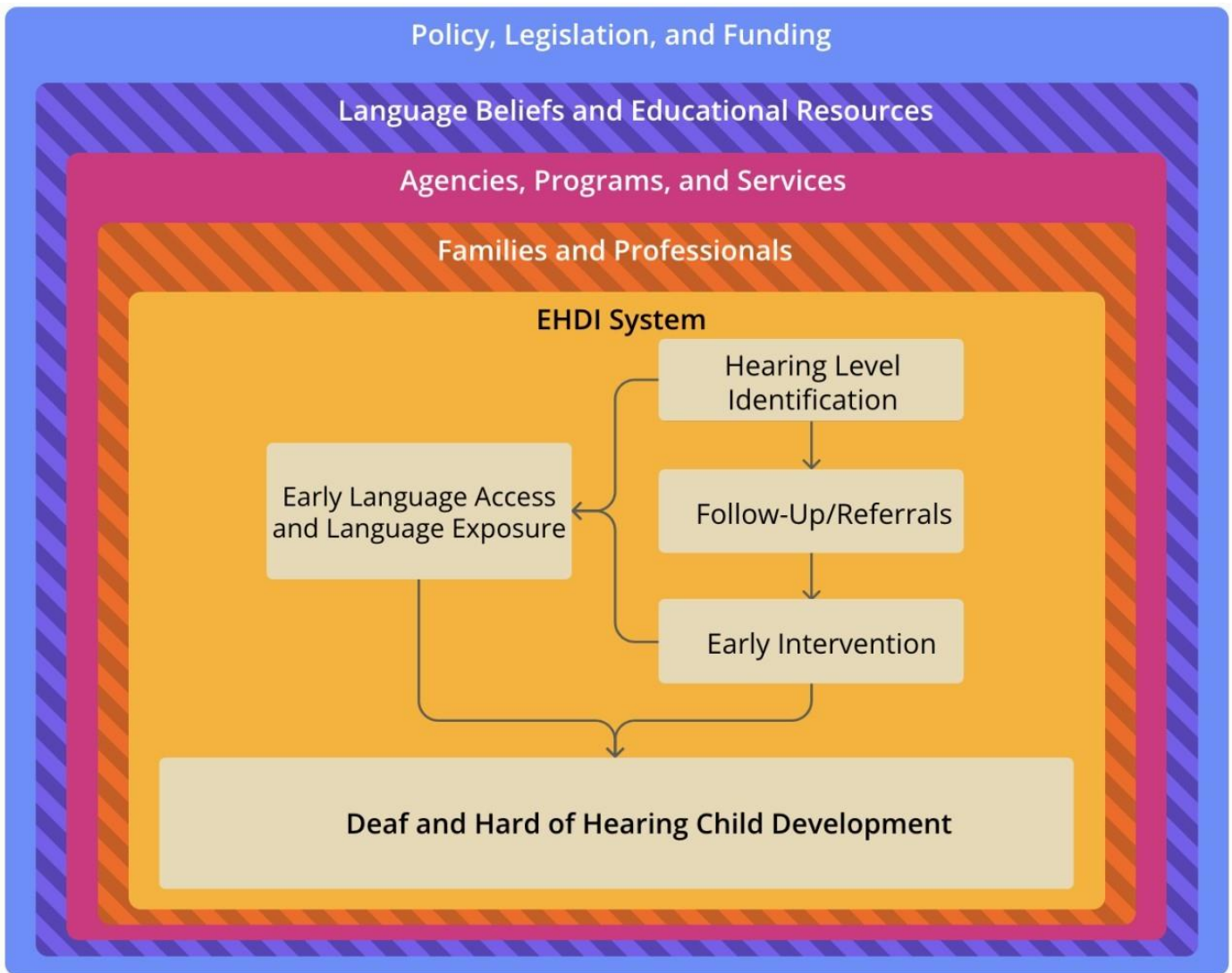
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## Overview

The Early Hearing Detection and Intervention (EHDHI) Impacts on Deaf and Hard of Hearing Child Development Model is an interpretation based on analyses of respondents' comments about EHDHI in response to the national public input survey that was disseminated by the Laurent Clerc National Deaf Center in 2017 and 2018. Respondents included parents and caregivers of deaf and hard of hearing children as well as professionals who work with those children and families. This survey asked respondents to comment about barriers that prevent deaf and hard of hearing students from achieving their academic, linguistic, and socio-emotional potential; EHDHI was one of the barriers receiving comments. EHDHI is a systemic process that provides each newborn with a hearing screening before the infant is released from the hospital. Diagnostic evaluations then follow for those infants needing their hearing levels confirmed by the age of three months. Then, if needed, the infants are enrolled in early intervention programs, and their families are provided with services and resources.

The EHDHI model shows a variety of factors (or layers) that influence the EHDHI system shared by respondents:

- Policy, Legislation, and Funding

- Language Beliefs
- Educational Resources
- Agencies, Programs, and Services
- Families
- Professionals
- EHDI System Components The EHDI system has its own layer showing the different components of EHDI services: hearing level identification, follow-up/referrals for hearing level confirmation, early intervention, and early language access and language exposure.

Each layer in the model demonstrates its influence on subsequent layers. For instance, Policy, Legislation, and Funding—the largest layer—influences layers embedded within, such as Language Beliefs and Educational Resources and Agencies, Programs, and Services. Each layer is assigned a specific color. Overlaps in components (e.g., Language Beliefs and Educational Resources) within a specific layer are demonstrated using striped patterns. Each of the five layers within the model is explained. Quotes from survey respondents are provided as examples.

### **Layer 1: Policy, Legislation, and Funding**

Starting at the outermost layer, Policy, Legislation, and Funding ultimately influences all inner layers and the deaf or hard of hearing children’s overall development. Several respondents discuss how some aspects of their individual state’s EHDI program or the absence of specific EHDI mandates have had adverse effects on deaf and hard of hearing children and their families. Additionally, some respondents express the opinion that current EHDI mandates need to be changed, added to, or expanded on to support deaf and hard of hearing children and their families more effectively, such as requiring more resources and professionals trained in deaf education and deaf and hard of hearing children’s language development. Another important aspect of the Policy, Legislation, and Funding layer is that the mandates vary state by state or location by location, and, as a result, they impact subsequent layers.

Examples of responses related to Policy, Legislation, and Funding:

- *"...Early intervention strategies need to be legislatively funded. There should be seamless transition from 0-3, 35, K-12. Standards for educators for direct communication proficiency need to be developed, assessed, and adhered to."*
- *"... we need policy when a child is born or lost hearing at certain age to connect with a center that provides resources and support from birth to young adult..."*
- *"...I know firsthand because I had to move from [state] to [state] to find a proper early intervention program to allow my child to flourish..."(parent)*

### **Layer 2: Language Beliefs and Educational Resources**

This next layer in the model includes both Language Beliefs and Educational Resources. Each factor has its own color, but the factors are striped to demonstrate their overlap. Each belief is also discussed individually and then the overlap between the two (as demonstrated by the striped pattern) is elaborated upon in the third section (Layer 3) below.

#### **Language Beliefs**

Language and communication beliefs held by parents and professionals involved with early intervention play a large role in EHDI. Some respondents discuss using a specific language with deaf

and hard of hearing children, such as American Sign Language (ASL) or English, while others share that all options need to be provided to families so they can choose for themselves and their children. Some discuss how EHDI is biased toward a specific option and may influence deaf and hard of hearing students and their families in what language or communication mode they decide on. Choices made can impact deaf and hard of hearing students' language development.

Examples of responses related to Language Beliefs:

- *"Fact: Early Hearing Detection and Intervention nationwide is geared toward listening and speaking."*
- *"...ASL should be readily available, and encouraged, for all children, up until and past the age of 5..."*
- *"...Many families are given wrong information about sign language. They are told not to sign to their child if they want them to learn to speak. I have seen the harm done by this..."*
- *"...Children who receive early cochlear implants and auditory-verbal therapy excel and achieve grade level literacy or above if their cochlear implants are maintained and if their parents follow through at home."*

Language beliefs overlap with educational resources as indicated in the model. Language beliefs influence how resources are developed, disseminated, and shared. In turn, resources influence language beliefs in that resource provisions can give people a specific perspective on deaf and hard of hearing children's language development or on how to support deaf and hard of hearing children in reaching age-appropriate language development milestones.

Some respondents discuss how resource availability can influence what modes of communication are used and how preferences can influence resource provisions. Other respondents discuss how different views can cause barriers to effective collaboration and communication among professionals, families, agencies, programs, services, and other EHDI providers, ultimately impacting deaf and hard of hearing students' development. Further, some respondents discuss the importance of consistent hearing assistive technology (an example of resources) used along with support for families and professionals. Overall, the responses analyzed demonstrate the intricacies of language beliefs and resources.

## **Educational Resources**

Educational resources, such as materials, support, training, and information, comprise an important part of the next layer below Policy, Legislation, and Funding, which influences resource provisions and how they are accessed. Educational resources impact agencies, programs, and services; professionals and families; and different components of the EHDI system in various ways. Many respondents discuss the need for more educational resources and specific types of resources, such as language and hearing assistive technology resources.

Examples of responses related to Educational Resources:

- *"I teach in [state], and I feel our state is providing very good services for our students who are deaf or hard of hearing. Even with Early Hearing Detection and Intervention and our Deaf Mentor program, many families still need more resources for language and communication."* (professional)

- *"In my experience having a deaf-blind child, it seems like there are lots of resources within early intervention programs—however, they appeared mostly to be utilized to provide specialist and interventionist services that focused on the child rather than training parents in ASL and building the right communication and language environment at home..."* (parent)
- *"Children from lower socio-economic backgrounds and families that are Hispanic do not receive early interventions, adequate amplification, and early language interventions and bombardment of any language, Spanish, English, or ASL..."*

### **Layer 3: Agencies, Programs, and Services**

Agencies, Programs, and Services comprise a layer between the Language Beliefs and Educational Resources and Families and Professionals layers. Respondents discuss how some programs and services need to be available, improved, or modified to better meet the needs of deaf and hard of hearing children and their families as well as the professionals who work with them. This includes resource provisions and professional training programs. Agencies need to work with each other more effectively. Some respondents discuss that services do not always provide every option available to families due to certain beliefs or knowledge, indicating the influence of language beliefs on subsequent layers. Also, agencies, programs, and services need to reach out more to parents and provide them with resources as well as develop a rapport with them. Additionally, an important influence on this layer is legislation, policy, and funding so some agencies, programs, and services respond accordingly in their EHDI implementation and training. Overall, the previous layers influence agencies, programs, and services in how they are established and carried out, and, in turn, they influence families and professionals and then the EHDI system with its components.

Examples of responses related to Agencies, Programs, and Services:

- *"...Each child with hearing loss and their home environment would need to be assessed to determine need. This service does not necessarily need to be school-related services but could be provided by an outside agency."*
- *"It is also frustrating that the [state] does not have any AuD programs that could potentially enhance early detection and intervention by the mere process of having more qualified staff available..."*
- *"...The agencies do not create or retain teachers of the deaf as service providers..."*
- *"...Maybe a deaf center could help identify students at a younger age and work more with all groups..."*
- *"...Change laws to include mandatory early hearing detection and refer to deaf organizations and schools to ensure the correct path for every deaf child..."*

### **Layer 4: Families and Professionals**

The Families and Professionals layer is between the Agencies, Programs, and Services and EHDI System layers. Respondents discuss families (e.g., parents, caregivers) and professionals and their roles in EHDI as well as their influence on how EHDI services are provided. They also discuss how professionals and families are influenced by previous layers; for instance, beliefs can influence the types of service provisions available to families, and resources that are available to professionals can influence their ability to support families and their deaf or hard of hearing children. What respondents



share about families will be discussed first; then the responses regarding professionals will be discussed; and, finally, the overlap between families and professionals will be elaborated upon.

## Families

Families play a large role in their deaf and hard of hearing children reaching expected developmental milestones and, subsequently, their life's goals. Respondents discuss various elements of families' roles, including lack of involvement, unawareness, misinformation, conflicting priorities, and needed support. Families are not always as involved as they should be and may not be consistent in following up with or participating in EHDI services. Therefore, families would benefit from information and training on how to best support their deaf and hard of hearing children. This includes accessing resources, such as parent education workshops and information. Also, educational resources benefiting families would include strategies for learning how to work with their children's hearing assistive technologies and for providing early language opportunities. Further, respondents discuss various challenges parents experience as well as how they affect their deaf or hard of hearing children's development. An example is managing time to learn how to best communicate with their deaf or hard of hearing children, such as learning ASL or another language or communication modality. Other challenges lie with families' backgrounds. For example, respondents discuss families' backgrounds, including socioeconomic status, location of residency, and home language, and how these variations influence families' access to EHDI services. These family influences and components of EHDI ultimately impact deaf and hard of hearing children's development and their abilities to achieve their linguistic, academic, and socio-emotional potential.

Examples of responses related to Families:

- *"... even with EHDI mandates, follow-up for infants and toddlers who are identified as at-risk can be difficult for new parents to do d/t lower socioeconomic status/transportation, lack of understanding/education, and the fragmentation between service providers in various organizations (hospitals, early intervention agencies, audiologists, etc)..."*
- *"...Many times children are provided with very early intervention services, but the family does not follow through with things such as amplification use, literacy and language opportunities..."*
- *"In early intervention, families struggle to understand the impact of hearing loss on their children, especially those with mild loss or unilateral loss..."*
- *"...Family involvement and support—Where do parents go to get help understanding the lack of incidental learning that affects language and communication? What are the next steps for parents after they learn their baby has a hearing loss?..."*

## Professionals

Trained and knowledgeable professionals are essential for effective EHDI processes and service provisions to support families and their deaf or hard of hearing children. Respondents discuss the following needs:

- More qualified and skilled professionals, including Deaf Mentors, language models, deaf professionals, counselors, social workers, and speech-language pathologists, who are comfortable working with deaf and hard of hearing children
- Professionals to receive training and information
- Professionals to work more effectively with each other
- Professionals to share unbiased information with families

Although many respondents discuss that more professionals are needed and they need to improve their knowledge and practice, respondents also recognize there are skilled professionals who support deaf and hard of hearing children and their families.

Examples of responses related to Professionals:

- *"...I feel that there is still a shortage of qualified personnel and access to them by parents at the birth to 3 level..."*
- *"There is only one teacher of the deaf employed at the state level to provide services and coordination of services to deaf and hard of hearing [children] in 0-3 programs."*
- *"...Early Intervention does not have enough qualified deaf and hard of hearing professionals nor speechlanguage pathologists who are comfortable working with children with hearing loss."*
- *"Early childhood intervention staff are not well trained in working with children who are deaf or hard of hearing, and this can create problems with IFSP [Individualized Family Service Plan] meetings, outcomes, and developmental services to children and families..."*
- *"...Then there are needs for strong foundation in collaboration between early hearing detection intervention team and early childhood and family education services. We have wonderful professionals who work hard daily to ensure that the children are developing language; however, there is often miscommunication about the process..."*

In this layer, professionals and families influence each other in how they navigate the EHDI system and its components. Respondents also discuss the need for collaboration between professionals and families; how professionals can control information that is shared with parents; and how families can determine what kind of interaction they want with professionals. Further, families may benefit from working with specific professionals, such as a counselor, to process their experiences as parents of deaf or hard of hearing children or a Deaf Mentor who can provide them with experiential knowledge.

Examples of responses related to Families and Professionals:

- *"Early detection programs often fail to follow through completely, especially due to poor collaboration with the family and physician..."*
- *"... In the early intervention stage, I have seen that families just don't get how important communication is. It doesn't matter what I do (as well as colleagues in several states); it just seems as though parents and pediatricians don't get it. If a doctor were to tell families to give their child a medication [sic], they would do it without question."*  
(professional)

## **Layer 5: EHDI System**

The final layer is the EHDI System. Respondents discuss how EHDI is essential for young deaf and hard of hearing children to reach language, cognition, and socio-emotional developmental milestones. Many respondents emphasize the need to start EHDI services as early as possible. They also discuss issues with consistency, availability, and accessibility of EHDI services. Respondents vary in their satisfaction with the EHDI system.

Examples of responses related to the EHDI System:

- *"I oversee our program in the public school for students identified as deaf or hard of hearing. When they come to us at the age of 3, there is a tragically large percentage that have [sic] not had ANY*

*access to language in their home or have [sic] had very little access to language. This is due to poor access to birth-to-3 services, lack of early identification, and poor family involvement..."*

- *"If EHDI doesn't happen, the deaf child will have difficulty developing language skills throughout life..."*
- *"...EHDI services are crucial in maintaining accountability in language development in the deaf child's home life..."*

Next, each of the EHDI system components is discussed in more detail. This comprehensive system includes hearing level identification or screening, follow-up/referrals for additional hearing screening, early intervention services, and early language access and exposure.

1. **Hearing Level Identification**—Hearing level identification is a component of the EHDI system that takes place before other EHDI components. Many respondents discuss the importance of early hearing screenings and follow-up to confirm children's hearing levels, how it seems that this step is missed, and, as a result, how not all families and their children receive the early intervention services they need. Thus, it is imperative that there is a follow-up for rescreening so that families can receive early intervention services as needed. Some challenges with identification include those who immigrate from other countries, those in foster care, and those who may have hearing levels that are not easily identified (e.g., mild or moderate hearing levels, unilateral hearing levels) and thus are identified later. This can impact families' access to other parts of the EHDI system.

Once hearing levels are identified and confirmed, respondents discuss the steps to be taken immediately afterward, including providing early intervention services and monitoring deaf and hard of hearing children's language and communication.

Examples of responses related to Hearing Level Identification:

- *"... Early hearing detection allows for early intervention to provide language and communication support in whatever modality the family chooses."*
- *"...Early hearing detection and intervention—although newborn screening has vastly helped identify hearing loss early on, many students who develop conductive losses after birth slip through the system. Also, the area where I work has a large immigrant population. Children brought into the country as babies miss the newborn screening and go undetected, especially those with mild to moderate losses. Then they show up in kindergarten with neither their home language nor English established and in the throes of all kinds of delays..."* (professional)
- *Relatedly, I've seen cases where a child's deafness wasn't even discovered until after the child was labeled with one or more developmental disabilities (that they likely don't actually have). In my state, districts can avail themselves of*

*highly specialized educational diagnostic services through three centers run by our Dept of Education, but from what I can tell, districts often reject to use this service...”(professional)*

- *... Early hearing detection and intervention needs more than just requiring a hearing aid and an amplification system. ... Many children, like my own, passed newborn hearing [screening], but there needs to be another screening between the ages of 2-3 and again prior to kindergarten so that there is rich language development happening in those early, formative years...”(parent)*

2. **Follow-Up/Referrals**—This component of the EHDI system takes place after hearing detection. Respondents discuss how this part is often overlooked or not implemented by either professionals or families. For instance, some professionals do not reach out to parents for follow-up, and some parents do not take the initiative in this regard. This includes getting appropriate hearing assistive technology and diagnostic evaluation. Respondents discuss the importance of this part so that they can receive early intervention services. When families miss this step or do not realize the importance of following up, they lose early intervention opportunities.

Examples of responses related to Follow-Up/Referrals:

- *“Even though most of our children receive newborn screenings, many do not receive follow-up to initiate early intervention services. Often, the services are offered, but the parents do not follow up. Therefore, early intervention services are not utilized. When the students arrive at [age] 3, 4, or 5 to school with no hearing aids or any language input, their future education is severely stifled!”*
- *“...There should be more required follow-up when a child fails a hearing screening...”*
- *“Early Hearing Detection and Intervention—The state-mandated ABR has made hearing loss detection relatively easy, but there is so little follow-up that lots of families are dropped—especially the ones who don't realize how very vital the follow-up is!...”(professional)*

3. **Early Intervention**—Early intervention plays a critical role in the development of deaf and hard of hearing children and in providing support for them and their families. Respondents discuss how early intervention needs to be better designed and more available to support deaf and hard of hearing children, including language acquisition, assessment, and language therapy. Some issues with early intervention include the following: inadequate reporting, lack of coordination between different components, and delays in service provisions.

Examples of responses related to Early Intervention:

- *“My daughter would benefit from more 1 to 1 support at her critical development age (early childhood). One visit every 2 or 3 weeks is hard for sustained development. Early intervention and support is key for understanding and development.”(parent)*

- *"In the state I live/work in, EI (birth to 3) does not provide a qualified DHH teacher to work with the family. As long as someone on the IFSP team can read an audiogram, they are in compliance with the law. I am a 3-21 public school teacher, and I can't tell you how many times I have received a case of a 3-year-old who hasn't any language due to lack of EI services."* (professional)
- *"...[There is a] lack of consistent and appropriately [sic] intensive early childhood and school-based services related to language development, developmental skills, and academic support..."*

4. **Early Language Access and Language Exposure**—Respondents discuss the impact of early hearing screening and hearing level identification on ensuring children receive immediate early language access and language exposure. Early intervention also enhances early language access and language exposure when implemented appropriately. Further, families and professionals also play an important role in supporting early language access and exposure

Examples of responses related to Early Language Access and Exposure:

- *"As we know, access to language at the earliest age allows the most growth and development of the child's language and critical thinking skills..."*
- *"Lack of access to language during early stages of life leads to many obstacles which are difficult and/or impossible to overcome..."*
- *"...Very often we see students enroll in elementary/middle school with very little language which can be from several things, but two I think are primary: lack of qualified professionals working with this student from the start and family involvement which also includes language access were they given the tools/support necessary to work on their child's language and access. (We have addressed early hearing detection and intervention, but there's a huge gap with acquiring language and during that time, how is the student accessing such?)..."*

## **Deaf and Hard of Hearing Child Development**

The model layers, along with the EHDI components, impact deaf and hard of hearing children's development.

Respondents discuss the need to provide appropriate supports for families of young deaf and hard of hearing children and professionals. The children needing these supports also include those with disabilities, those placed in foster care, and/or those whose families immigrated from other countries to the United States as well as children with mild and/or unilateral hearing levels whose families are less likely to be provided with services for their needs. Children and their families of diverse backgrounds may also not receive the support services needed for these children to reach key developmental milestones.

## **Conclusion**

The EHDI model provides an overview of findings and themes based on respondents' comments about EHDI. Respondents emphasize the importance of EHDI for deaf and hard of hearing children to achieve their academic, linguistic, and socio-emotional potential, and they provide various perspectives about different influential factors or layers.

The outermost layer, Policy, Legislation, and Funding, as shared by respondents, influences how EHDI services are implemented. Respondents discuss the need for improvements, including revising specific policies and reallocating funds for resources. This ties to the next layer, Language Beliefs and Educational Resources. Language beliefs play an important role in EHDI in that families and professionals may hold specific perspectives about the best language and communication modes for deaf and hard of hearing children to reach key developmental milestones. In this same layer, educational resources are essential in ensuring families and their deaf or hard of hearing children, as well as the professionals who work with them, receive the materials and information they need to support their children. Language beliefs can influence what educational resources are provided, and, in turn, educational resources provided can modify language beliefs. This connects to the next layer, Agencies, Programs, and Services, in which language beliefs and resources can influence how agencies, programs, and services implement EHDI services. This ranges from teacher preparation programs, to training professionals involved with EHDI, to hospitals with specific services. Subsequently, the final layer is EHDI with its components: Hearing Level Identification, Follow-Up/Referrals, Early Intervention, and Early Language Access and Language Exposure. Respondents discuss the importance of EHDI and ensuring families and their deaf or hard of hearing children receive EHDI services, including early hearing screening, follow-up, and early intervention. An important aspect of early intervention is ensuring there is early language access and language exposure for deaf and hard of hearing children right from the beginning.

This model offers a glimpse into the perspectives that some families with deaf or hard of hearing children and the professionals who work with them have of EHDI.

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