

Understanding Experiences of Families of Deaf/Hard of Hearing Children in the EHDI System

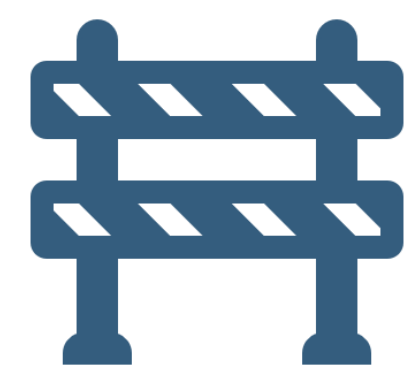
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BACKGROUND

The Joint Committee on Infant Hearing (JCIH) provides a framework for screening, diagnosis and intervention often referred to as the 1-3-6 rule. The best outcomes are observed when these milestones are met (Yoshinaga-Itano et al., 2017).



Multiple barriers have been identified that may prevent families from completing a smooth journey within the EHDI program. Families of children with developmental disabilities (DD) may encounter additional barriers. Children with DD or cognitive delays can experience challenges in obtaining reliable hearing thresholds during behavioral audiometry testing, postponing diagnosis and proper intervention (Trudeau et al., 2021). Late identification combined with late enrollment in early intervention results in discrepancies between their cognitive and language development; these areas of development align when reduced hearing is identified early and the family is enrolled in early intervention (Yoshinaga-Itano, 2003).



Most available studies reflect the positive experiences of families of DHH children within the EHDI program (Muñoz et al., 2013; MacNeil et al., 2007). However, DHH children with DD are often excluded from outcome studies and less is known about their experiences.

OBJECTIVES

To investigate families' experiences of children who are D/HH, including those with co-occurring developmental disabilities, within the EHDI system and to identify areas of improvement regarding hearing screening, diagnosis, and intervention.

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METHODS

Participants: Families of children who are D/HH, including those with co-occurring developmental disabilities who participated in the EHDI program within the last 10 years.



Method: A survey was developed through a combination of individually developed questions as well as questions pulled from published articles (MacNeil et al., 2007; Muñoz et al., 2013; Ward et al., 2019; Reynolds et al., 2023). Survey questions include demographic information, likert scales assessing satisfaction with screening, diagnosis and intervention processes and systems, as well as open-ended questions.

	Definitely no ⇒ Definitely yes					
I feel like my child's DHH interventionist understands my child's developmental needs...	1	2	3	4	5	Not sure <input type="checkbox"/>
My DHH interventionist helps me understand what concerns are related to hearing versus which require additional/different intervention...	1	2	3	4	5	Not sure <input type="checkbox"/>
I feel like my child's other early interventionists understand my child's hearing and communication needs...	1	2	3	4	5	Not sure <input type="checkbox"/>

Analysis: Preliminary qualitative analysis was conducted on participant answers and responses to open ended questions regarding their experiences. Data collection is ongoing and current sample size does not allow for comparison between families of children with and without developmental disabilities.



RESULTS

Survey was piloted in Colorado; thus, all current responses reflect experiences from those in Colorado. Currently, all but one participant has had access to Deaf adults, have met 1-3-6 goals, and have had access to ASL instruction.



Preliminary data suggests majority of respondents are highly satisfied with DHH specific early intervention services and report that systems are reasonable to navigate with support from DHH providers.

AREAS FOR IMPROVEMENT

Hearing screening:

- Challenging for rural families not screened by midwife
- Language used upon screening referral felt like a “set up” that hearing loss is unlikely; making the diagnosis more surprising



Diagnosis:

- Concerns for high cost for diagnostic testing, not covered by insurance



Intervention:

- Families expressed interest in earlier introduction to Deaf adults and meeting other families in similar situations
- Most families expressed positives experiences with access to ASL instruction. The perception that services are “skewed” toward ASL and the desire for similar access to more options such as cued speech was also indicated.
- Desire for earlier access to funding information for devices not covered by insurance.



DISCUSSION/FUTURE DIRECTIONS

Through future analyses we hope to:

1. Assess satisfaction of families of children with and without disabilities regarding screening, diagnosis, and intervention services.
2. Determine areas of strength within the EHDI system and areas for improvement.

Thank you to the families who have participated thus far and to individuals at Hands and Voices, CHIP, JFK Partners, and Children's Hospital Colorado for helping to distribute this survey. Data collection is ongoing. For access to the survey use the QR provided.



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