Introduction

- Critical period of language acquisition is approximately first 5 years of life.
- Language deprivation syndrome is "a constellation of recognizable social, emotional, intellectual, and other consequences" and is an unintended outcome of a wellintentioned care team.
- The majority of deaf/Deaf and Hard-of-Hearing (d/DHH) children are born to hearing parents.
- This study explored three aspects of experiences encountered by hearing parents with a d/ DHH child: emotional experiences after hearing loss identification, barriers to early and adequate language exposure, and facilitators of early and adequate language exposure.

Methods

- Hearing parents with a d/DHH child from across the US participated in individual, qualitative, semi-structured interviews.
- Purposive sampling was used to identify families with diverse communication modalities that they adapted over time.
- Data collection occurred over the span of one year.
- Interview transcripts were analyzed using a thematic analysis approach.
- The analysis was completed by three medical students: one identifies as Hard-of-Hearing, the other two identify as hearing.

Participant Demographics

- Parents came from 12 US states.
- All parents had completed at least some post-high school education.



Parent Marital Status At Time of Interview



Discussion

- Parent perspectives are critical to assess existing programs and inform new interventions to support families with d/DHH children.
- Current education and support services are not meeting the needs of families with a d/ DHH child.
- Increased education about hearing loss in the healthcare field is needed. •
- Increased involvement of d/DHH community members will be critical to creating successful systems improvement.

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Looking through the Yellow Pages... Experiences of hearing parents navigating childhood hearing loss

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> "...having the advantage of the insight from Deaf adults is worth its weight in gold...'

...focus on your child being bilingual, because that foundation just will be such a sturdy foundation, because as they grow, they will decide what works best for them."

"And one of the real advantages to having a cochlear implant... was being able to have access to all of that culture... it is super important for my son and his identity and, you know, kind of knowing who he is in the world, right?"

> "I had a very different experience than most parents, because I had people celebrating with me..."

"But, you know, everything had changed for me in terms of my expectations and what does that mean, how do I parent him, you know? I knew that this was going to be very different than my daughter, and I didn't know what that looked like."

"So, I kind of feel like maybe they should just give you the facts, but not add anything extra like, oh no big deal, it's just fluid in the ears, because in a lot of cases it's not just fluid in the ears, it's a hearing loss."

"So, there's been so many avenues that are so out there, that would be nice if they were all together... rather than just looking through the Yellow Pages to find an audiologist."

"But it always involved compromises, it often involved fights, it, you know, took a lot of emotional and psychological energy to be able to get these programs in place. It was demanding on her part and it just reinforces how the system is not sufficiently responsive to the needs of deaf kids and deaf students."

...they sort of accepted the least, the minimum that she could do or that she did and they treated her as if she was a genius, like when she wrote her name... every hearing kid can write their name, why is it such a big deal a deaf kid can write their name?"

