



Decision-Making Factors of Caregivers When Choosing an Oral-Only Communication Modality in Children with Hearing Loss



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Introduction

- Parents and caregivers of children who are born with congenital hearing loss must undergo the 1-3-6 timeline (Joint Committee of Infant Hearing, 2007) to make decisions about the communication modalities for their children that could impact them for a lifetime (Porter et al., 2018).
- Sign language is often recommended as a “last resort” option for learning language, which may be past the critical time period (Hall, 2017).

Methods

Two groups of participants were recruited using purposive and snowball sampling methods. Semi-structured interviews took 60-90 minutes on Zoom and were transcribed using Otter AI. The first group never used sign language with their child, and the second group initially used sign language but later shifted to oral-only.

- **Inclusion criteria:** Caregivers whose children were identified with any type of hearing loss in the first three months of birth and currently use an oral-only communication modality.
- **Exclusion criteria:** Caregivers who only use sign language with their DHH child.

Interview questions included:

- What did you worry about most after learning of your child’s hearing loss?
- Describe all the ways that you were taught how to communicate with your DHH child.
- What were your priorities around the importance for your child to learn a spoken language?

The study was approved by the Institutional Review Board at California State University, Sacramento (22-23-46).

Results

1. Information, Resources & Recommendations from Professionals:

- Availability of resources and information about each modality at the time of diagnosis
- Quality and clarity of information presented by audiologists, technicians, EI team, etc.
- Influence of audiologists and other professionals from the time of being in the hospital to later academics
- Trust in medical and educational professionals to provide best information
- Misinformation or conflicting information

P7: *“I remember her saying to me, ‘the first three years or so crucial’ ...for her development, for her speech development, for her brain.”*

P9: *“We were encouraged greatly to no longer sign.”*

P12: *“Initially, I wasn't too excited because it was all about sign language...and I had a lot of hope that there were alternatives... I thought that was my only option. I feel like all of the resources were not presented in the initial phases.”*

2. Communication Goals:

- Desire for the child to integrate into mainstream society, schools, participate in “traditional” activities and how it would be if they do not
- Hope that the child will be able to communicate easily with extended family and peers and utility of ASL

P7: *“Will she go to a normal school, and will she be with normal children? I am absolutely horrified that I asked that question now.”*

P2: *“...you'd see the boys playing video games with like seven kids... if they were deaf and using sign language, I don't think there'd be any kids over here.”*

3. Technological Advancements:

- Availability and coverage of amplification

P15: *“The fact that we have to potentially pay for the hearing aids at the beginning... then Kaiser Permanente gave us for free...these are testers.”*

4. Family Identity:

- Family's views on Deaf culture and identity
- Potential concerns about the child feeling isolated or “different” from siblings or peers
- Previous experience with hearing loss in the family or community
- Personal beliefs influencing decision-making
- Home Environment

P3: *“How is she gonna be around her cousins, like who's gonna try to learn sign language to be around my daughter?”*

P8: *“I see it as something that makes life harder but doesn't make life worse.”*

P13: *“I got hearing aids, I didn't wear them from like, first grade to like college because I was like, embarrassed by them.”*

5. Practical Concerns:

- Geographical accessibility to CCHAT and similar programs
- Availability of resources to learn ASL

P4: *“It's 45 minutes away from our house versus some people that come from much further away.”*

P11: *“I didn't have enough resources or the time to commit to us as a family fully learning ASL.”*

6. Perceived Challenges:

- Beliefs about the challenges of raising a Deaf child who uses ASL (e.g., concerns about communication, school, sports, etc).
- Understanding of the undertaking for learning ASL and continuing to use it – commitment.

P1: *“I would have to learn it first [sign language] and the process of learning it in my mind would take away from the time to communicate with him orally.”*

7. Expectations, Hopes for the Future, Child's Progress & Feedback:

- Observations of the child's progress and success with oral-only communication
- Child's own preferences or inclinations
- Long-term goals for the child's communication skills
- Anticipation about the child's social interactions, academic achievements, and career opportunities

P4: *“...he hears and talks really well. He's been luckily very successful with the cochlear implants. He's been pretty resistant to signing.”*

P8: *“...it is going to affect his career?... whether we like it or not, whatever laws are in place, people are going to feel uncomfortable with the hearing loss and prefer to hire somebody they're more comfortable to be around.”*

8. Peer & Community Support:

- Interaction with other parents/caregivers of children with hearing loss – peer support
- Involvement in parent support groups or forums
- Peer or community recommendations and experiences

P16: *“I wish I'd known about California Hands & Voices when my kid was born. That's my greatest regret because I had no support for the first like six years... I really needed it back then.”*

9. Emotional Responses:

- Feelings of guilt, fear, hope, or uncertainty
- Emotional journey and evolution of feelings over time

P1: *“where do you even begin to raise a child that that can't hear you?”*

P5: *“I felt some dread, you know... that fear of the great unknown...I wish I could tell myself then it's going to be okay.”*

Discussion

- With over 90% of DHH children being born to hearing parents, this is often the families’ first experience with deafness (Mitchell & Karchmer, 2004).
- Audiologists are the first professionals that parents encounter when learning about their child’s hearing loss.

Recommendations:

- Discuss the risks of language deprivation and the critical time period for language development.
- Discuss the importance of wearing hearing devices soon after diagnosis to access sound for acquiring spoken language skills (Ching, 2015).
- Encourage parents to use sign language to support spoken language acquisition (Pontecorvo et al., 2023).
- Learn about resources available in the local community and/or nationally to support individuals who are DHH (Bhatia et al., 2022).
- Provide resources for all communication modalities at each appointment.
- Understand that communication modalities within families can change anytime or as often as desired.
- Remain compassionate towards families' experiences throughout their journey.

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Acknowledgements

I would like to thank Scott Levin and Dr. Katie Isbell at Children's Choice for Hearing & Talking (CCHAT Center), the educational audiologists Drs. Christina Barbao and Amy Vargo-Kite at the Placer County Office of Education, and Cora Shahid at California Hands & Voices for sharing my research flyer. I would also like to thank my committee members, Drs. Laura Gaeta, Soumya Venkitakrishnan, and Hamid Motallebzadeh for their feedback and support on this doctoral research project.