



VOICES FROM THE START:
PARENT-TO-PARENT SUPPORT FOR FAMILIES WITH
DEAF/HARD OF HEARING CHILDREN

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PARENT MENTORS' NOTES

Spoke to mom. Per mom, baby is 2 months and recently had a hearing test done. Mom asked me to further explain what a moderate hearing loss means. I explained to mom that with a moderate hearing loss, most children benefit with hearing aids. Mom said doctor told her baby will need HA, and mom was not too sure what they would do to her baby.



PARENT MENTORS' NOTES

Mom took everything in and seemed a bit overwhelmed. She said she had no idea. She hasn't met any other parents, she hasn't done much research, she just assumed what the school district offered and what her doctors were telling her was all she needed to do.



PARENT MENTORS' NOTES

Mom hesitated and finally asked me directly what sort of communication I use. When I said we do everything mom sighed with relief and said, finally "someone who is doing what we want to do."

Agenda

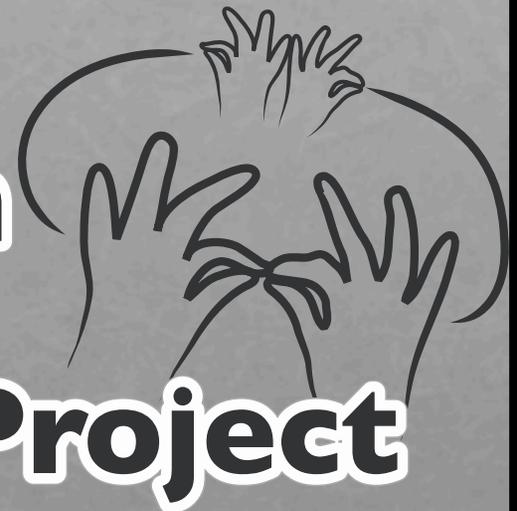
- Voices of parent mentors
- Characteristics of families and children
- The process for data collection and analysis
- Findings



Families with children
birth- 3 years

Families with
children
3-22 years

**Deaf
Education
And
Families Project**





CONTEXT: PARENT-TO-PARENT SUPPORT

- 4 parent mentors providing outreach, resources, information, support, and education
- Primarily phone support
- Face-to-face support through monthly events and trainings:
 - Children's play groups
 - Family Fun Days (i.e., aquarium, zoo, park days, science center)
 - Trainings (i.e., Embrace your culture, Read with your child)
 - ASL Classes
- Families located in Southern California (12 counties)
- Over 1000 families March 2009-August 2011

CONTEXT

- Project database with demographic and narrative information pertaining to families.
- 4 parent mentors make “real time” or “after the fact” notes in a database.
- Contacts are primarily through phone conversation, but not exclusively.
- My analysis pertains to the content in the database.

RESEARCH QUESTIONS

1. What are the demographics of families within the database?
2. What is the nature of the supports provided to parents?
3. Do the “conversations” and supports differ between Spanish-speaking and English-speaking families?

MIXED-METHOD ANALYSIS

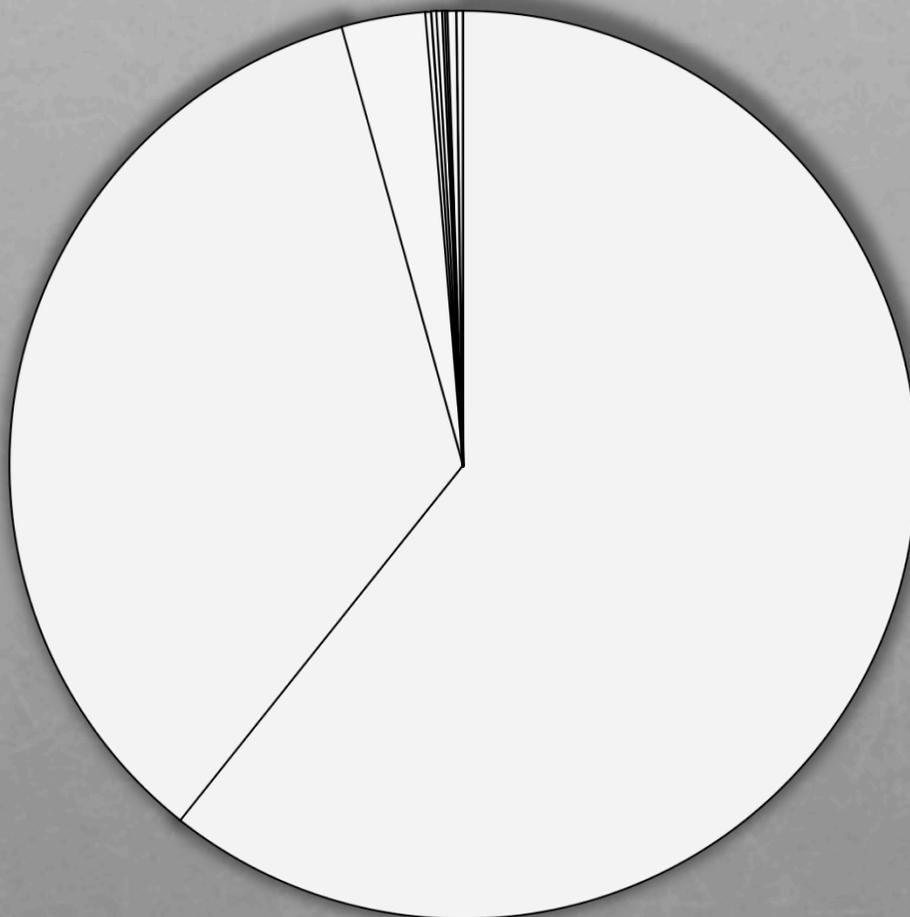
- Quantitative analysis applied to demographic information
- Qualitative analysis applied to Parent Mentors' notes in talking and interacting with families
- Iterative
- Codes identified
- >1000 individual families; >5,000 coded excerpts



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CONTEXT: FAMILY DEMOGRAPHICS

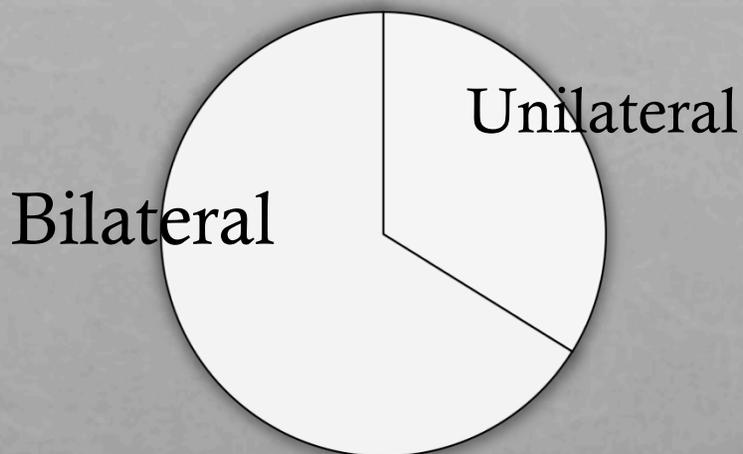
Home Language



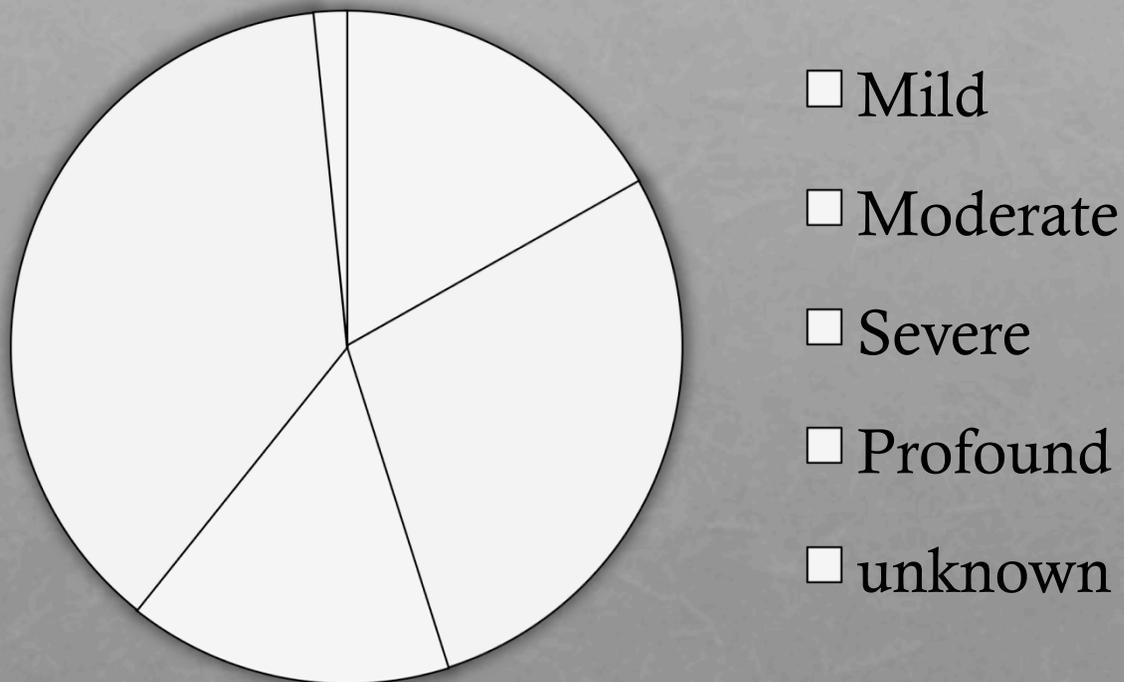
- English
- Spanish
- ASL
- Cantonese
- Other
- Arabic
- Mandarin
- Hindi
- Korean
- Vietnamese

CONTEXT: CHILD CHARACTERISTICS

Hearing Laterality



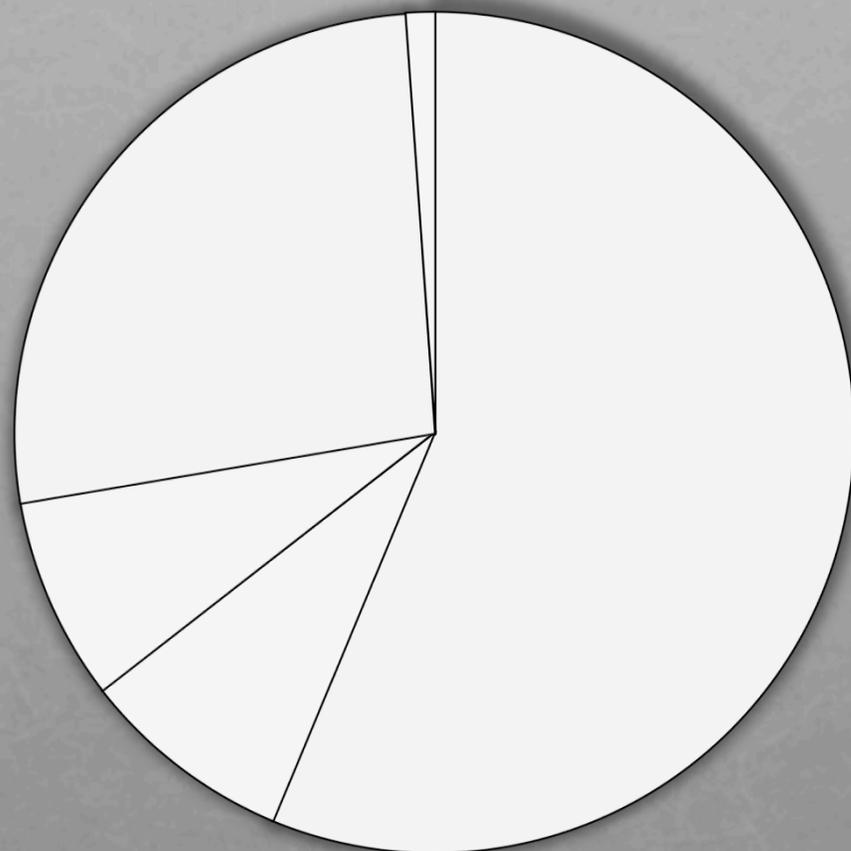
Hearing Level N=583





CONTEXT: CHILD CHARACTERISTICS

Hearing Characteristic N= 741



- Sensorineural
- Mixed
- AN
- Conductive
- Unknown

THEMES WITHIN THE CONVERSATIONS

- Parents WANT to talk about hearing tests, hearing aids, cochlear implants, speaking and listening, and sign language.
- Parents are confused by the early intervention.
“Isn’t my child too young to...”
- Parents are dealing with more than “just” their baby being DHH. ~30% with multiple disabilities.

QUALITATIVE DIFFERENCES BETWEEN SPANISH AND ENGLISH SPEAKING FAMILIES

- Resistance of or *disagreement with* identification.

“Cultural mismatch” (Harry, 2008)

- Speaking with dads.
- Need to explain the California Children’s Services process for receiving medical care (including hearing aids).
- Need to explain what hearing loss “means”, vocabulary/ terminology usage, what “language” means.

RESISTANCE TO IDENTIFICATION CULTURAL MISMATCH

Spoke with mom for the first time.
She claims that her daughter does
hear because when she turns on
the radio or tv, the baby turns
toward the sound.



PARENT MENTORS' NOTES

EMAIL

“... am sorry if I am taking up your time, but once I received your information in the mail I remembered that a lady named April would call me every now and then when my daughters hearing loss was first diagnosed. We were so overwhelmed everything was a big blur. Now that things are a bit more settled, I need the information.

RESEARCH BASE

Parent-to-Parent Support:

- Increases parent acceptance and sense of being able to cope.
- Increases parents' ability to move forward in areas of individual need.



- The more contacts, the more “satisfied.”
- This kind of support is unique and can not come from other sources.

RESEARCH BASE FAMILIES WITH DHH CHILDREN

- “Healthy families” require support from within family, friends, professionals, and the community

One family said, *“We talked with many parents of deaf children and were encouraged by them.”*

(Luckner & Velaski, 2004, p.329)

- Discussion with parents of DHH children was rated as highest preferred informational resource (Jackson, 2011).
- Consistent need for parent-to-parent support throughout the child’s school-age years

(Jamieson, Zaidman-Zait, & Poon, 2011).

RESEARCH BASE FAMILIES WITH DHH CHILDREN

- Social supports and frequent interaction with other parents reduces stress (Hintermair, 2006).
- Interacting with “similar others” reduced anxiety and provided a sense of belonging (Zaidman- Zait, 2007)

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