

Understanding Hearing Priority for Parents of Children with Down Syndrome

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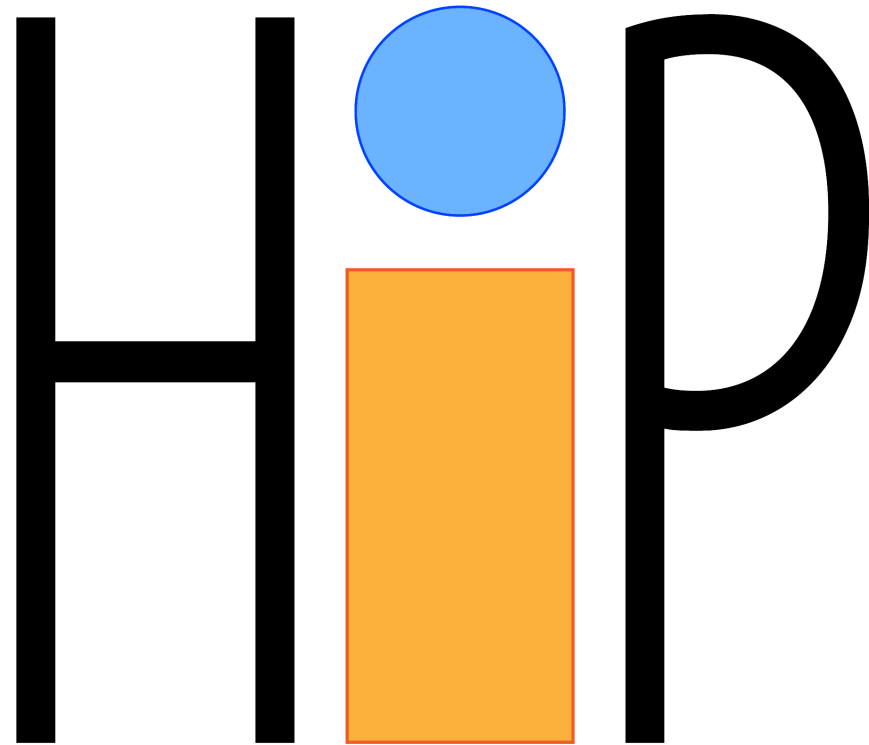
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The presenters have no financial or non-financial disclaimers





Hearing Impact Project
Research Lab

Objectives



After completing this sessions, attendees will be able to:



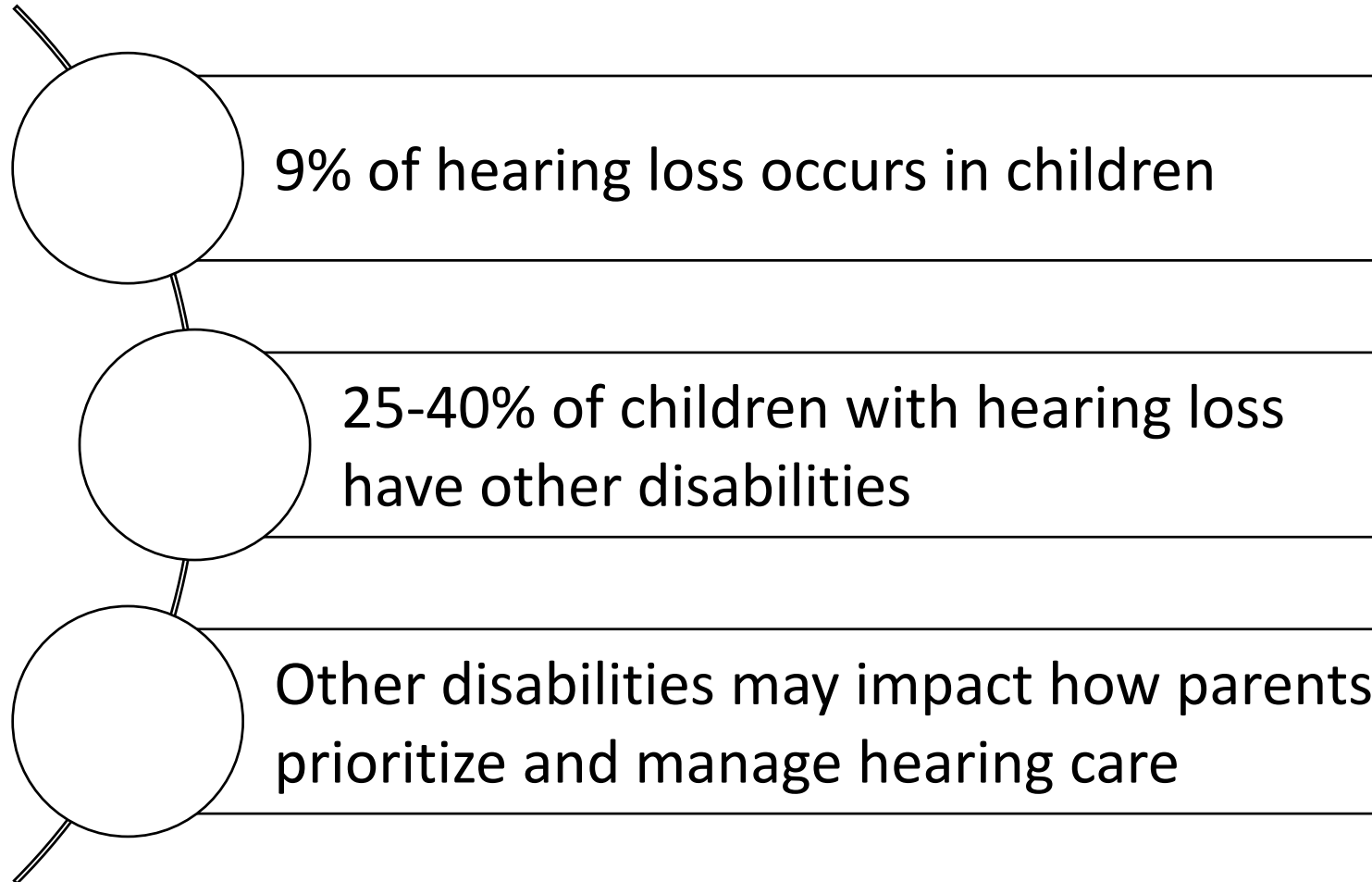
1. Describe influences for hearing care priority among parents of children with Down syndrome



2. Explain implications for low hearing care priority on speech-language and other developmental outcomes



3. Describe counseling strategies to support parents of children with Down syndrome



Personal and Family

Burnout

Planning/coordinating

Decision-making

Family support

Medical and Educational Services

Collaboration

Attitudes

Parent involvement

Child Communication and Behavior

Communication barriers

Behavior management

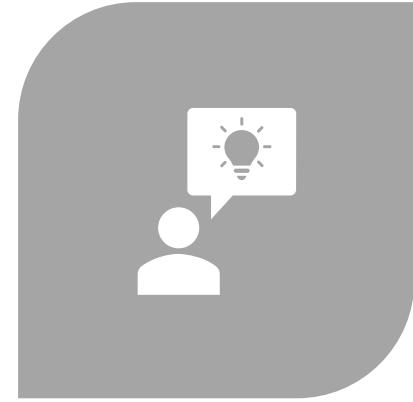
Deaf or Hard of Hearing + Down syndrome



90% OF CHILDREN WHO ARE DHH ARE BORN
TO HEARING PARENTS



CARING FOR A CHILD WHO IS DHH REQUIRED
MASTERY OF NEW KNOWLEDGE AND SKILLS
OTHERWISE UNFAMILIAR TO PARENTS



OTHER DISABILITIES MAY IMPEDE HOW
PARENTS PRIORITIZE NEW KNOWLEDGE AND
SKILLS

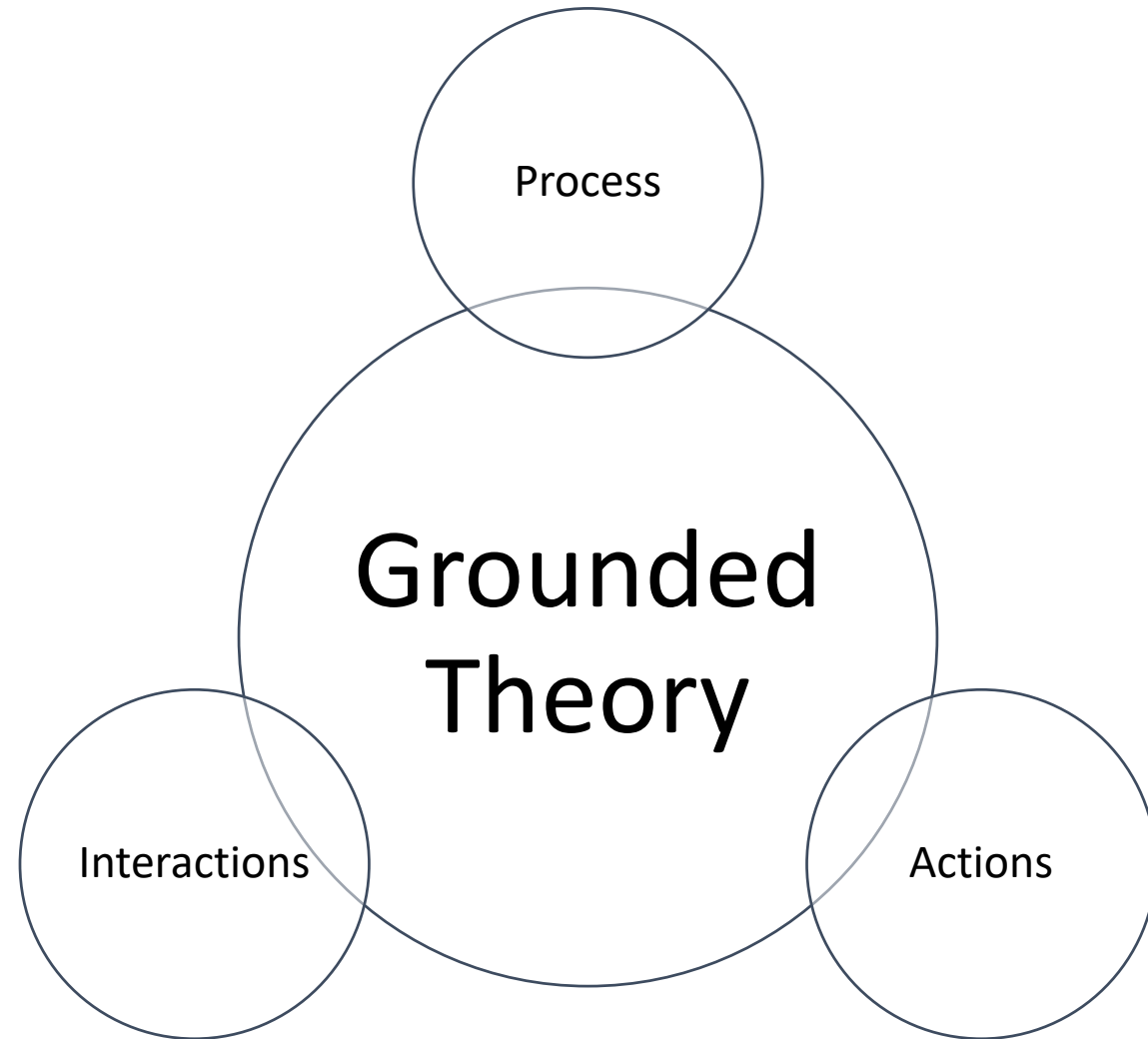
Mitchell & Karchmer, 2004



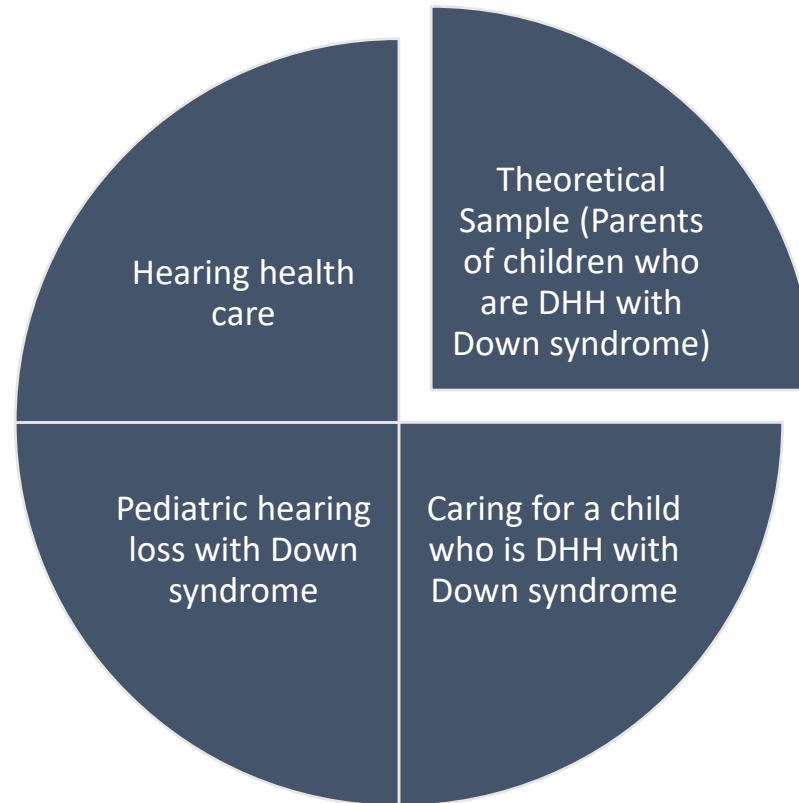
Purpose:

Describe the factors that influence the decision-making process parents experience when prioritizing hearing care for children who are DHH with Down syndrome.

Methods



Participants



Corbin & Strauss, 1990



Any caregiver of a child who is
DHH with Down syndrome birth
to 21 years old



English language proficiency



Reside in the United States

Inclusion Criteria

Sample Size

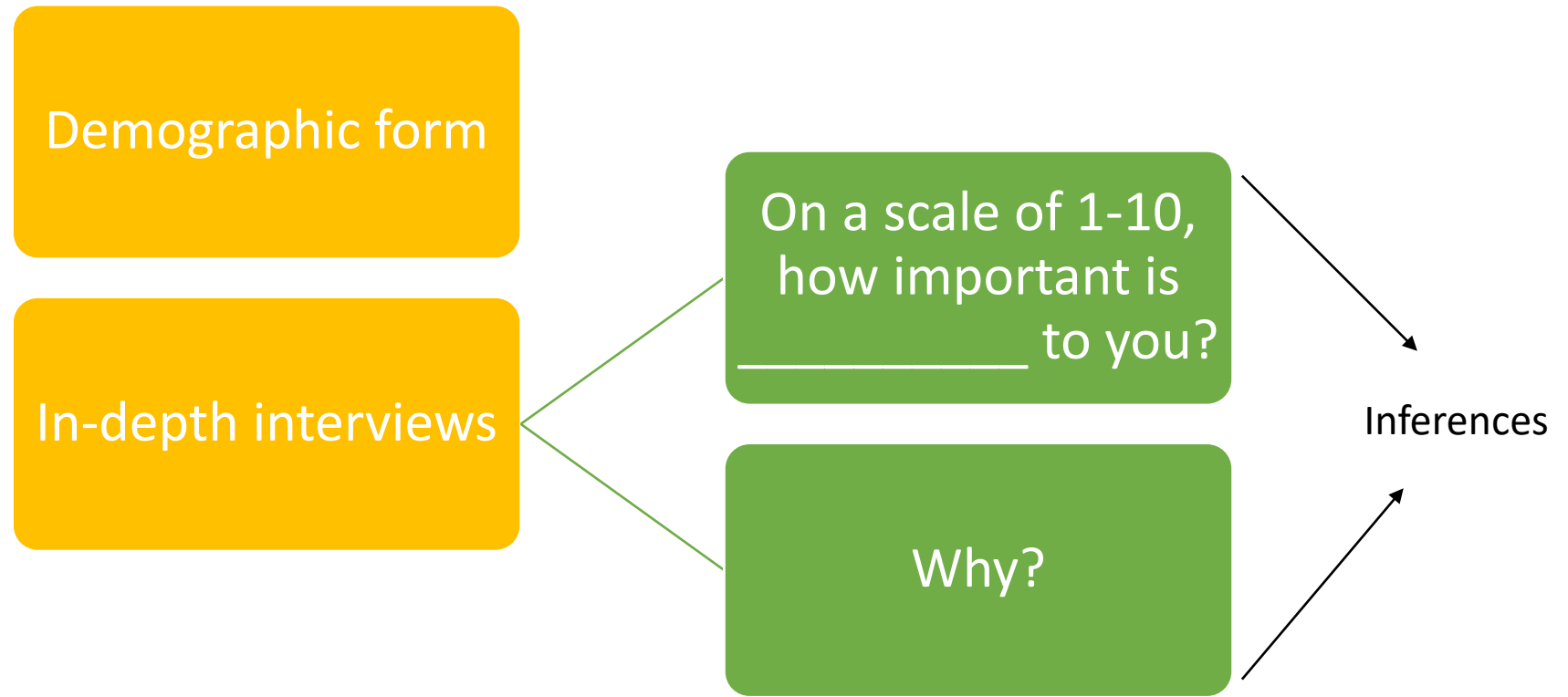


DATA SATURATION



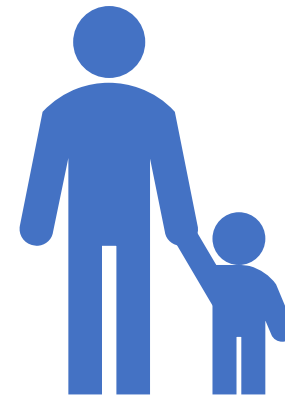
18 PEOPLE

Instrument

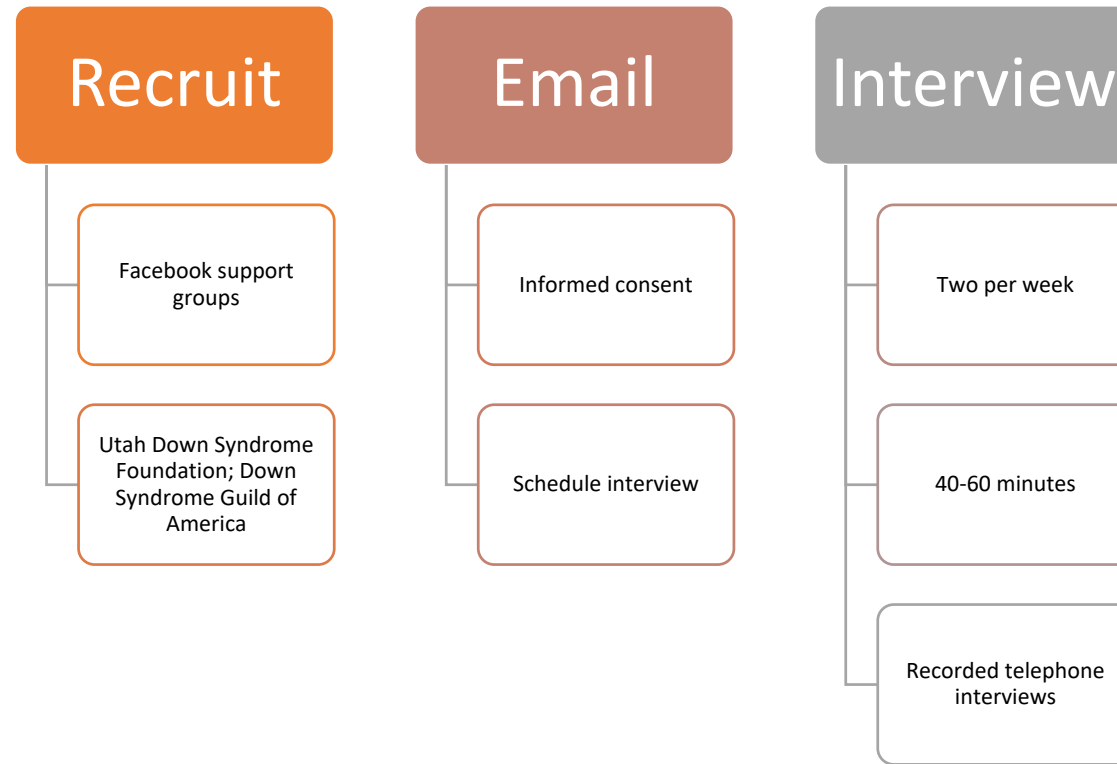


Demographic Form

- Parent role
- Parent gender
- Parent race/ethnicity
- Parent income
- Parent education
- Parent age
- Child age



Procedures



Analysis



Coding

- Open
- Axial
- Selective



Memoing

Reliability



Two researchers



Compare/Contrast



Resolve differences

Revisit transcripts
together



Member checking

Results



100% Mothers



Male: 44%; Female: 56%



Child Age (years): 8.3 (5.5), 16 mos-20 years



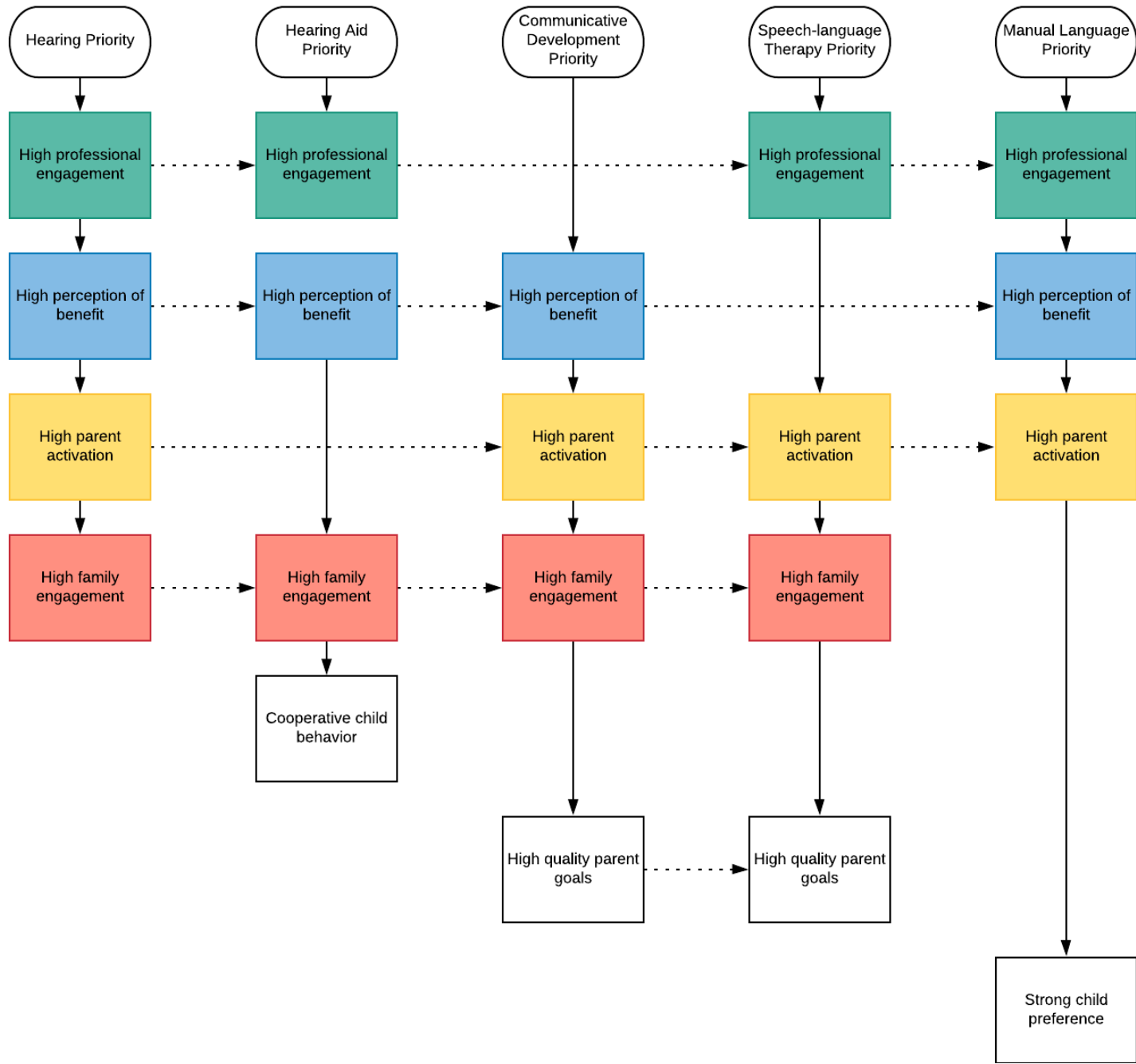
Interview Length (minutes): 36.4 (7.5), 21-51 minutes

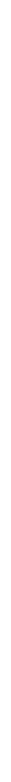
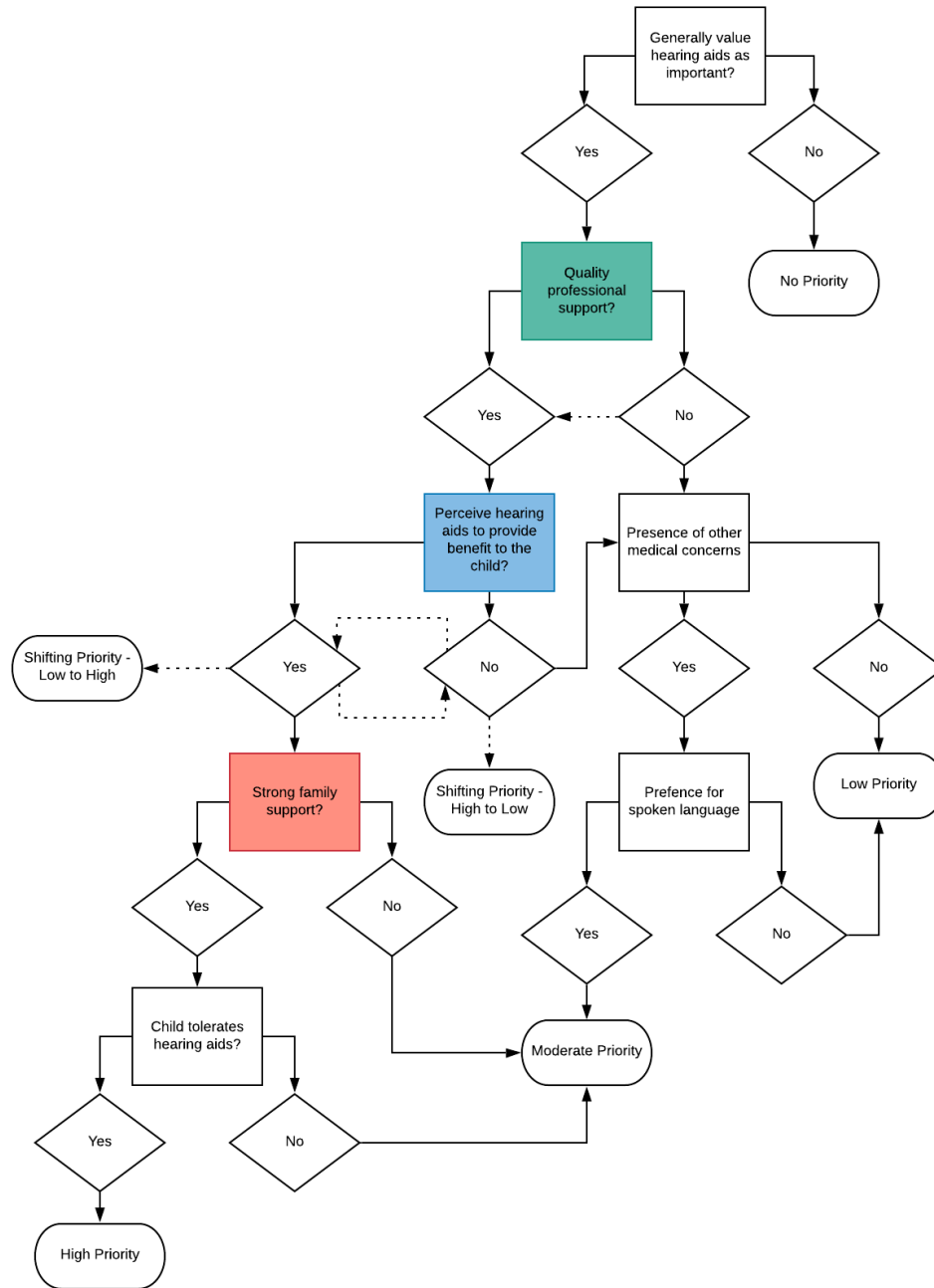
Theory – Hearing Care
and Management
Priority

The higher the extent of

- 1. engaged professional support,*
- 2. perception of benefit for child,*
- 3. parent activation, and*
- 4. family engagement,*

*the higher the priority for hearing care
and management will likely be.*





Discussion

Limitations



Researcher bias

Leading questions

- Inaccurate reflection of essence of experiences



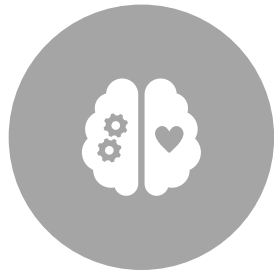
Systematic grounded theory

Designed to mitigate this limitation

Key Findings



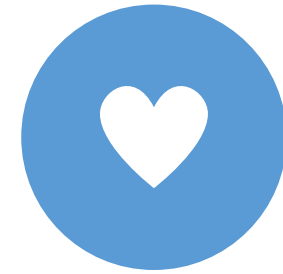
PROFESSIONAL
ENGAGEMENT



PERCEPTION OF
BENEFIT



PARENT
ACTIVATION



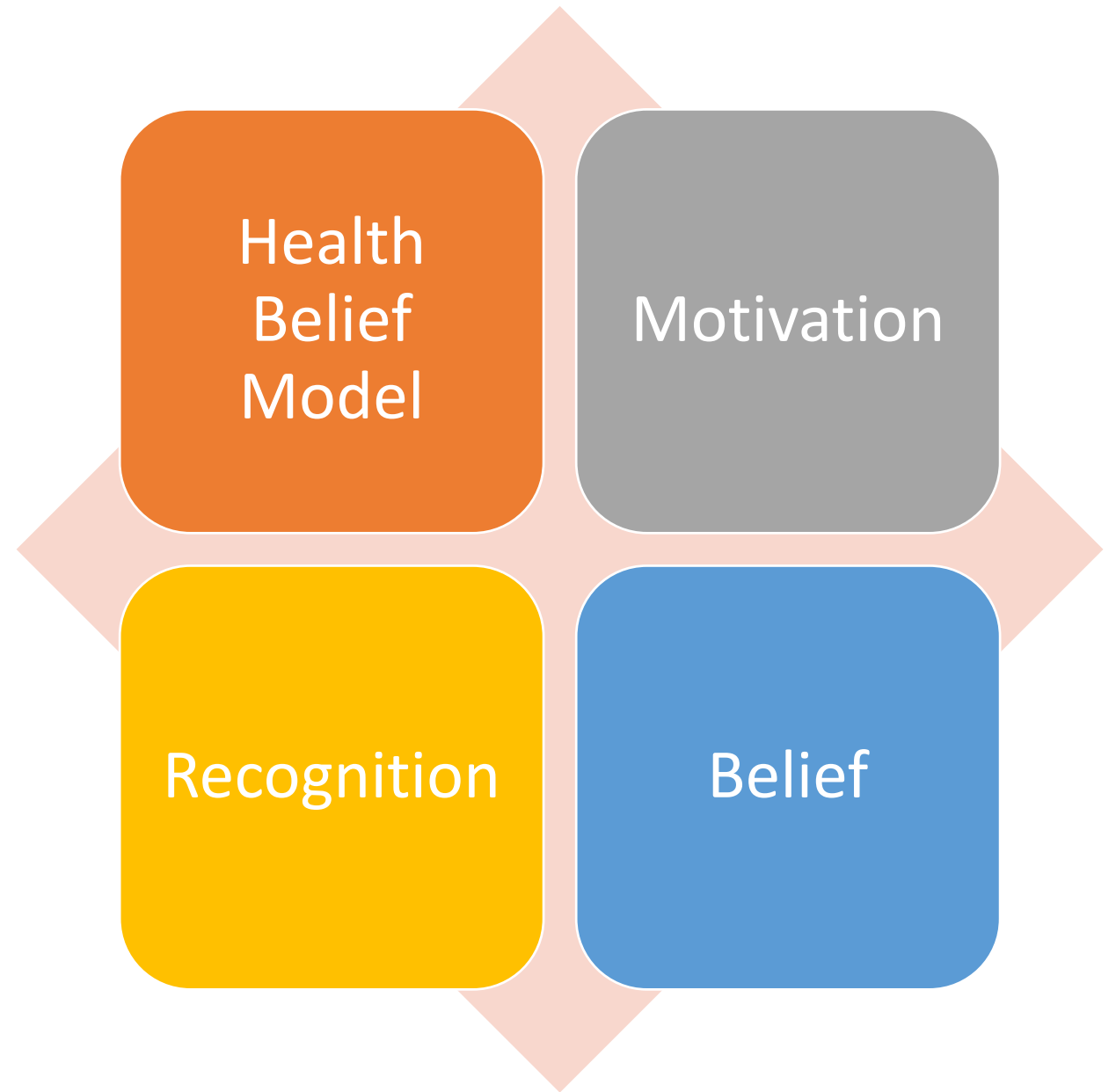
FAMILY
ENGAGEMENT

Professional Engagement

Interactions
matter

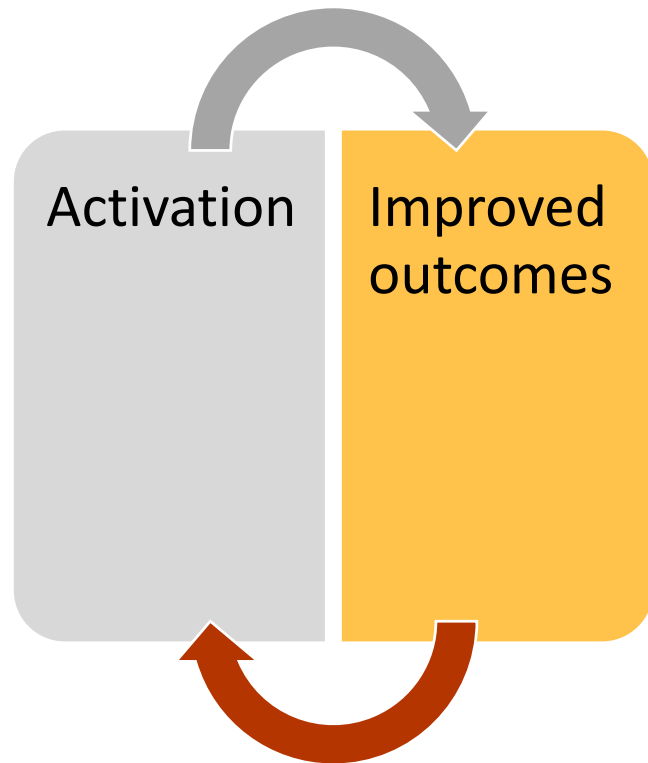
Optimizing
information
delivery

Perception of Benefit



Rosenstock, Strecher, & Becker, 1988

Parent Activation

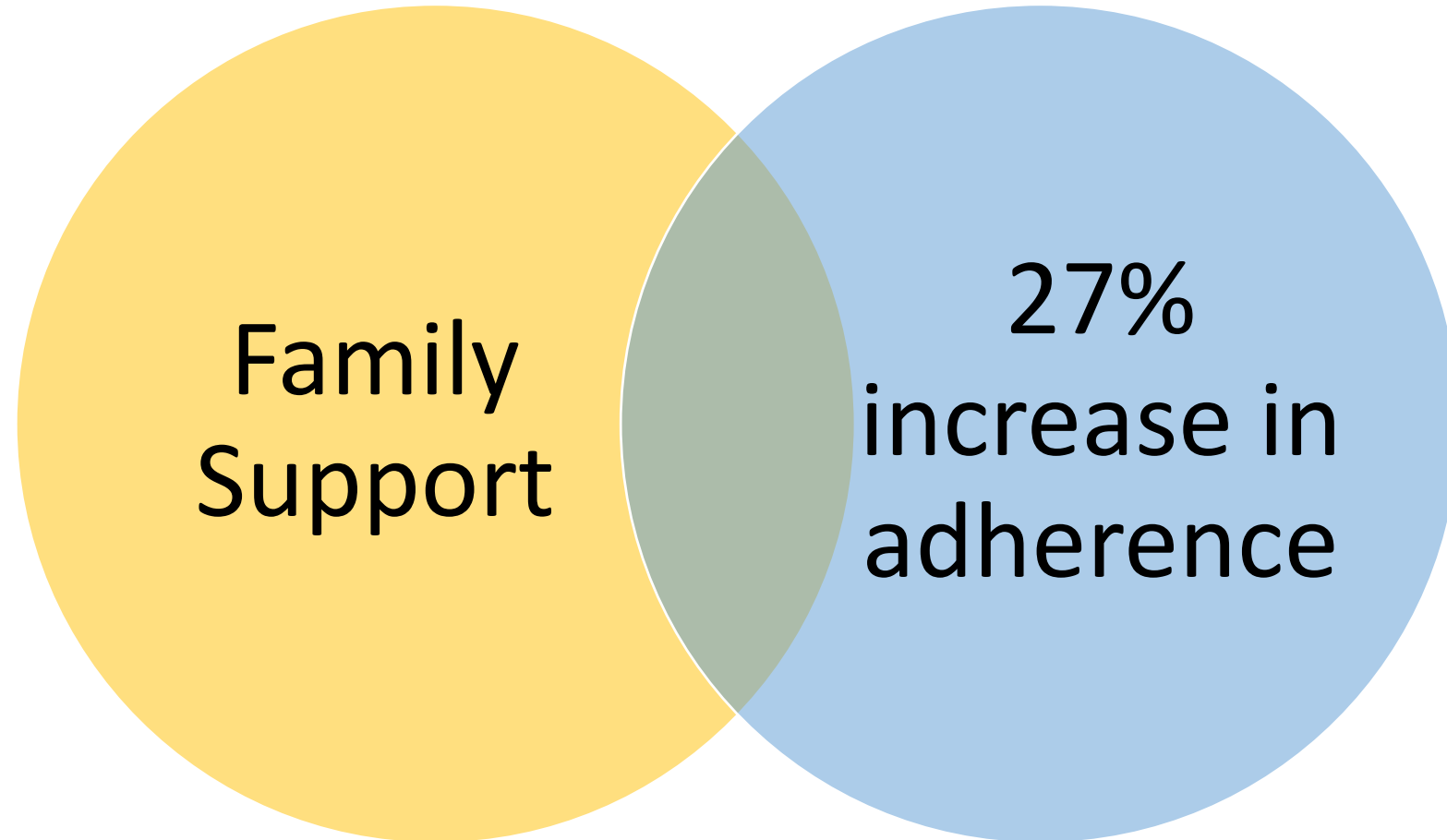


Parent Age

Emotional Functioning

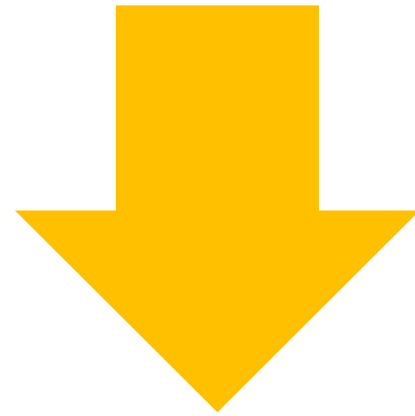
Duration of Condition

Family Engagement



DiMatteo, 2004; Miller et al., 2013; Carter-Edwards et al., 2004; Gallant, 2007; Reynolds et al., 2019

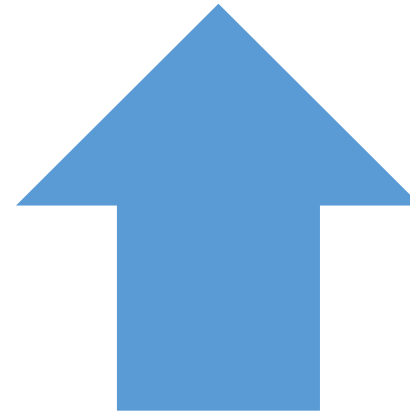
Clinical
Implications



Values



Practice



Hayes et al., 2006; Rollnick et al., 2008

Learning Activity

Rebecca is the mother of a now 8-year-old boy with Down syndrome (DS) named Henry. He failed multiple newborn hearing screens, but had a rough birth history, including the need for open heart surgery, and respiratory concerns. The nurses repeatedly told parents that the failed screen was likely due to middle ear fluid, which is common in children with DS. Parents did not seek diagnostic testing until Henry was 18 months old at the recommendation of his ENT. He was subsequently diagnosed with bilateral moderate mixed conductive and sensorineural hearing loss. Parents indicated they wished for Henry's communication to be spoken English. They were recommended hearing aids; however, Henry was still struggling with other health issues, and they did not think he needed hearing aids, because he responds clearly to sound. They eventually got hearing aids when Henry turned 4 years old. He had no significant change in his hearing.

Turn to your neighbor and discuss

- In which of the elements to explain high priority for hearing care (professional engagement, perceived benefit, parent activation, family engagement) was there a break down?
- How might you address this breakdown?

Role Play

Susan has four children, ages 3 to 13 years old. Her youngest child, Destiny, has Down syndrome (DS) and moderate bilateral sensorineural hearing loss, and a strong history of chronic ear infections. She is on her third set of tubes. Susan has a husband, but she has taken on the role as the primary caretaker for all four children and does not feel supported in her endeavors to help Destiny with her audiologic and early intervention needs. The father thinks Destiny does not need hearing aids and does not use Baby Signs to facilitate communication with Destiny like Susan does. Destiny has difficult behaviors resulting in minimal hearing aid use at home, and Susan feels burnt out. She now only enforces hearing aid use when the Early Interventionist comes to the home.

Turn to your neighbor and act it out

- One of you be the mom
- One of you be the professional (audiologist, ToD, SLP, EI)

Debrief

- What strategies did you use to address the breakdown?
- Those in the role of mom: what was helpful to you in your conversation? Was there something that could have helped more?
- Those in the role of professional: How did you feel about your counseling/communication? Was there something mom said that stumped you?



Questions/Comments