

What Parents Want from their Audiologist: Opportunities for Self- Determination

Dave Gordey, Ph.D.
**Director of Pediatric Audiology and
Research**
**Center for Applied Audiology
Research**



Children with hearing loss and their families



**Newborn hearing
screening**



**Better hearing
technology**



**Evidence-based
practice**



Education

Parent health literacy

- Parents represent the health and well-being of their children.
- Parent health Literacy is defined as the ability for a parent to obtain, process, and understand, information provided to them and feel they can make decisions based upon that information.
- The quality of audiologist communication skills has direct implications for patient satisfaction, adherence, and course of care.

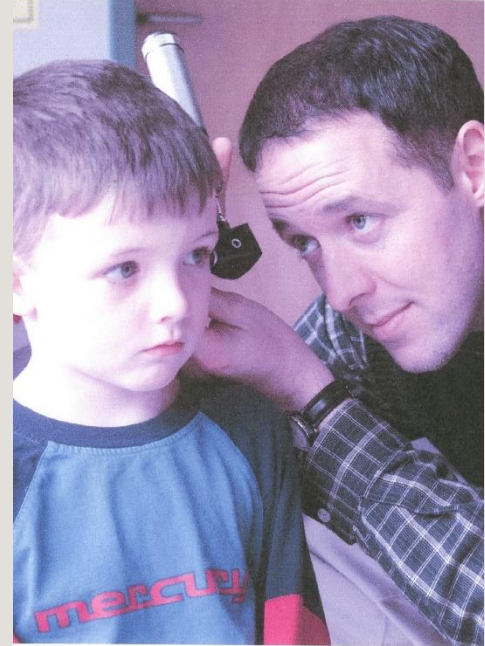
A profile of the 21st century parent

- Access to a wealth of information.
- Parent support networks.
- Desire to seek “best advice” on managing the health care of their child.
- Parents express their preferences.

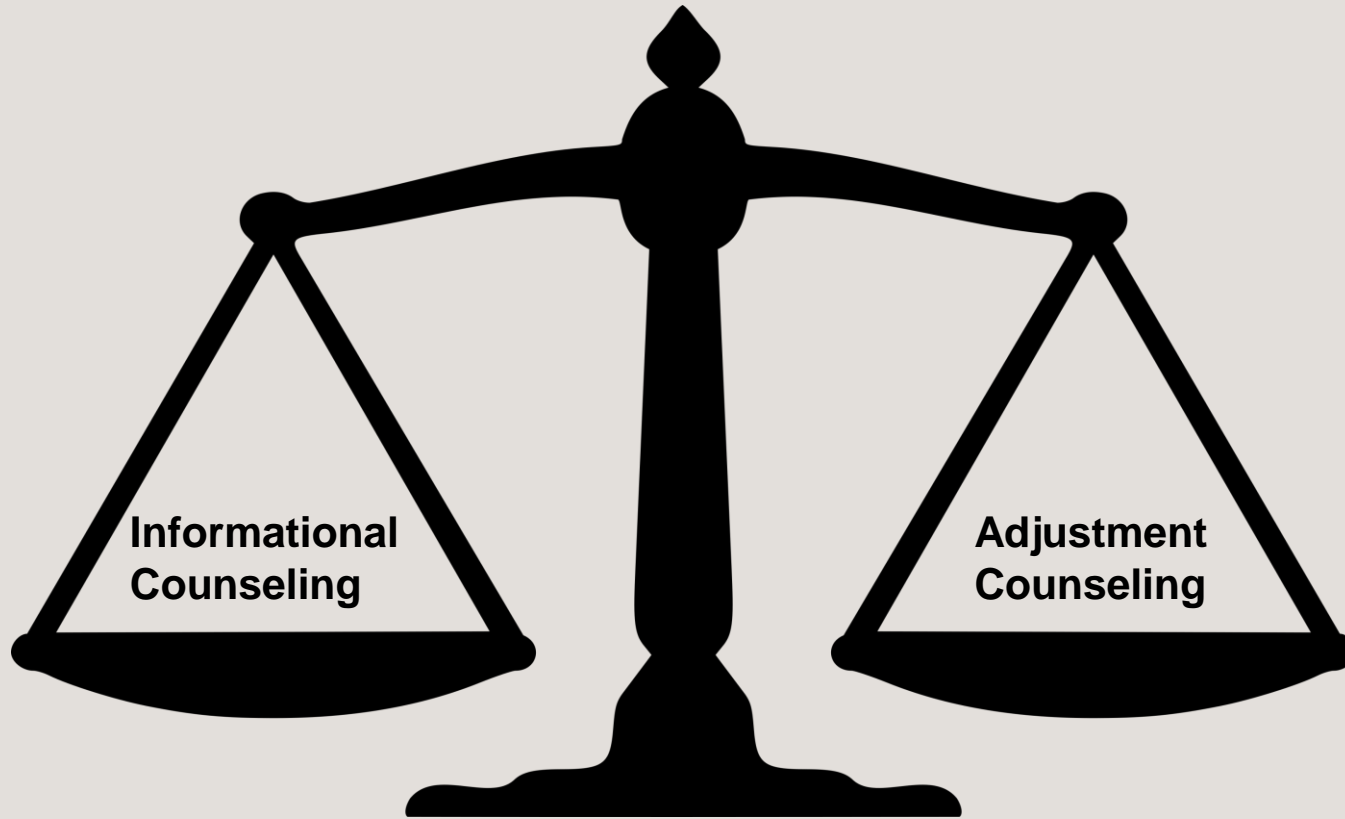


The 21st century pediatric audiologist

- Emotional, adaptation, relational support – the predictors of well-being, have been integrated into many of today's pediatric audiology clinics.
- Family-centered care.
- Shared decision-making.



The development of informed and empowered families





Research question

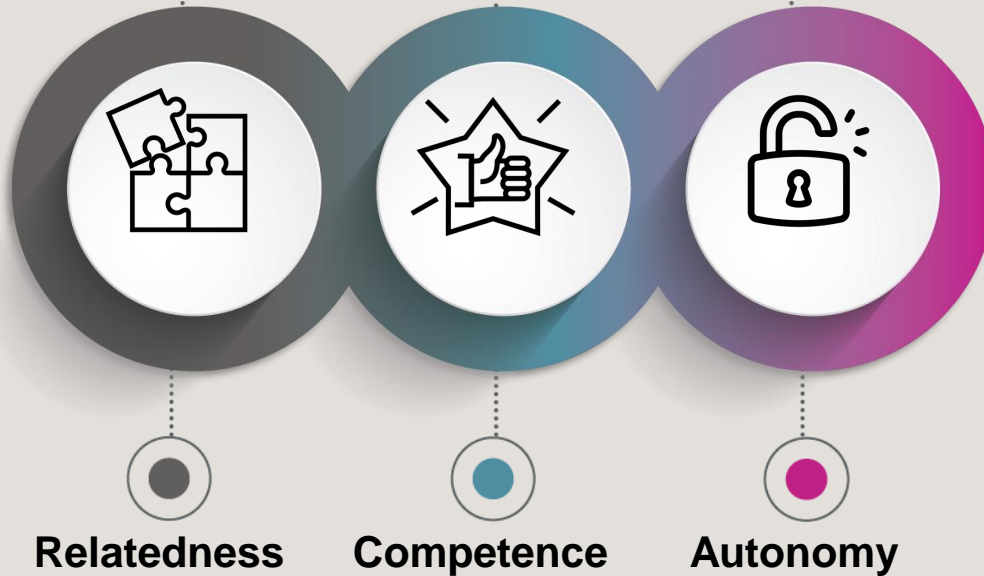
For parents of children who are deaf or hard of hearing, what information and additional supports do they want to receive from their clinical audiologist?

Self-determination theory (SDT)

- Children have a natural motivational propensity to take in behaviors and to make them their own.
- There are three identified needs that are essential for optimal functioning, integration, constructive social development and personal well-being.



Self-determination theory (SDT)



Relatedness



- Relatedness can be thought of as the desire or need to have positive, understanding relationships that will facilitate motivation and growth.
- It is the starting point for self-determined functioning.



Competency



- Competency can be described as “a general desire to succeed in achievement-tasks and to perceive one’s own success”
- The process of active engagement to learn about oneself and the environment and therefore, to feel in control and successful.



Autonomy



- Experiencing a sense of autonomy and choicefulness is critical for peoples optimal functioning.
- Autonomy is helped by a supportive, non-coercive family climate.
- Parent's promotion of choicefulness has been shown to be a strong predictor of children's well-being, adherence to care and academic functioning.



Exploratory research study

Qualitative Study

- Interview research
- ZOOM

Participants

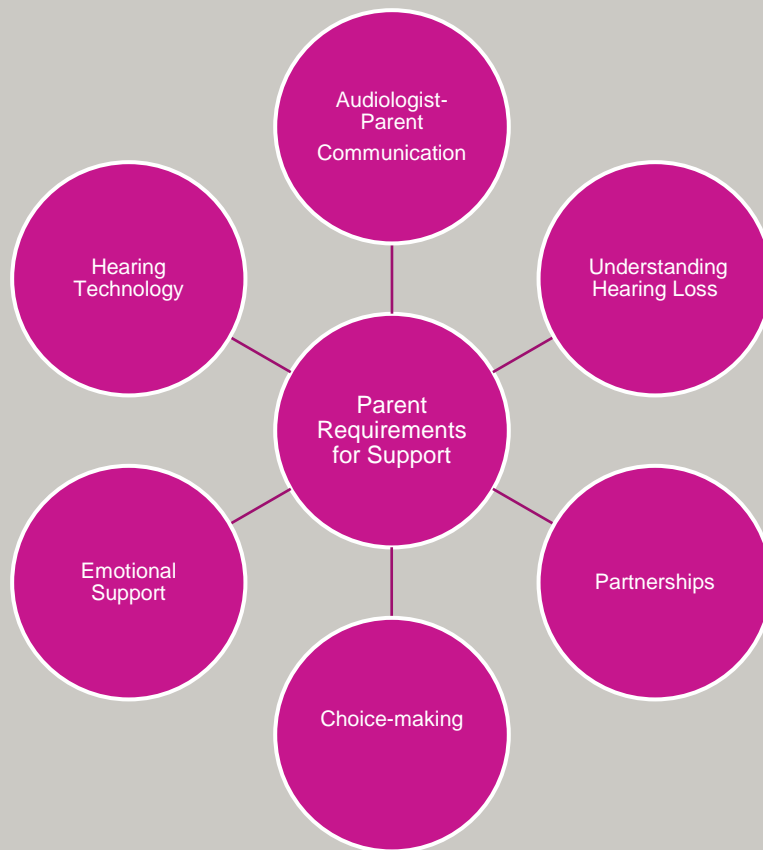
- American and Canadian parents of children who are deaf or hard of hearing.
- Parents were asked to reflect upon their experiences working with their clinical audiologist.
- n=6 (mothers of children who are deaf or hard of hearing)



Parent interview questions

- Tell me about your experiences with your clinical audiologist.
- How did the clinical audiologist support you and your child?
- Describe any opportunities for additional support?
- What advice would you give to a new audiologist who will be working with children who are deaf or hard of hearing and their families?

Main themes



Relatedness

- Partnerships
- Audiologist-parent communication
- Audiologist-child relationship



Partnerships

- Desire for a relationship where decision-making is shared, and the parent voice is valued.
- Accommodating and understanding of parent and their life outside of the clinic.
- Create an agenda together.
- Clinic appointment activities can be discussed at the beginning with the opportunity to integrate and address parent concerns.



Partnerships

“

I would say how nice it was that the audiologist followed my lead which I did not expect. My daughter, was a preemie, I really did not want her sedated for the ABR. The audiologist worked really hard with me over two days to get an unsedated, ABR so that we did not have to put her to sleep.”

Mother of girl with hearing loss

Partnerships



Sometimes when I arrive to the clinic our chit chat gets me off base and I forget what I wanted to talk about. It could be nice to start each clinic visit with having the audiologist ask, tell me, what are your expectations for this appointment?" It could set us up nicely to understand what needs to be done. "

Mother of girl with hearing loss

Audiologist-parent communication

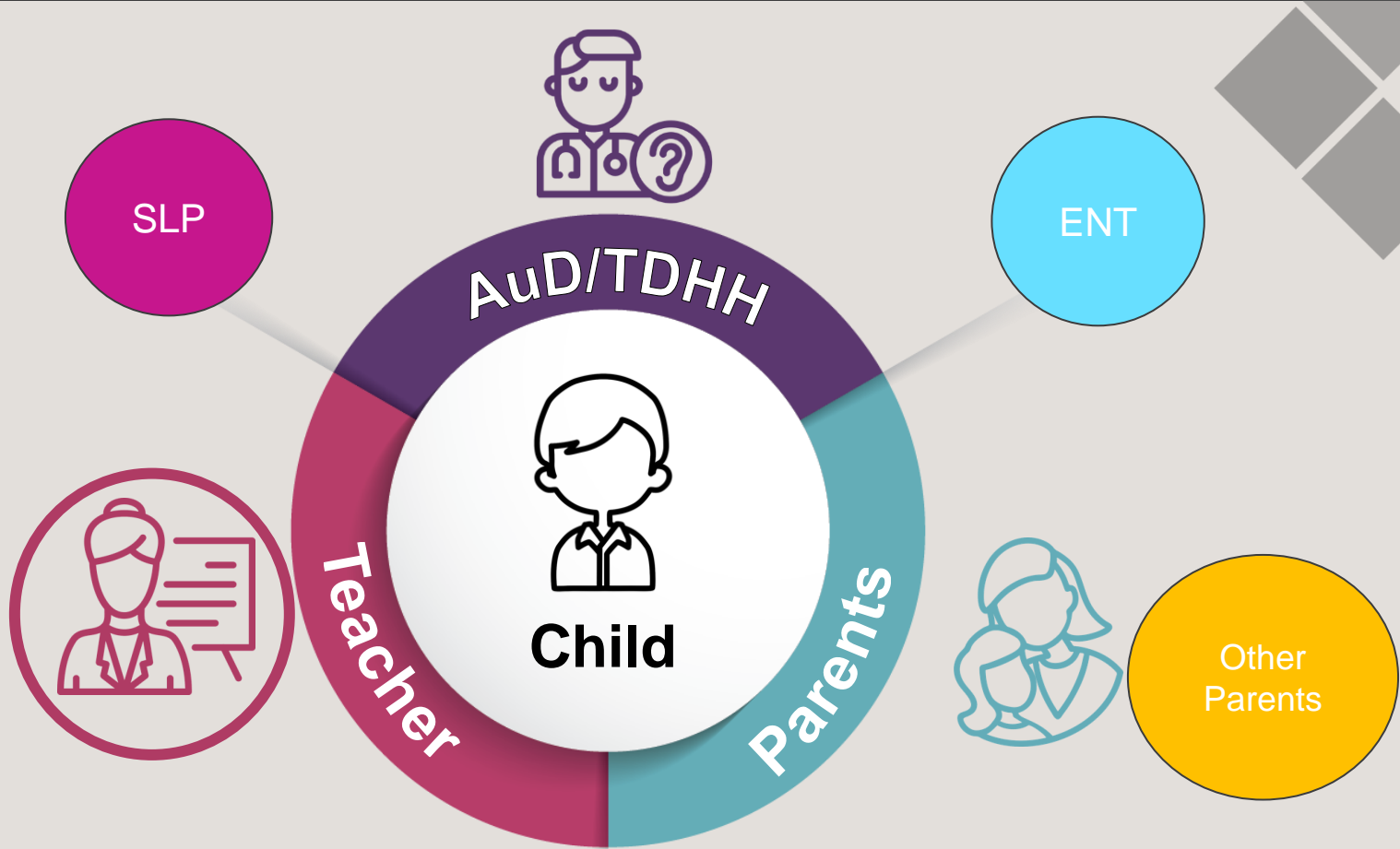
- Clear and concise. Neutral language.
- Grief can impede understanding. Check in for comprehension.
- Prepare parents with a possible set of outcomes. (e.g., CI activation).



Audiologist-parent communication

- Positive conversations about child's hearing loss.
- Pose questions that help create descriptive answers and discussion.





Audiologist-parent communication



I wonder if audiologists understand that parents may have learning differences? Having multiple access points for communication is really important.”

Mother of boy with hearing loss

Audiologist-child relationship

- This is a long-term relationship. Critical for the audiologist to connect and bond with their child.
- Even on bad appointment days, provide a positive conversation.
- Plan with parent when to shift from family-centered to child-centered hearing care.



Audiologist-child relationship

“

Some of my favourite pictures are those of my audiologist and my child at the clinic. They are playing a game while they did some hearing aid testing. They have these big expressions and are laughing. I feel very lucky to have this.”

Mother of boy with hearing loss

Competency

- Understanding hearing loss
- Hearing technology



Understanding hearing loss

- Provide lots of options for learning about hearing loss.
- Most important – the need to understand the impact of hearing loss on daily activities children.
- Help me connect my child's hearing loss with their daily life.



Understanding hearing loss

- Use audiograms designed for non-audiologists with pictures and speech and environment sounds.
- Plan to teach my child about their hearing loss - how to read their audiogram.



Understanding hearing loss



When people give you information, sometimes they expect you to connect the dots and this does not happen for everyone, especially if you are really anxious. The information can be very confusing, and I need the audiologist to tell me what this will mean for them in the real world. ”

Mother of boy with hearing loss

Understanding hearing loss



When I was shown the audiogram and the audiologist explained the hearing loss, all I could think, what does this paper mean for our lives? ”

Mother of boy with hearing loss

Hearing technology

- Connecting the use of hearing technology as **access** to learning, brain development, friendships, and the child's future.
- Explanation of why they hear some sounds without wearing their hearing technology.
- Selection of hearing technology can be hard (e.g., choosing a cochlear implant).



Hearing technology

- Hearing technology assessments that can estimate performance in real world hearing activities.
- Give information in drips. Repeating that information and checking for comprehension is crucial.
- Prepare me for the ups and downs. Hearing device tips and tricks.



Hearing technology



If he is at the movies with friends, in the lunchroom at school, in his classroom, or at a family event, I want to understand if his hearing technology will help him.”

Mother of boy with hearing loss

Hearing technology



I am a quiet person, but it really helped when the audiologist told me I had to become a broadcaster, a commentator of everything that was going on all the time. This would help my son develop speech and language.”

Mother of boy with hearing loss

Autonomy

- Choice-making
- Emotional support



Choice-making

- The need for some control during a time when things seem out of control.
- The audiologist shares information that empowers me to make choices for my child and family.
- Children need opportunities to make choices and feel some control in their own hearing care.



Choice-making



Now that he is 10 years old, the audiologist asks him what he wants to do. This is wonderful as he does not have a lot of control when it comes to his hearing. They are his ears after-all. ”

Mother of boy with hearing loss

Choice-making



If there could be an element of choice for my child as soon as possible, this would be great. I want him to practice making choices. ”

Mother of boy with hearing loss

Emotional support

- Within a day of hearing loss being identified, parents would like contact with the audiologist by phone to check in.
- Parents described being flooded with questions the day after their appointment.



Emotional support

“

But it was the time between appointments that started thinking, what did I do? Did I drink some bad water while I was pregnant? I just didn't know enough information to prevent the blaming or what-ifs.”

Mother of boy with hearing loss



Study conclusion

- Parents in this exploratory study had fantastic, nurturing relationships with their clinical audiologist.
- Parents report that audiologists are using many elements (found in family-centered care) when working with them and their children who are deaf or hard of hearing.



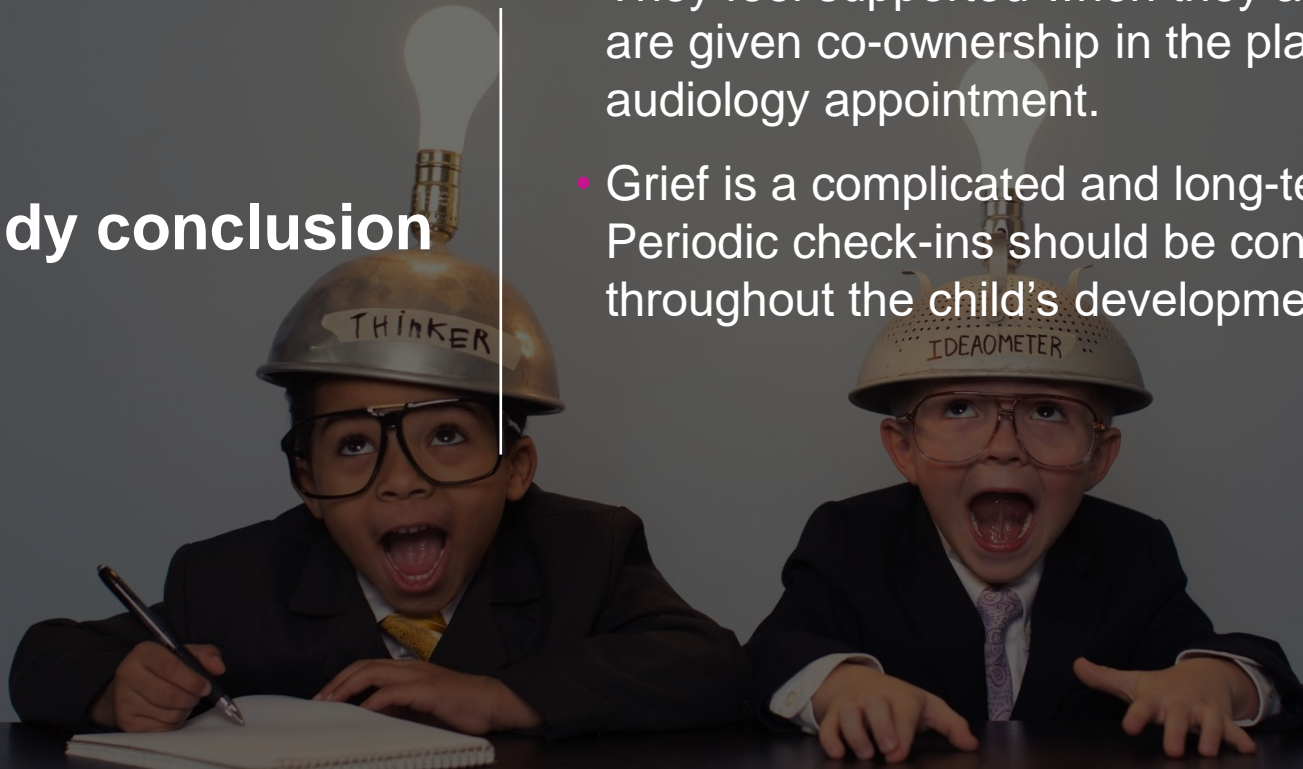
Study conclusion

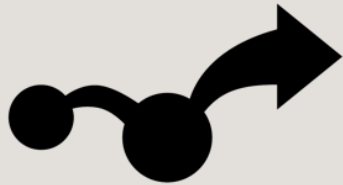
- Parents find the process of learning about hearing loss and hearing technology intimidating.
- They want different options for learning, and explanations how hearing loss will impact their child's development, learning and daily life.



Study conclusion

- Parents value their visits to their audiologist. They feel supported when they and their child are given co-ownership in the planning of the audiology appointment.
- Grief is a complicated and long-term condition. Periodic check-ins should be considered throughout the child's development.





Limitations

- This exploratory study captured the views of six parents.
- Cultural background, gender, and parent education were homogenous.



Next steps

Future research

This exploratory study has informed the development of future research.

This will include a larger scale, mixed methods study that will aim to include:

- Parents from diverse socio-economic background.
- Culturally diverse sample.
- Parents with diverse education background.





Thank you

davg@oticon.com