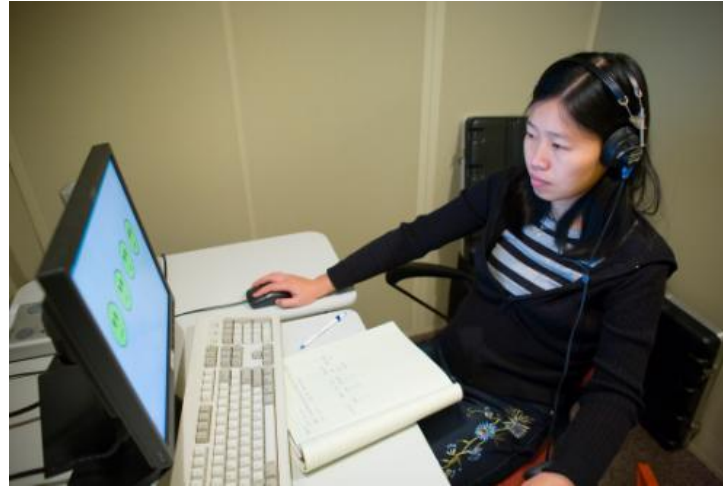


# The Importance of Family-Centered Care in Pediatrics

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# One day in clinic:



- Returning patient: Marta, age 13
  - Dx with HL at birth
  - Immediately fit with hearing aids
- Today's appt:
  - Father mentions Marta's HL similar to her mother's congenital HL
  - Mother also fit with HAs in childhood
  - Discontinued use years ago, preferring to "get by"

- Father enthusiastic about new HAs
- Marta not engaged
- Declares she wants to “get by” w/o HA like mom





## Flashback: How many times ??

- From beginning or along the way, family not fully committed to child's consistent use of amplification
- Outcome: children grow up also uncommitted to optimal hearing

# Forgetting a Family Truism...



Children have never  
been very good at  
listening to their elders,  
but they have never  
failed to imitate them.

*James Baldwin*

# Long Observed: Alternate Universe



RESEARCH

# Family-Centered Adult Audiologic Care: A Phonak Position Statement

Published on March 25, 2016

Research | April 2016 *Hearing Review*

Recommendations for moving toward a family-centered model in hearing healthcare



# Consulting with Colleagues:





# Consensus:

- A shared concern – almost universal
- When families are “stuck,” conventional counseling/toolbox insufficient:
  - encouragement
  - hearing loss simulations
  - hearing aid demonstrations
  - support from other parents
  - connect with D/HOH adults
  - refer to social worker or family therapist
- Helpful? Facilitate breakthrough, forward movement?



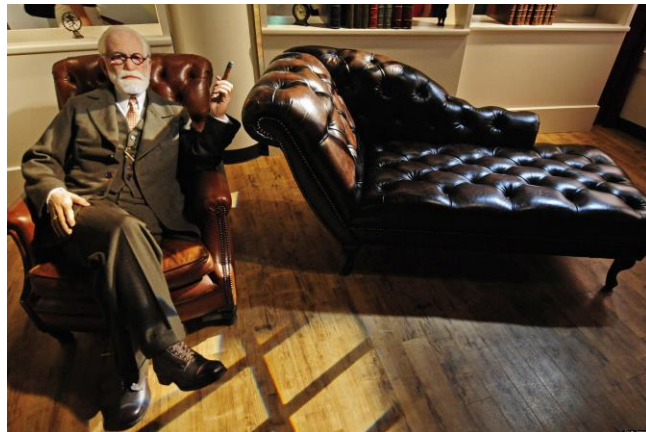
# Challenge: Intervene *before* non-commitment is entrenched

- How?
- Interviewed 13 colleagues from 9 professions:
  - Social work
  - Pediatric medicine
  - Pediatric psychology, psychiatry
  - Professional clinical counseling
  - Marriage and family therapy
  - Early Intervention
  - SLP, Auditory Verbal
- Interview format:
  - Does this situation present itself in your profession?
  - How does your profession work with it/Your advice?

# Unanimous: Yes, a Common Situation

## Advice: Actively Intervene

- “Engage with family”
  - Talk with them, draw them out
  - Explore issues
  - Develop strength-based approach to change...



# Goal: New tool, minimal stress



Familiar practices: counseling with “communication aids”

**ida**institute  
THE HEARING CO-OPERATION

## Tools



### **Motivational Engagement**

Assess client motivation and encourage people with hearing loss to take action.

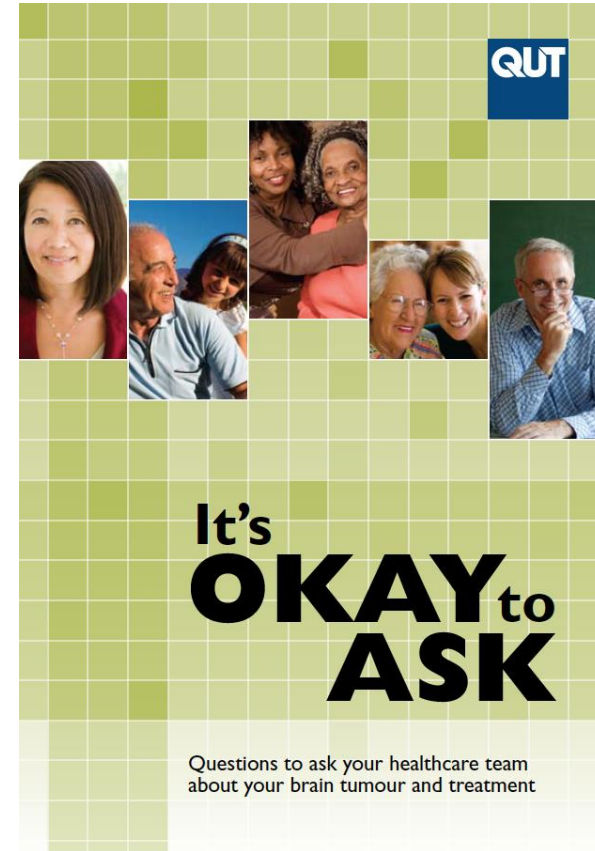


### **Communication Partners**

Work with clients to identify the most important people in their social network and to develop a shared strategy for communication.

# Researching Communication Aids: Question Prompt List (QPL)

- QPLs used in med specialties > 20 yrs
- Resembles FAQ, *but*
  - Only questions, no answers
  - Invitation to choose question(s) *patients or parents* want to discuss, in any order, revisited as desired at each appt
    - Pts often forget to ask their questions
    - Pts may get impression that only some questions are welcome
- Epitome of pt/family-centeredness



# Most QPLs are fact-based, e.g.,

- ❖ Who can develop ADHD and how common is the disorder? (Pharm et al., 2015)
- ❖ What caused my Chronic Kidney Disease and how does it affect my day-to-day life? (Lederer et al., 2016)
- ❖ Will the illness get worse or spread? What are the treatment options? Do they have side effects? (Yeh et al., 2014)
- ❖ What do palliative care hospitals offer? How do I access services/what is the cost involved? (Clayton et al., 2003)



who can develop ADHD

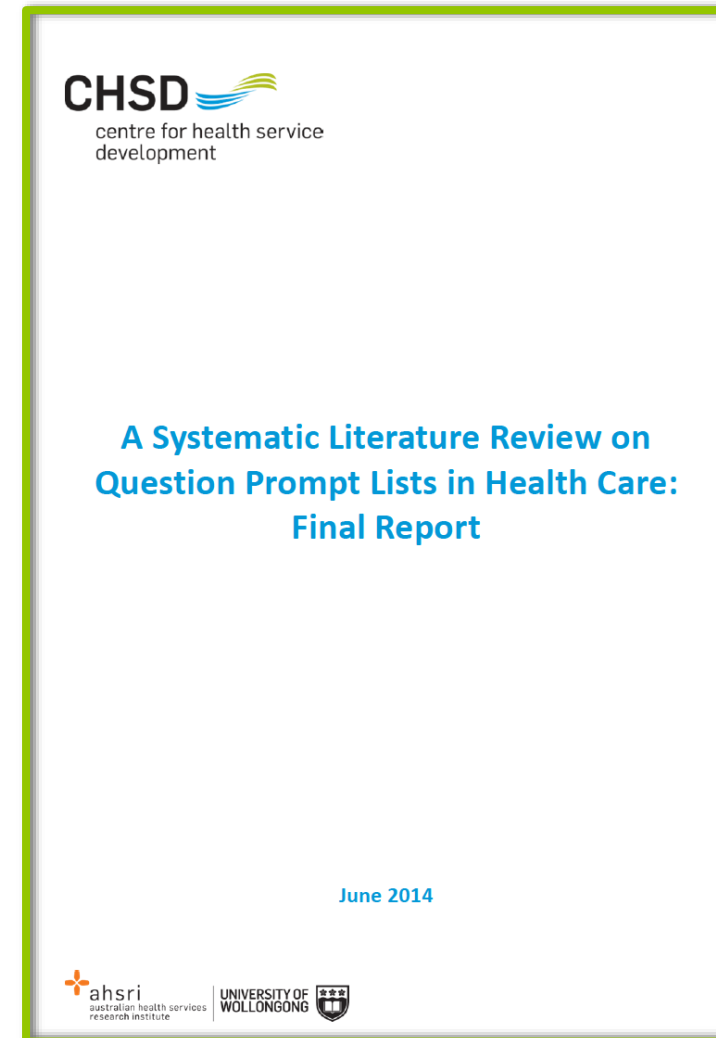
# To address our concerns --

- We saw the need for a QPL that included both fact-based and adjustment-based questions



# Developing Childhood HL QPL

- Reviewed literature (Sansoni et al., 2014)
  - 99 research articles specific to QPLs
    - (+ 4 more after 2014)
  - 53 general articles: using communication aids inc. QPLs
  - 47 articles in “gray literature” (not academically published) on comm/decision support aids





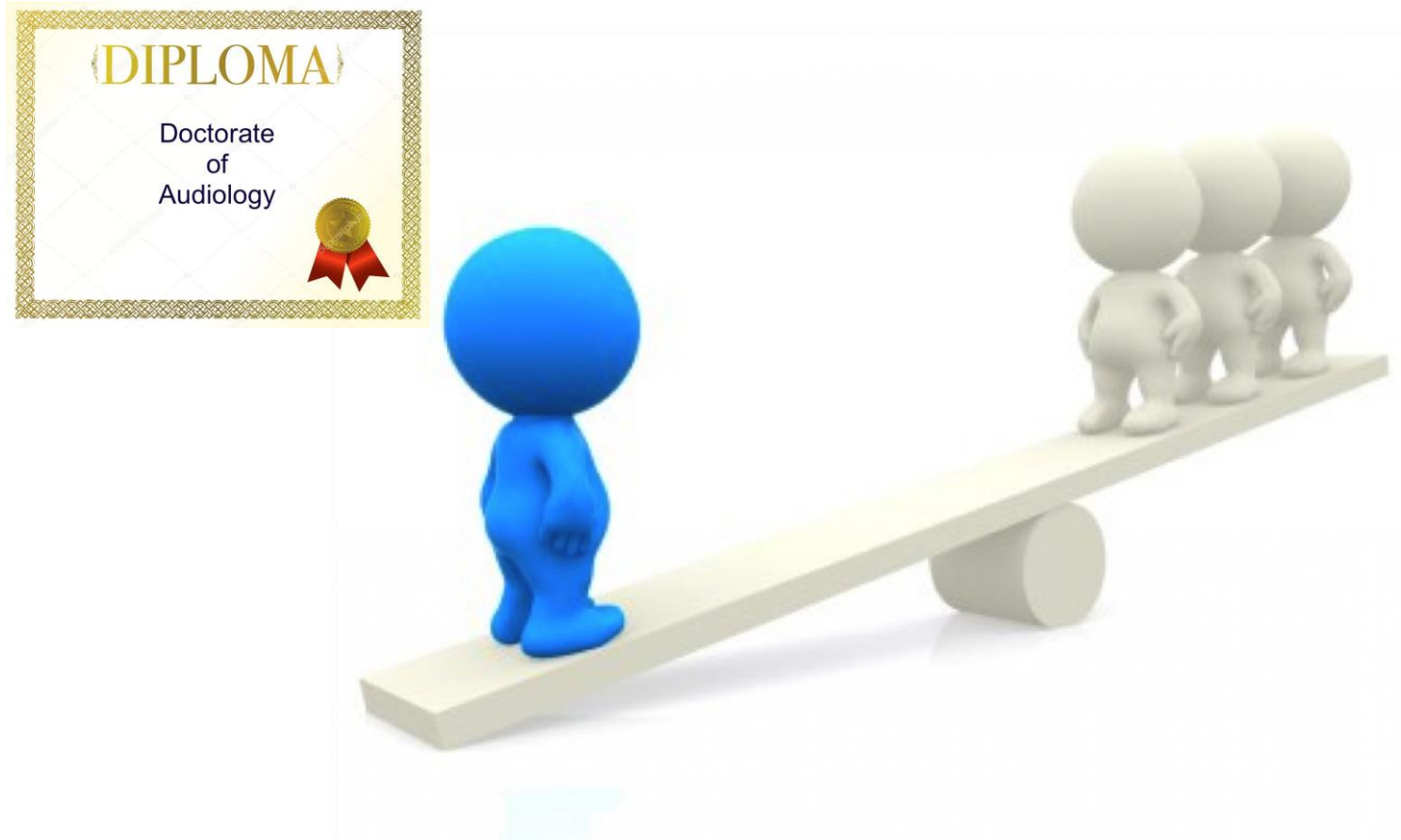
# Usual Methodology

- Most use focus groups, semi-structured interviews of patients and providers to develop questions
- Proposed questions are reviewed/categorized
- No recommendation for appropriate length
  - Range: 17-112 questions
  - Langbecker et al. (2012) : 33 pages long!
- Usually pilot-tested with small groups
  - Soliciting only general feedback: “Did you understand question?”
- “No gold standard”

# Which is better?

- Use questions developed by clinicians?
  - “patronizing, paternalistic” (Wells, 2004)
- Use patient-generated question?
  - Useful identifying unexpected questions clinicians would not have thought to address

# Our Concern: Power



# Our Approach:

- Authors first developed a set of 13 “jump-start” questions drawn from their clinical experiences with families
- JDG, KM, MPM (United States) and KLR (United Kingdom) shared this first version (**QPL 1.0**) with 21 parents
- Parent input resulted in expanded set of questions (N = 49), which were organized into categories/themes for ease of use (**QPL 2.0**)

- **QPL 2.0** reading level ratings: 5.8
  - Flesch-Kincaid reading grade level software
  - Met recommended readability standards for patient education materials (National Institute of Health, 2017; Weiss, 2003)
- **QPL 2.0** was then reviewed by a second cohort of parents (N = 16)
  - Thanks to EW (United States) and KLR (United Kingdom)
  - A second round of modifications resulted in **QPL 3.0** (N = 47)



- **QPL 3.0** was then shared online
  - Qualtrics survey system
  - Aug. 4-18, 2017
- Parents known to authors invited to review **QPL 3.0**
  - Vote item by item: keep as is, keep with revisions, or omit?
- Parents could bypass questions without responding, resulting in a range of final answers



# Results: Descriptive Data

- 281 parents opened survey
- 196 responses: “In what country do you currently reside?”

Country	%	Count
United States of America	77.04%	151
United Kingdom	14.29%	28
Canada	3.06%	6
Australia	1.53%	3
Ireland	1.02%	2
Algeria	0.51%	1
Andorra	0.51%	1
Hungary	0.51%	1
Italy	0.51%	1
Singapore	0.51%	1
Spain	0.51%	1
<b>Total</b>	<b>100%</b>	<b>196</b>

Open-Ended Questions	N	Responses
Child(ren)'s age	184	2 mo to 31 yrs M = 7.3 yrs, SD = 5.43
Year child(ren) HL identified	162	1997 to 2017 M = 2010; median 2012
Amplification, if any	164	Hearing aids: 51% CI: 33% Baha or bimodal or none: 18%
Primary communication modality	165	Spoken language: 56% Spoken language + sign: 38% Sign only, Cued Spch, Gestures: 6%



# Results: Survey

- 47 questions were posed:
  - Keep as is
  - Keep but revise
    - Wordy
    - Avoid leading questions (e.g., “Do most families find the diagnosis stressful?”)
    - Frame with optimism
  - Omit ( $\geq 25\%$  parent vote)
    - E.g., “How concerned should we be?” Feedback: “It’s up to me how concerned I should be!”
- After review, 32 questions accepted for final version
  - 3 questions omitted; others merged to reduce redundancy

# Final 32: Four Categories

- I. Our Child's Diagnosis
- II. Family Concerns
- III. Management of Devices
- IV. Support Systems, Now & in Future

# Intro: (Flesch-Kincaid reading grade level: 3.9 )

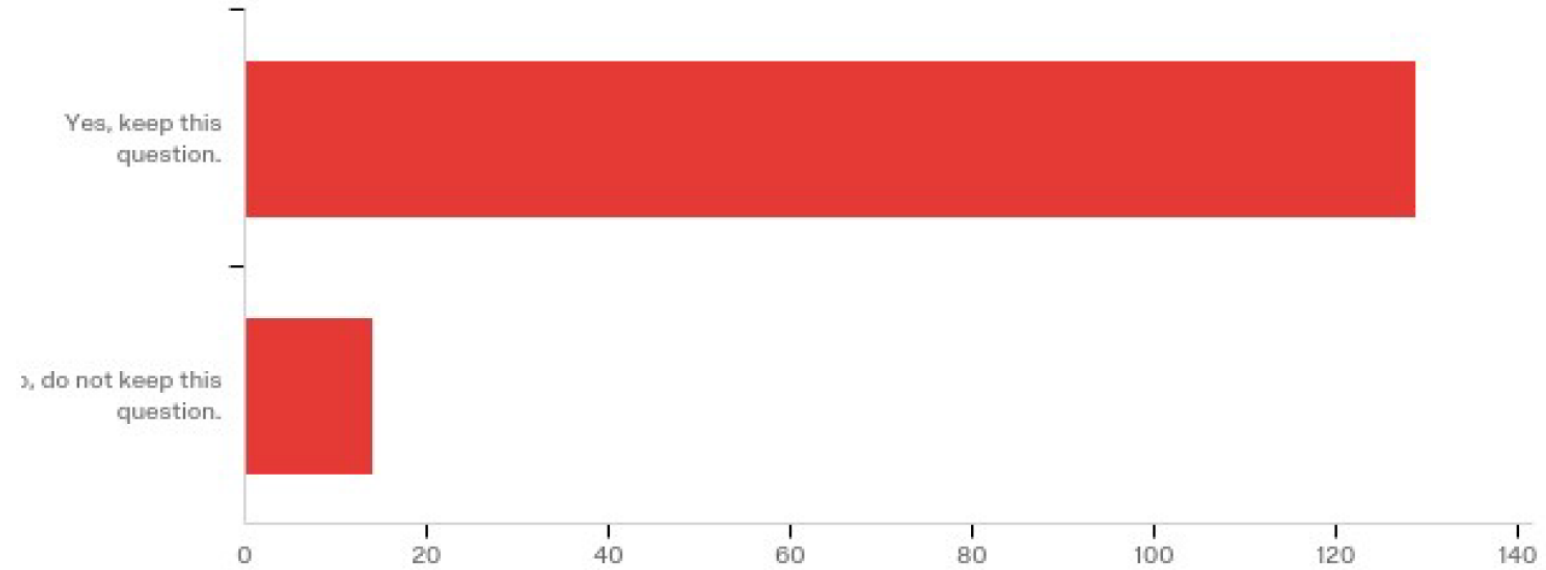
Many parents have questions or concerns about their child's hearing loss that they want to discuss with their audiologist. During busy clinic visits, parents may forget to ask their questions. Parents like you helped create this question sheet to help parents get the information and support they are looking for. The questions on this list are organized by topic. Some questions may matter more to you than others.

**If you find it helpful**, you can use this list to help you remember what to ask. For today's appointment, circle 2-3 questions that interest you most, or write down your own questions before your clinic visit. We hope you use this list for each appointment to make sure we eventually discuss all of your concerns.

# I. Our Child's Diagnosis

1. What kind of hearing loss does my child have?
2. Why does my child react to some sounds?
3. Are there tools to help me and others experience what hearing is like for my child?
4. Will my child's hearing get better/worse over time?
5. Do hearing aids fix hearing loss in the way glasses fix vision problems?
6. How do you and my family decide what technology, if any, is right for my child?
7. Is it likely that my child's speech will be affected?
8. We often feel overwhelmed with the decisions we have to make. Can you help us prioritize these decisions?
9. Are there related medical concerns I should know about?
10. Why is it recommended that we see a geneticist?
11. I'm finding it hard to come to terms with the diagnosis and it might mean for my child and family. How can I get support?

**Q109 - Are there tools to help me and others experience what hearing is like for my child, with and without hearing aids or implants?**



#	Answer	%	Count
1	Yes, keep this question.	90.21%	129
2	No, do not keep this question.	9.79%	14
	Total	100%	143

# I. Our Child's Diagnosis

1. What kind of hearing loss does my child have?
2. Why does my child react to some sounds?
3. Are there tools to help me and others experience what hearing is like for my child?
4. Will my child's hearing get better/worse over time?
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9. Are there related medical concerns I should know about?
10. Why is it recommended that we see a geneticist?
11. I'm finding it hard to come to terms with the diagnosis and it might mean for my child and family. How can I get support?

## II. Family Concerns

12. How can I share the importance of hearing devices with family and others?
13. What resources are there to help us pay for our child's hearing needs?
14. What can we do at home to encourage our child's communication development?
15. What resources are there to build children's confidence, resilience, social skills?
16. If we want to learn sign language, how/where do we start?
17. What are some effective ways to get my child's attention and communicate?
18. What should I be looking for at home to know if my child is making appropriate progress?

# III. Management of Devices

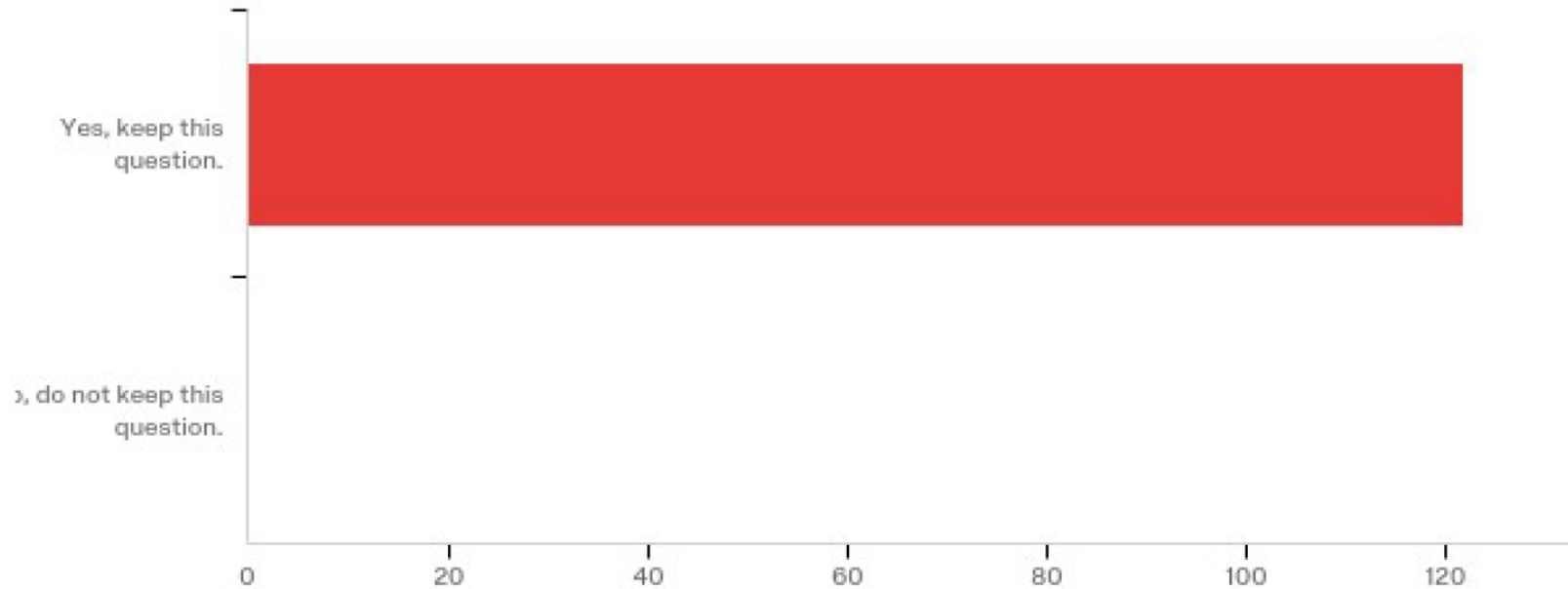
19. How much should my child use his/her hearing devices?
20. How do I take care of the hearing devices?
21. What strategies do parents use to keep the devices on a child's ears?
22. What do we do if the hearing aids stop working?
23. How can I encourage my child to feel confident about using hearing devices?
24. Will it take awhile for my child to get used to his/her hearing aids?
25. Should we take the hearing aids off when our child naps, breast/feeds, etc?
26. When the hearing aids are touched, does the feedback noise bother our child?



# IV. Support Systems, Now & in the Future

27. I'd like to talk to other people in our situation. How can I meet other parents with children with a hearing loss, and/or adults who are deaf or hard-of-hearing?

78 - I'd like to talk to other people in a similar situation. How can I meet other parents of children with a hearing loss, or older children or adults who are deaf or hard of hearing?



#	Answer	%	Count
1	Yes, keep this question.	100.00%	122
2	No, do not keep this question.	0.00%	0
	Total	100%	122

# IV. Support Systems, Now/In the Future

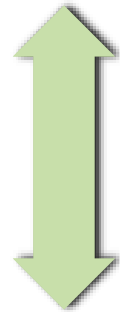
- 27. I'd like to talk to other people in our situation. How can I meet other parents with children with a hearing loss, and/or adults who are deaf or hard-of-hearing?
- 28. What agencies are available to help our family?
- 29. If I wanted support from a social worker or family counselor, how would I obtain a referral?
- 30. How can I help our childcare provider support our child's communication needs?
- 31. Do children with my child's level of hearing typically go to their local school?
- 32. What kind of help will my child need if he/she wants to participate in sports, music, and other activities?

# Discussion

- Aimed to develop a QPL for families of children with HL
- Could be used by audiologists to encourage families to engage in both fact-based and adjustment-based questions
- Impetus: to facilitate more family-centered practices in EI

# Based on Counseling Principle:

Understand what  
is happening



Being understood

- Questions re: dx, rx, related reservations, fears (Parts I, III)
- Questions re: adjustment-based concerns (Parts II, IV)

# Limitations

- Not yet tested
  - But in process: London, Cleveland Ohio, Logan Utah
- Initial 13 questions were developed by practitioners
  - However, initial two phases of parent review probably minimized this potential bias
    - Only one clinician-created question “survived” parent review (“Why does my child respond to some sounds?”)

# From 51 parent comments:



- Great questions/great project/great resource
- Great list/I wish I would have had a list like this
- Excellent/invaluable/all questions are important/all questions are perfect

# But three parents “not fans”

- “A lot of these questions would be better answered by a Child Find (early intervention specialist in the US) aide than an audiologist.”
- “Audiologist are experts in the ear and should refer everything else to H&V (Hands&Voices), DHH EI team, and deaf mentors. Audiologists are biased with technology and that will have a negative impact on families.”
- “Many of the questions are excellent but are better suited for early intervention providers or parent support resources.... The advice and information the audiologist provides should be limited to the medical facts of the hearing loss.”





# QPL available:

- <https://www.phonakpro.com/us/en/resources/counseling-tools/family-centered-care/fcc-children/family-centered-care-qpl.html>

Download CHL-QPL (EN)

Download CHL-QPL (ES)

- In progress: Chinese translation(s)

# Future Research:

- Clinical trials: audiologists, parents
- Effective, practical ways to incorporate into clinical setting
  - When should the tool be introduced?
  - How regularly should the QPL be reviewed with families?
  - If QPL is kept on file, should it be consistently be referred to, even if different audiologists rotate through family appointments?
- Explore relationship of QPL to:
  - Knowledge recall
  - Parent satisfaction
  - Perceived value of audiologic support
  - Adherence to recommendations???
- “Family of QPLs” for adolescents, adults re: acquired loss

# Sansoni et al. (2014):

- QPLs are not a “substitute for effective communication and cannot ‘fix’ poor communication” (p. v)
- One parent anticipated this concern:
  - “Will you offer suggestions for Audiologists to [help them] answer these questions?”
  - (Answer: yes, training is in development)

# Conclusion



- Achieved goal: Developed 1<sup>st</sup> QPL in Audiology
- Purposes of Childhood HL QPL:
  - Alert pediatric audiologists to potential “non-commitment” before it becomes established family routine
  - Help audiologists develop confidence with difficult conversations (English et al., 2016)
  - Provide a parent/family-centered platform to support these conversations



*Would You Use  
This New Tool?*

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