



# Implementing Family-Centred Care in Early Intervention for Children with Hearing Loss: Engaging Parents with a Question Prompt List (QPL)

**Keiran Joseph (CS)**

Clinical Lead, Paediatric Audiology  
St Thomas' Hospital

## **Acknowledgements:**

Kris English, PhD; Elizabeth Walker, PhD; Kerri Farah; Karen Muñoz, EdD; Angela Pelosi, MAuDSA; Nerina Scarinci, PhD; Janet DesGeorges; Holle Aungst, AuD; Jane Madell, PhD; Mary Pat Moeller, PhD; Josephine Marriage, PhD; Carol Flexer, PhD, and Christine Jones, AuD

# Background: Challenges in Paediatric Audiology

## Common Challenges

- Families struggle to understand the nature of hearing loss and the need to amplify their child's world
- Perceived “disconnect” between the diagnosis and their own observations creates hurdle to acceptance
- Possible grief and guilt, embarrassment, a sense of inadequacy, lack of support, or conflicting advice from family and friends.



# Background: Challenges in Paediatric Audiology

## Typical solutions

- Educate families using hearing loss simulations and hearing aid demonstrations
- Provide support from other parents or family support groups
- Connect with deaf or hard-of-hearing adults
- Refer to a social worker or family therapist



# Background: How Do We Break The Cycle



# Background: What is Family Centred Care

## Family Centred Care best practice principles:

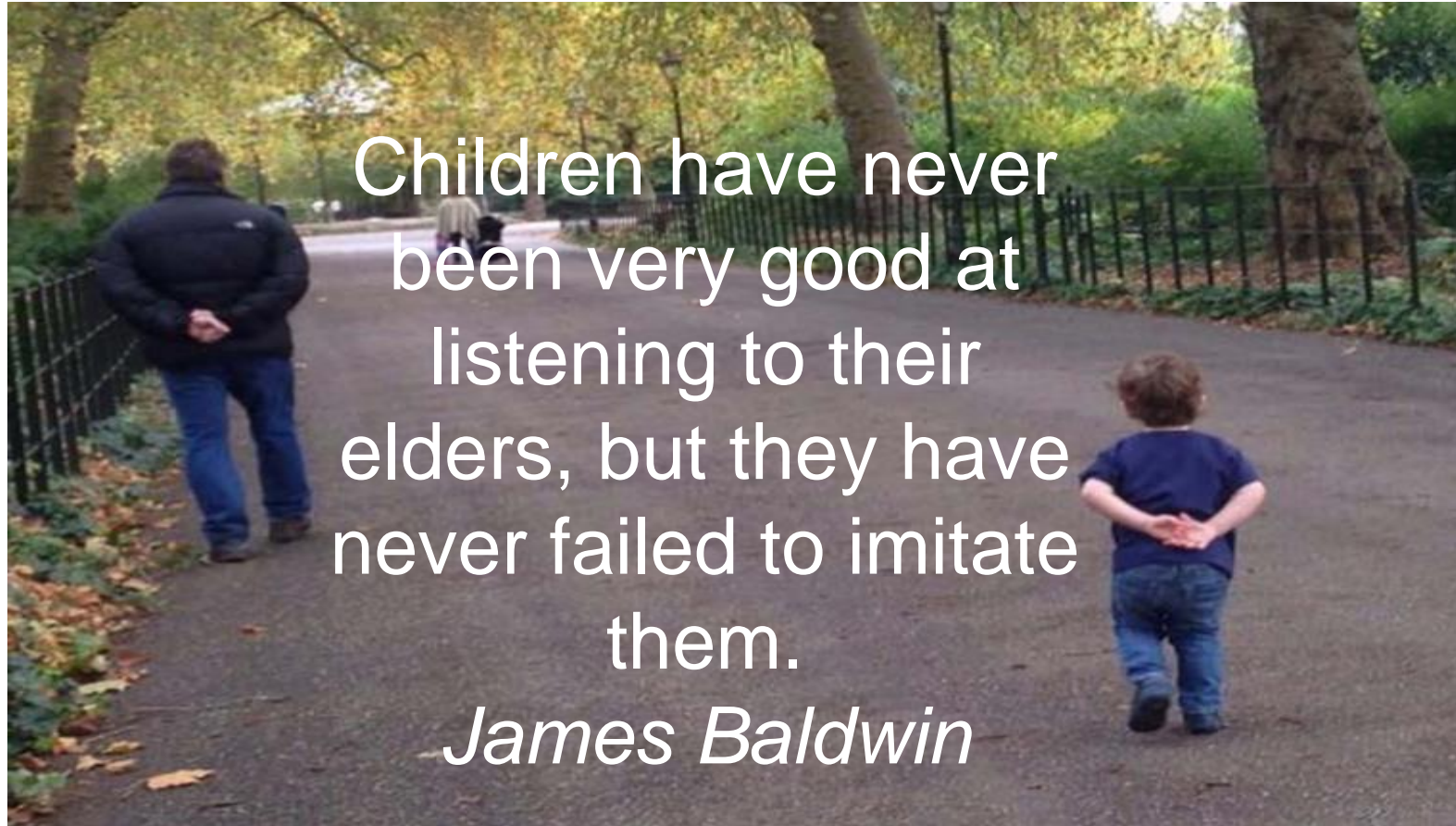
1. Early, timely, equitable access to services
2. Family-provider partnerships
3. Informed choice and decision making
4. Family, social, and emotional support
5. Family-infant interaction
6. Use of assistive technologies and supporting means of communication
7. Qualified providers
8. Collaborative teamwork
9. Progress monitoring
10. Program monitoring

# Background: Scenarios

- Returning patient: Marta, age 13
  - Diagnosed with hearing loss at birth
  - Immediately fitted with hearing aids
- Today's appointment:
  - Father mentions Marta's hearing loss similar to her mother's hearing loss
  - Mother was also fit with hearing aids in childhood
  - Discontinued use years ago, preferring to "get by"
- Father enthusiastic about new hearing aids but Marta not engaged
- Declares she wants to "get by" without hearing aids like mother



# Background: Scenarios



# Background: How Do We Break The Cycle

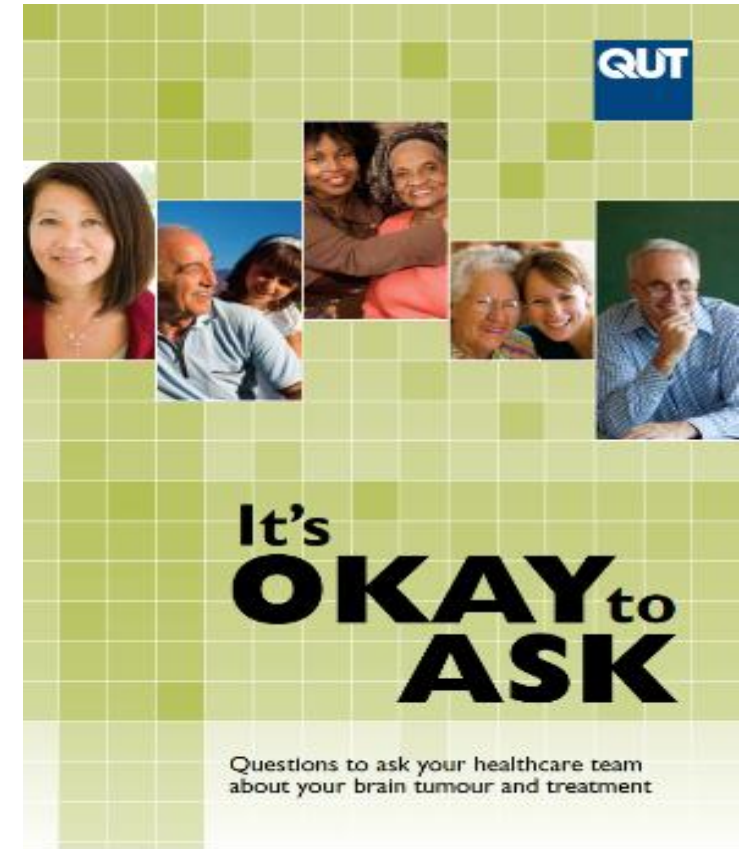
- Limited guidance in the audiological counselling literature about how to manage these situations
- 13 colleagues from 9 professions interviewed about the hypothetical scenarios and asked:
  - How does this situation present itself in your profession?
  - How does your profession work with this kind of situation?
  - What advice can you offer?

***Engage with families by talking with them, drawing them out, exploring their issues, and developing a strength-based approach to change.***



# Development: What is a Question Prompt List (QPL)

- QPLs used in medical specialties > 20 years
- 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 appointment
    - Patients often forget to ask their questions
    - Patients may get impression that only some questions are welcome
- Epitome of patient/family-centeredness



## Development: QPL (3.0)

1. Developed 13 “jump-start” questions (QPL 1.0) and shared with 21 parents
2. Parent input resulted in an expanded set of questions (n = 49) (QPL 2.0)
3. QPL 2.0 evaluated and met recommended readability standards for patient education materials before being reviewed by a second cohort of parents (n= 16)
4. Further modifications resulted in QPL 3.0 with 47 questions
5. Parents reviewed QPL 3.0 online via Qualtrics and indicate whether each questions should be kept, revised, or omitted (n=281)

# Development: QPL (3.0) Evaluation Demographics

Table 1: Answers to survey question, "In what country do you currently reside?"

<u>Country</u>	<u>%</u>	<u>Count</u>
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>

# Development: QPL (3.0) Evaluation Demographics

	N	Responses
Child's age	184	2 months to 31 years Mean = 7.3 years, SD = 5.43
Year child hearing loss identified	162	1997 to 2017 Mean = 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 Speech, Gesture: 6%

# Development: QPL (3.0) Evaluation Demographics

- 47 questions were posed:
  - Keep as is
  - Keep but revise: Wordy, Avoid leading questions, 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
- Divided into four areas: 1) Our Child’s Diagnosis; 2) Family Concerns; 3) Management of Devices; and 4) Support Systems, Now and in the Future

# Development: QPL

## Childhood Hearing Loss Question Prompt List (QPL) for Parents

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 what 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 a while for my child to get used to his/her hearing aids?
25. Should we take the hearing aids off when our child naps, breastfeeds, etc?
26. When the hearing aids are touched, does the feedback noise bother our child?

### IV. Support Systems, Now and 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?

A Sonova brand

# Implementation: Paediatric Audiology Service



# Implementation: Service Preparation

1. Audiologists asked to review QPL and determine which questions they were comfortable with and which needed support
2. Resource bank developed for each question to aid signposting
3. Team training session on questions marked as needing support
4. Audiologists felt confident supporting families with any questions on QPL





# Implementation: Project Plan

- Introduced into service in August 2018
- 2 Audiologists leading on project responsible for implementation of QPL and review data collation
- QPL issued at HL confirmation appointment for patients due to be fitted with HAs
- Reviewed at HA fitting (4 weeks post issue); Qs asked by family documented
- Reviewed again at first HA review (4-6 weeks post fitting); family and audiologist feedback questionnaires completed

# Initial Findings: Outcomes

## Current progress

- 21 questionnaires issued
  - 3/21 had questions from QPL at hearing aid fitting (2/21 non QPL q's).
  - 0/20 asked questions at hearing aid review (1 not yet seen)
- 18 of the 32 questions have been asked, some multiple times:
  - Q20 - How do I take care of the hearing devices?
  - Q21 - What strategies do parents use to keep the devices on a child's ears?
  - Q16 - If we want to learn sign language, how/where do we start?
  - Q17 - What are some effective ways to get my child's attention and communicate?
  - Q18 - What should I be looking for at home to know if my child is making appropriate progress?
  - Q24 - Will it take a while for my child to get used to his/her hearing aids?

# Initial Findings: Family Feedback Questionnaire

	Agree/ Strongly Agree	Neutral/ No comment	Disagree/ Strongly Disagree
QPL is easy to understand	9/10	1/10	-
QPL is relevant to parents and families	10/10	-	-
Would use QPL in future appointments	10/10	-	-
Would recommend QPL to other Audiology departments	10/10	-	-
QPL was a comfortable experience	7/10	3/10	-
QPL helped my discussion with my Audiologist	6/10	4/10	-
QPL seemed unnecessary/caused anxiety	-	-	10/10

## Initial Findings: Family Comments

*“[incorporated] questions we wouldn’t have thought to ask”/ “Questions I never thought about”*

*“Useful to consider issues of Audiology more holistically”/ “This was helpful as I have never had to consider Audiological issues before”*

*“I felt the QPL was aimed for older children but helped influence our questions”*

*“Was really helpful especially during a week when we had to take a lot of new information on board”*

# Initial Findings: Audiologist Feedback Questionnaire

	Agree/ Strongly Agree	Neutral/ No comment	Disagree/ Strongly Disagree
Families asked to discuss the QPL	1/10	-	9/10
When the QPL was mentioned families were interested	4/10	-	6/10
QPL is easy to use with families	7/10	3/10	-
QPL is relevant to parents and families	9/10	-	1/10
Found QPL helpful	6/10	4/10	-
Would use QPL in future appointments	9/10	1/10	-
Would recommend QPL to other Audiology departments	10/10	-	
Using the QPL was a comfortable experience	8/10	2/10	
Using the QPL helped discussion with families	4/10	6/10	

# Initial Findings: Questionnaires

All families said they found the questionnaire helpful, would use it again themselves and would recommend it to other audiology departments



BUT



Only 1/10 families asked to discuss the QPL at their review appointment and when brought up only 4/10 were interested in discussing it

# Initial Findings: Questionnaires

- Possible reasons for low patient uptake?
  - Performance bias – possibly?
- The service already adopts a family focused approach:
  - Audiologist continuity
  - Counselling training
  - Resource development and support videos
  - ‘Buddy parents’
- In the UK families received support from a broad MDT including Audiologist, ToD, SALT, CCP, ENT and charities such as the NDCS



The ears: doorways to the brain



Information for parents/carers who want their children to use spoken language to communicate<sup>1</sup>.

# Future Considerations

- Compile data at end of collection window and disseminate across regional, national, international networks
- Review data against two services in the USA
- Trial the QPL in a service where family centred care is not already an embedded practice?
- Longitudinal outcome study to review impact of QPL on family acceptance of hearing loss?







[Keiran.joseph@gstt.nhs.uk](mailto:Keiran.joseph@gstt.nhs.uk)

## References

Clayton J et al. (2003). Asking questions can help: Development and preliminary evaluation of a question prompt list for palliative care patients. *British Journal of Cancer*, 89, 2069-2077.

English K et al. (2016). Family-centered audiology care: Working with difficult conversations. *Hearing Review*, 23(6), 14-17.

Langbecker D. (2012). Developing and piloting of a brain tumour-specific question prompt list. *Euro Journ Cancer Care*, 21(4), 517-526.

Lederer S. (2016). A question prompt sheet for adult patients with chronic kidney disease. *BMC Nephrology*, 17, 155-164.

National Institutes of Health. (2017). *How to write easy to read health materials*. Available at: <http://www.nlm.nih.gov/medlineplus/etr.html> Accessed September 15, 2017.

Pharm R et al. (2015). Development and validation of a question prompt list for parents of children with attention-deficit/hyperactivity disorder: A Delphi study. *Health Expectations*, 19, 234–252.

Sansoni J et al. (2014). *A systematic literature review on Question Prompt Lists in health care (Final Report)*. Centre for Health Service Development, University of Wollongong, New Zealand.

Weiss BD (2003). *Health literacy: A manual for clinicians*. Chicago, IL: American Medical Association.

Wells T et al. (2004). The patient's written word: A simple communication aid. *Patient Education and Counseling*, 54(2) 197-200.

Yeh J et al. (2014). Using a question prompt list as a communication aid in advanced cancer care. *Journal of Oncology Practice*, 10(3), 3137-3141.