

Pediatric Family-Centered Care

The importance of family involvement
for pediatric patients



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Learning Outcomes

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- Participants will be able to explain the benefits of adopting a Family Centered Care (FCC) approach in their practice.
- Participants will be able to identify the tools best used in pediatric FCC.
- Participants will be able to evaluate conversations with patients and family members according to pediatric FCC best-practices.

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Agenda 01

1. Definition
2. Core concepts
3. Population
4. Challenges
5. Principles
6. QPL
7. Publications
8. Experts

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Definition

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Family-Centered Care (FCC) definition

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- Family-centered care is an approach to health care that respects the central role of family in a patient's life.
- It upholds the importance of the family as a partner on the health care team.

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Core concepts

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Core Concepts

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Family focus

- An understanding that family is the constant in the child's life is integral to FCC.

Respect

- FCC requires trust and respect of the family's values, beliefs, religion and cultural background.

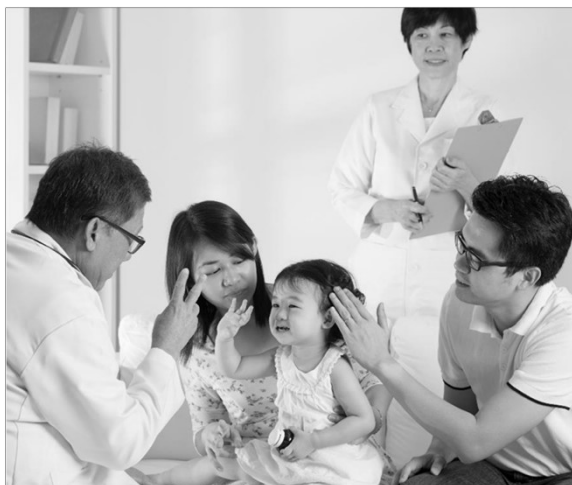


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Core Concepts

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Educated choices

- Families are provided the information needed to make educated choices about treatment.

Information sharing

- Active listening allows for sharing of information, builds trust and contributes to the partnership between families and caregivers.

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Core Concepts

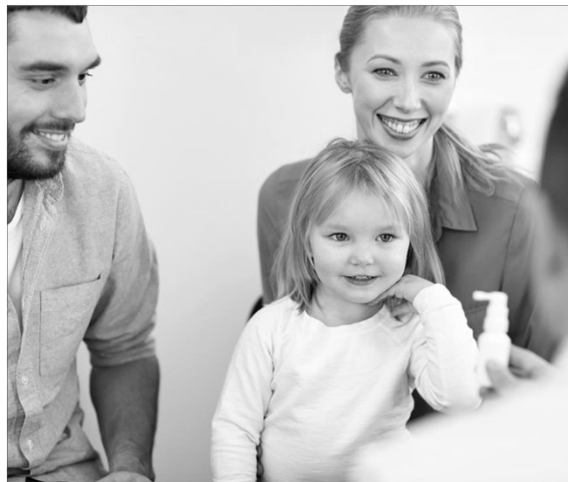
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Support

- Families are given ongoing support (e.g., by offering comfort as they cope with a new diagnosis, respecting their decisions throughout treatment, their confidence in their ability to care for their child).

Flexibility

- FCC emphasizes that professionals be flexible to meet the needs and preferences of all families.

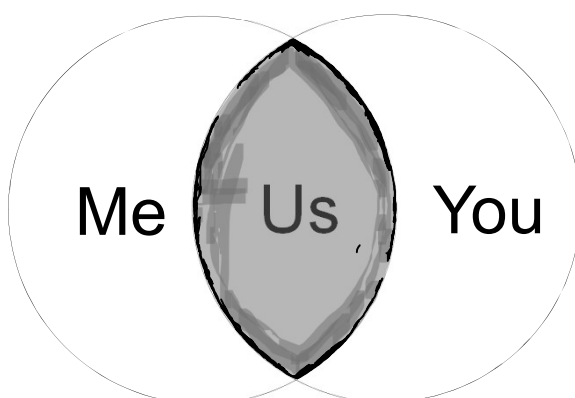


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Core Concepts

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- Collaboration
- As partners in care, professionals and family members work together in the best interest of the child.
- Empowerment
- The core concepts of FCC empower families in the care of their children.

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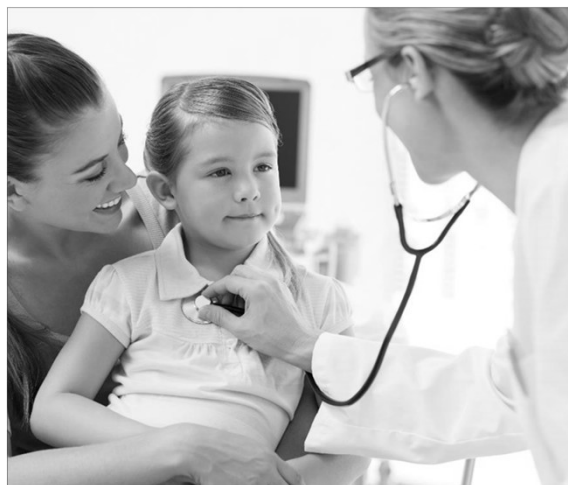
Population

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FCC pediatric population

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- FCC is becoming increasingly relevant
 - increased need to manage hearing loss in infancy
 - new opportunities for enhancing language development in natural and everyday contexts.
 (Tattersall and Young 2006, Young and Tattersall 2007)
- Various medical bodies/ authorities have established guidelines to facilitate family involvement.



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Challenges

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Some of the challenges...

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1. Managing difficult conversations with families
2. Building and maintaining a family's trust
3. Increasing family involvement in decision-making process

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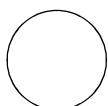
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Principles

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10 best practice principles

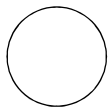
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Provide early, timely, and equitable access to services



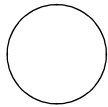
Use assistive technologies and support means of communication



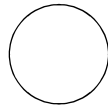
Develop balanced family and provider partnerships



Ensure qualified providers



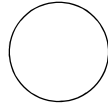
Promote informed choice and decision making



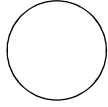
Engage collaborative teamwork



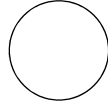
Provide family social and emotional support



Conduct progress monitoring and assessment



Promote family-infant interactions



Conduct program monitoring

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Childhood Hearing Loss Question Prompt List (QPL) for Parents

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What is a Question Prompt List (QPL)

- Resembles FAQ information sheets, but focuses on asking questions, not providing answers
- Includes communication aids to encourage patients and families to actively participate in discussions
- Assists in providing social and emotional support, and facilitates informed decision-making
- Encourages family members to ask questions about their concerns and available support systems
- Provides opportunities to ask questions about diagnosis and intervention options
 - (e.g., “Will my child’s hearing get better/worse over time?”)

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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?

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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?

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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?

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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?

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Publications

Publications

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Kris English (PhD)
Professor of Audiology
The University of Akron/NOAC, USA

See all 3 videos here:



- Family centered care practices
 - Why we need to focus on facilitating Family-Centered Care practices with children
- Challenges when working with little patients
 - Challenges audiologists face when working with families with children who have hearing loss
- CHL-QPL for audiologists
 - Why the Family-Centered Care expert panel created the CHL- QPL for audiologists

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Publications

Hearingreview.com / November 2017

- Pediatrics / Family centered care in early intervention

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PEDIATRICS / FAMILY-CENTERED CARE IN EARLY INTERVENTION

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

A new tool for engaging more families in a child's hearing management and development

By KIM ENGLISH, PhD, ELIZABETH WALKER, PhD, KERRI FARAH, KAREN MURCE, EdD, ANGELA PELCO, MAJDA, NEENA SCHARNO, PhD, JANET DINGESSON, HOLLY RAINOFF, PhD, JANE MAGILL, PhD, MARY PAT MOKLER, PhD, JOSEPHINE MARRIAGE, PhD, CAROL FLEXER, PhD, and CHRISTINE JONES, PhD


Editor's Note: As detailed in a June 23, 2017 Hearing Review online news article, Phonak has convened an international expert panel to provide recommendations for Pediatric Family-Centered Audiology Care, marking an expansion of the Pediatric Family-Centered Care (PFCC) initiative launched in October 2015. The PFCC panel, chaired by Dr. Kim English, includes a select group of experts who believe that, in order to provide optimal patient counseling and treatment, audiological care must shift to emphasize both patient and family involvement during the entire treatment process as a means to enhance the value of hearing care services.

The authors have developed a Question Prompt List (QPL) that can be used by audiologists to encourage families to engage in both fact-based and adjustment-based questions during audiology appointments. The impetus for developing this QPL was to facilitate more family-centered practices in early intervention.

Family-Centered Care (FCC) has long been presented as best practice in the provision of hearing healthcare services for children who are deaf or hard-of-hearing and their families.^{1,2} Although there is some variation in the definition of FCC among researchers and clinicians, there is consensus in the field of early intervention for children who are deaf or hard-of-hearing that the following 10 best practice principles should be applied:

- 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-informed assessment;
- 6) Use of assistive technologies and supporting means of communication;
- 7) Qualified providers;
- 8) Collaborative teamwork;
- 9) Program monitoring; and
- 10) Program monitoring.³

In many ways, the early, timely, and equitable access to services for families of children



Kim English, PhD, is a professor at the University of Akron (UAK) and an assistant professor in the Department of Communication Sciences and Disorders at the University of Akron in Akron, Ohio. **Scott Egan, EdD**, is the Clinical Lead of UAK's deaf and hard-of-hearing program. **Dr. Janet Dingesson** is the Associate Professor of Audiology and Hearing Department Head, Communication Disorders and Chief Educator at Ball State University. **Angela Pelco, MAJDA**, is the Clinical Head of Pediatrics at Phonak AG. **Christine Jones, PhD**, is a senior lecturer in Speech Pathology and Audiology at the University of Queensland, Australia. **Deborah** is the parent of a deaf daughter and the Executive Director of Deaf & Hearing is parent support organization. **Heidi James, PhD**, is a pediatric audiologist, speech language pathologist, US Army retired, specialist, and consults nationally and internationally on managing hearing in children. **Mary Pat Mokler, PhD**, is the Director of the Center for Childhood Deafness, Language and Learning Research at Baylor Scott & White Medical Center in Dallas, Texas. **Josephine Marriage, PhD**, is the Director of CHAD (England) is a Clinical Scientist in audiology and registered hearing aid dispenser. **Carol Phonak Audiology Research Center (PARC)** in Warrneville, IL.

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Experts

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Phonak Expert Circle on Pediatric Family-Centered Care



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Nerina Scarinci, PhD



Elizabeth Walker, PhD



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Future resources and research direction for Ped FCC



- Clinical trials: with 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 audiological support

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Pediatric FCC

**for a
child,
family is
everything**

Together,
we change lives

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