Pediatric Family-Centered Care
The importance of family involvement for pediatric patients

Learning Outcomes

• 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.
Definition
Family-Centered Care (FCC) definition

- 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.

Core concepts
Core Concepts

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.

Core Concepts

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.
Core Concepts

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.

Core Concepts

• 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.
Population

FCC pediatric population

- 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.
Challenges

Some of the challenges...

1. Managing difficult conversations with families

2. Building and maintaining a family’s trust

3. Increasing family involvement in decision-making process
10 best practice principles

- Provide early, timely, and equitable access to services
- Develop balanced family and provider partnerships
- Promote informed choice and decision making
- Provide family social and emotional support
- Promote family-infant interactions
- Use assistive technologies and support means of communication
- Ensure qualified providers
- Engage collaborative teamwork
- Conduct progress monitoring and assessment
- Conduct program monitoring
Childhood Hearing Loss Question Prompt List (QPL) for Parents

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?”)
Purpose of a 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

Childhood HL - Question Prompt List (QPL)

Available as PDF in English, Spanish, Chinese and English-Chinese
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?
Publications

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
Publications

Hearingreview.com / November 2017

- Pediatrics / Family centered care in early intervention

Experts
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
Pediatric FCC

for a child, family is everything

Together, we change lives

Presented in Partnership with

[Continued]
References

References


