

## Understanding Family Centered Care - The Patient and Beyond

A Phonak Audiology Initiative



A Sonova brand

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## Learning Outcomes



- Participants will be able to explain the benefits of adopting a Family Centered Care approach in their practice.
- Participants will be able to demonstrate how to adopt a Family Centered Care best-practices in their office culture, staff knowledge and training.
- Participants will be able to explain how to evaluate conversations with patients and family members according to Family Centered Care best practices.

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## Family Centered Expert Circle est. 2016



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## Family Centered Expert Circle



- Louise Hickson
- Kris English
- Joe Montano
- Gurjit Singh
- Mary Beth Jennings
- Sigrid Scherpiet
- Ora Buerki
- Ulrike Lemke
- Barbra Timmer
- Gabrielle Saunders
- Jill Preminger
- Stef Launer
- Nerina Scarinci
- Christopher Lind
- Patricia McCarthy
- Christine Jones
- Bettina Turnbull
- Jana Besser

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## What is Family Centered Care?

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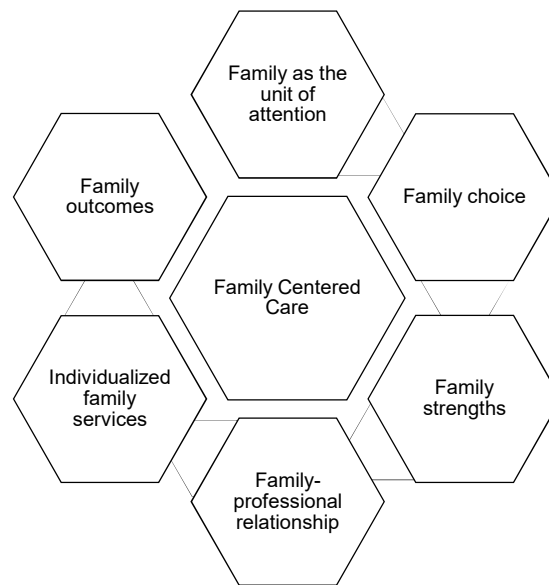
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## Evolution of FCC



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## Starting with a definition

**Family =**  
any individual who plays  
a significant role  
in an individual's life



**Two or more persons**  
who are related in any way, be it  
through a continuing biological,  
legal or emotional relationship



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## Is there sufficient evidence to support FCC?



*"Yes, and while most of it is currently coming out of audiology, there is a great amount of research in other areas of healthcare reporting the positive benefits and importance of including families. Benefits revolve around the fact that:*

- *Patients likely to be more satisfied with any treatment they receive, more likely to be more compliant with the treatment recommended to them, and more likely to have ongoing improvements in quality of life*

*Recent work in FCC has shown you can improve the uptake and outcomes of hearing rehab if you have positive support from family and reduce the negative consequences of hearing loss for the family member if you engage them in the process of hearing healthcare "*

*-Louise Hickson, PhD*

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## What is current research telling us about the concept of FCC?



Family support is a key reason why adults seek help for hearing impairment



Positive family support is associated with improved outcomes



Family experience third party disability because of the hearing loss as well as the patient and will benefit from audiologic care as well

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## Benefits of FCC



### Patient

- QOL improvement
- Adherence to rehab goals
- Higher satisfaction with outcomes

### Family

- Greater awareness of effect of hearing loss
- Less third party disability

### Clinician

- Improved patient provider trust
- Increased job satisfaction
- Referrals

### Business

- Higher rate of hearing aid adoption
- Fewer returns
- New patients & referrals

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## The impact of hearing loss on the family



Psychosocial Stress

Communication challenges

Embarrassment

Changes in relationships

Quality of life

Emotional reactions

Avoidance of social activities

Changes in roles &amp; responsibilities



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## How much impact does hearing loss really have on family?



*"It's been acknowledge for a long time that family members experience the effects of hearing loss on their own life as a result of their SO hearing loss.*

*Recent studies we've conducted in Germany and Australia with spouses of older adults with typical mild to moderate hearing loss suggest that impacts of hearing loss on family is only mild – however family members have consistently reported that they experience effects across numerous aspects of their life.*

*We found that following participation in family centered rehabilitation program, the family members reported that this impact of hearing loss on their life had lessened.*

*-Nerina Scarinci, PhD*

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## Third party disability

Impairments, activity limitations, and participation restrictions experienced by the family due to the health condition of their significant other"

-World Health Organization



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## FCC in real life: The current status in clinical practice



- Audiologists report attendance rates of family members to appointments to be relatively low, ranging from 10% to 50% with the majority of audiologists speculating attendance to be **lower than 30%**
- Observational studies indicate that attendance by family is even **less than 30%** at initial assessment appointments

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## FCC in real life: The current status in clinical practice



- Family members did not know they could attend appointments
- Family members only observed and were not included in the conversation
- Family members self selected to speak, self initiated additional information and questions
- Audiologist typically shifted the conversation back to the patient

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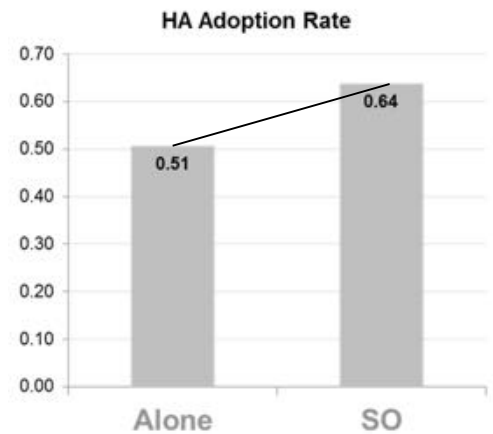
## Impact of involving the family member

A retrospective study completed in the UK explored the impact of whether or not hearing aid adoption is associated with significant other (SO) attendance at audiology appointments

- 60,964 patients
  - 33,933 patients attended appointments alone
  - 27,031 patients attended appointments w/SO

### Results

- **13 point improvement** in adoption rate HA adoption when the patient attended audiology appointments with a SO vs. alone



Singh, G. & Launer, S. (2016) Social context and hearing aid adoption

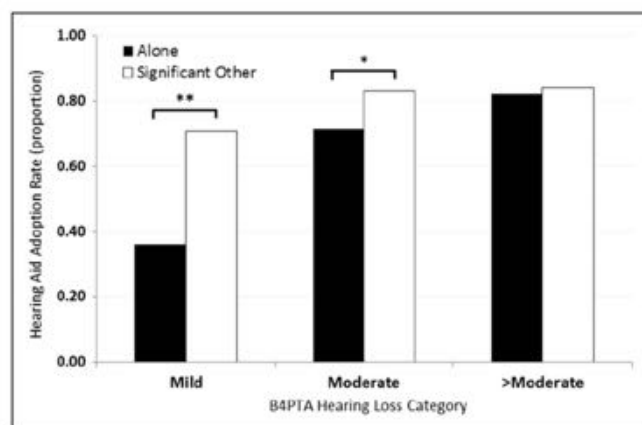
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## Impact of involving the family member

- SO involvement is positively associated with hearing aid adoption
  - Particularly for individuals with mild hearing loss (**96%**)



Singh, G. & Launer, S. (2016) Social context and hearing aid adoption

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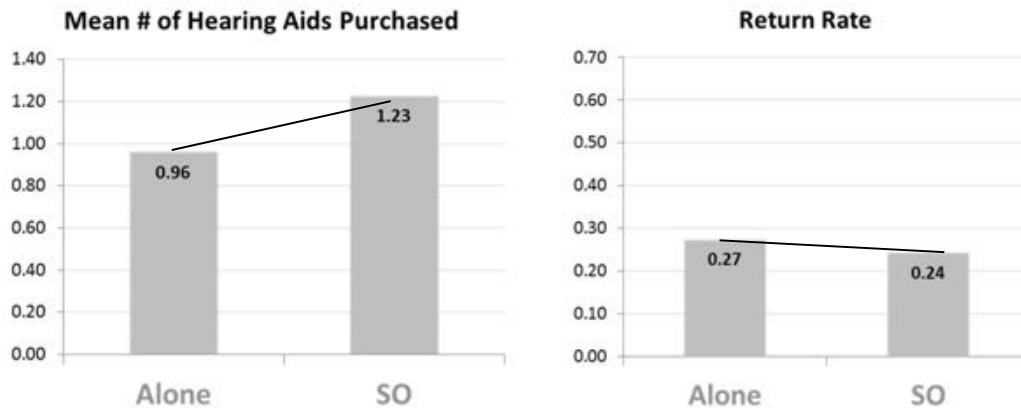
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## Impact of involving the family member



Singh, G. & Launer, S. (2016) Social context and hearing aid adoption

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## What is the impact of involving the family member?



*"Hearing aid adoption is significantly higher when family members attend and participate in audiology appointments.*

*The effect is not small and upwards of **15% greater** adoption of hearing aids when family attends versus by themselves. Also, return rates are slightly lower than when family members attend audiology appointments.*

*Family members are helping people to **overcome that final hurdle** as they decide to move on with amplification as a component of their hearing rehabilitation."*

-Gurjit Singh, PhD

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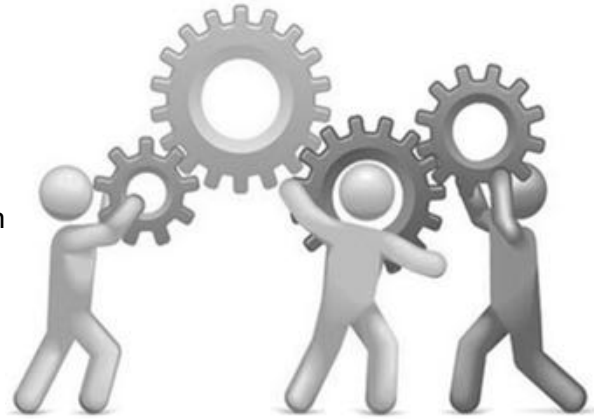
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## Involving the family member in hearing rehabilitation



- Family can
  - Encourage seeking help
  - Advocate for the adoption of hearing aids
- Family can
  - Act as cheerleaders and provide motivation during rehab
- Family can
  - Reduce hearing aid difficulties for the person with hearing impairment

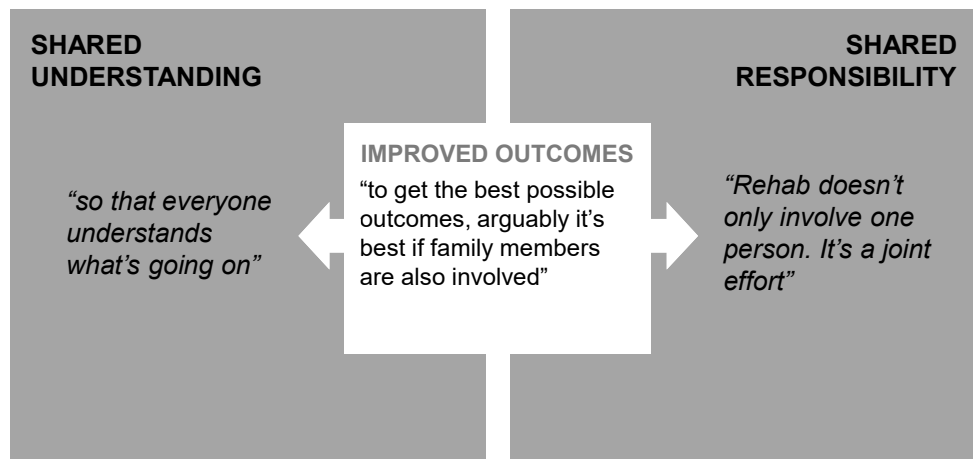


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## Family involvement: What do audiologists think?



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## Bridging the research - practice gap



- **Lapses** in communication
- **Service delivery** issues, lack of **public awareness**
- Lack of **scalable implementation**
- Interventions **too narrowly focused, complex** or difficult



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## Why should audiologists care about FCC?



*"It's a matter of **trust**. Research has shown that the more trust patients have in their healthcare providers, the more likely they will follow our recommendations.*

*When we, from the beginning, let patients know that a family member is welcomed and valued, the patient hopefully gets a positive impression that we are **open, transparent, and interested in their lives – all trustworthy characteristics.***

*If the patient and family member **both** trust the audiologist, we are more likely to count on a team approach to rehabilitation but only if the **family member** has been **included** from the beginning.*

*Bottom line: FCC gives us the opportunity to create patient trust, which is strongly correlated to patient success."*

*-Kris English, PhD*

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## Implementation – First steps

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## Implementing FCC



- 1** Get a family member (or important conversation partner) in the room
- 2** Set up the room
- 3** Start the conversation differently
- 4** Measure outcomes for patient and family

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The real “first step”



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**Step 1**  
**Get a family member or**  
**important communication**  
**partner in the room**

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## Step 1: Get a family member in the room



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## Step 1: Reflection



- 1 Get a family member (or important conversation partner) in the room ✓
- 2 Set up the room

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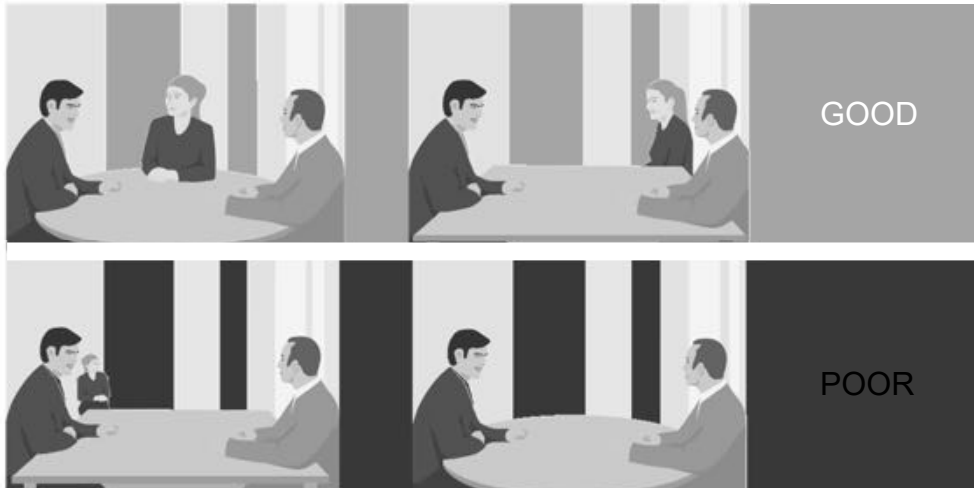
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# 2

## Step 2 Setting up the room

Set up the room



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## Step 2: Reflection



- 1 Get a family member (or important conversation partner) in the room ✓
- 2 Set up the room ✓
- 3 Start the conversation differently

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# 3

## Step 3 Starting the conversation

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### Step 3: Starting the conversation



- The aim is to set up from the start of the appointment a **collaborative approach**, promoting shared power and developing a team mindset.
- The clinician lets the patient and family know that **both** will be included and listened too with the understanding of a goal to attain an integrated understanding of the patient's needs and the family's needs.

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### Step 3: Starting the conversation



- Set boundaries
- Asked for permission
- OK with "dead air"
- Waited & listened

- Third party disability
- Shared goals

Inclusive physical setup

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### Step 3: Practical Application



- When starting the conversation:

- *"We are going to do a lot today. For the next 10 minutes, I want to find out about your hearing and then I want to find out about this from your perspective."*
- *"Tell me about your hearing and why you've come here today?"*
- *"How do you see things (family member)?"*



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### Step 3: Reflection



- 1 Get a family member (or important conversation partner) in the room ✓
- 2 Set up the room ✓
- 3 Start the conversation differently ✓
- 4 Measure outcomes for patient and family

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# 4

## Step 4 Measure outcomes

### Step 4: Measure outcomes

- Measure outcomes of the treatment plan agreed upon by the patient and the family member
- Has the treatment and rehabilitation process effected the goals?
- FOCAS
- IOI-HA & IOI-HA-SO



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## FOCAS

- Family Oriented Communication Assessment and Solutions
- Developed to address efficiency and efficacy of family involvement
- Goal oriented, benefit measurements
- Goals are rated on the importance they play in the patient & SO life
- Helps patients express themselves
- Helps patients gain self-awareness about the impact on QOL

**FOCAS – Family Oriented Communication Assessment and Solutions**

**1. Details**

Client name: \_\_\_\_\_ Clinician: \_\_\_\_\_  
 Family Member(s): \_\_\_\_\_ Outcome Date: \_\_\_\_\_  
 Access Date: \_\_\_\_\_

**2. Hearing and communication challenges**

**A - Client**

Client – challenging situations and impact: \_\_\_\_\_ Client's perspective on family's experience and impact: \_\_\_\_\_

1. \_\_\_\_\_ 1. \_\_\_\_\_  
 2. \_\_\_\_\_ 2. \_\_\_\_\_  
 3. \_\_\_\_\_ 3. \_\_\_\_\_

**B - Communication partner / family member**

Family – challenging situations and impact: \_\_\_\_\_ Family's perspective on Client's experience and impact: \_\_\_\_\_

1. \_\_\_\_\_ 1. \_\_\_\_\_  
 2. \_\_\_\_\_ 2. \_\_\_\_\_  
 3. \_\_\_\_\_ 3. \_\_\_\_\_

**3. Shared and individual hearing and communication goals**

How much do you agree or disagree with the goal or goal of the family? (Rate 1 to 5, 1 = strongly agree, 5 = strongly disagree)

What would the family like to achieve?	How?	How?	Importance	Optional Solution	Outcome
1. _____	_____	_____	_____	_____	_____
2. _____	_____	_____	_____	_____	_____
3. _____	_____	_____	_____	_____	_____
4. _____	_____	_____	_____	_____	_____
5. _____	_____	_____	_____	_____	_____

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## IOI-HA

- 7 item questionnaire
- Applicable in evaluating the effectiveness of hearing aid treatment
- Simple, easy to use
- Available in many languages
- Includes question about the effect of hearing aids on the SO

### International Outcome Inventory – Hearing Aids (IOI-HA)

1. Think about how much you used your present hearing aid(s) over the past two weeks. On an average day, how many hours did you use the hearing aid(s)?

none      less than 1 hour a day      1 to 4 hours a day      4 to 8 hours a day      more than 8 hours a day

☐      ☐      ☐      ☐      ☐

2. Think about the situation where you most wanted to hear better, before you got your present hearing aid(s). Over the past two weeks, how much has the hearing aid helped in that situation?

helped not at all      helped slightly      helped moderately      helped quite a lot      helped very much

☐      ☐      ☐      ☐      ☐

3. Think again about the situation where you most wanted to hear better. When you use your present hearing aid(s), how much difficulty do you STILL have in that situation?

very much difficulty      quite a lot of difficulty      moderate difficulty      slight difficulty      no difficulty

☐      ☐      ☐      ☐      ☐

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## IOI-HA-SO

- Designed to be answered by the family member (SO)
- 7 item questionnaire
- Applicable in evaluating the effectiveness of hearing aid treatment
- Simple, easy to use
- Available in many languages

### International Outcome Inventory – Hearing Aids – Significant Other (IOI-HA-SO)

1. Think about how much your partner used their present hearing aid(s) over the past two weeks. On an average day, how many hours did your partner use the hearing aid(s)?

none ☐      less than 1 hour a day ☐      1 to 4 hours a day ☐      4 to 8 hours a day ☐      more than 8 hours a day ☐

2. Think about the situation where you most wanted your partner to hear better, before getting their present hearing aid(s). Over the past two weeks, how much has (have) the hearing aid(s) helped in that situation?

helped not at all ☐      helped slightly ☐      helped moderately ☐      helped quite a lot ☐      helped very much ☐

3. Think again about the situation where you most wanted your partner to hear better. When your partner use their present hearing aid(s), how much difficulty does he or she STILL have in that situation?

very much difficulty ☐      quite a lot of difficulty ☐      moderate difficulty ☐      slight difficulty ☐      no difficulty ☐

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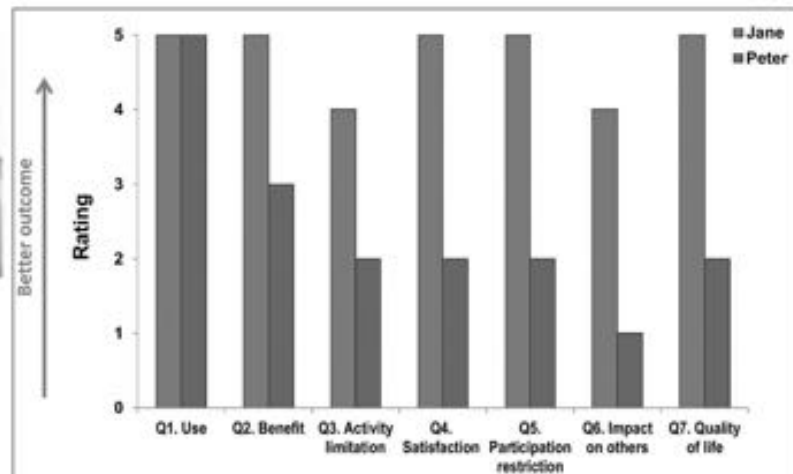
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## Step 4: Practical application



Jane & Peter

- Jane recently received hearing aids



IOI-HA & IOI-HA-SO scores

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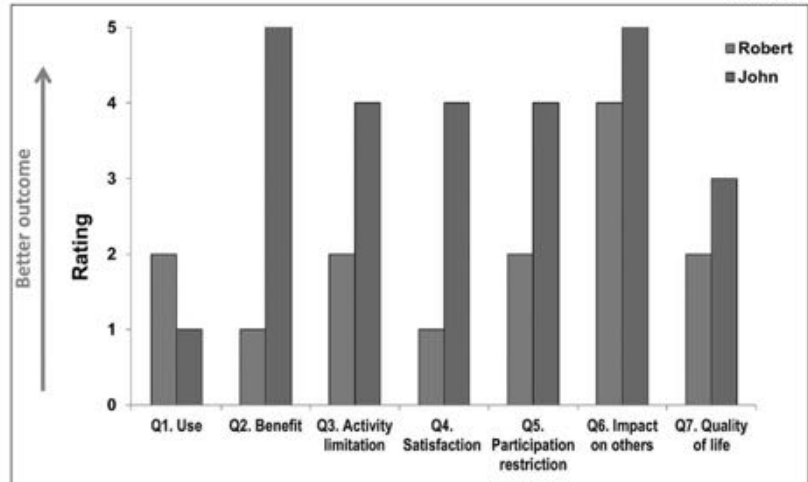
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## Step 4: Practical application



Robert & John

- Father & son
- Robert recently received hearing aids



IOI-HA & IOI-HA-SO scores

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## Step 4: Incongruent Outcomes

When a family member is included, the complexity of the conversation inherently increases and can often catch us off guard.

- What if patient and family perspective contradict each other?
- Will we lose control of the appointment?
- Will the patient feel defensive?

This is called having *"difficult conversations"* and managing *"incongruent outcomes"*.



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## Moving forward: Implementing FCC

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## Implementing FCC

**1**

Get a family member (or important conversation partner) in the room

**2**

Set up the room

**3**

Start the conversation differently

**4**

Measure outcomes for patient and family

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Tools to support you

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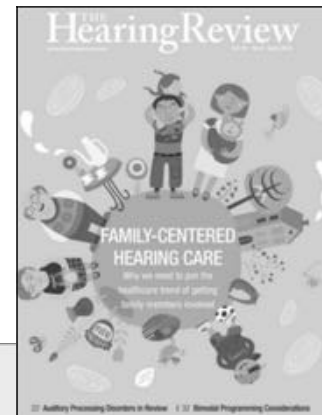
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## 10 Recommendations to Implement Family-Centered Care

- 1) Invite a family member along to audiologic appointments. When making appointments say: "Our experience is that it is very helpful if you can bring a friend or a loved one along to the appointment. Who would that be?" If patient asks for more information, you could say "There is a lot to discuss and it helps to include family and friends in the process." This information should be reinforced in any written information provided to patients regarding appointments.
- 2) Set up the physical environment so that family are comfortably included in the consultation rather than being relegated to a seat at the back of the room. An inclusive physical environment fosters a sense that everyone can equally provide their thoughts and perspectives.
- 3) Start the appointment by letting the patient and the family member know that input will be sought from both of them—patient first and then the family member. The clinician could say "We are going to do a lot today. For the next 10 minutes, I want to find out about your hearing and communication (directed to the patient) and then I want to find out about this from your perspective (directed to the significant other)." The goal is to listen so as to attain an integrated understanding of the patient's and family's physical, social, and emotional needs.

- 4) Set joint hearing and communication goals with patient and family. Discuss what they would both like to achieve (eg, TV at a lower volume, easier conversation) and prioritize together. The Client Oriented Scale of Improvement (COSI)<sup>16</sup> could be used or the Goal-Sharing Partnership Strategy (GPS).<sup>17</sup>
- 5) Present options for rehabilitation that address the needs and goals of both the patient and the family. For example, whereas a hearing aid alone can address the problem of communicating with one's spouse at the dinner table, a hearing aid and a remote mic can be used when trying to communicate across greater distances.
- 6) When developing the treatment plan, aim for shared decision-making, with patient, family, and clinician as equal partners in the process. Use decision aids to guide discussions about options for hearing rehabilitation (see Lagarde-Lévesque, Hickson, and Wernli<sup>18</sup>). Decision aids provide a simple summary of all options and the advantages and disadvantages of each. Confirm there is a mutual understanding of all communication goals.



- 7) Remember that the patient and the family are the experts. They live with the hearing loss every day. For example, the patient and family could be asked "What do you want to do about your hearing loss?"
- 8) Actively encourage involvement of the family at all stages of the care process (eg, history taking, rehabilitation planning, hearing aid fitting, follow up, and annual review).
- 9) Measure outcomes of interventions for both the patient and the family. You could revisit the goals identified at the start by both patient and family and find out how much the treatment has affected those goals. There are many outcome measures for patients and a smaller number for family that could also be helpful: the Significant Other Scale—Hearing (SOS-HEAR)<sup>19</sup> and the Hearing Impairment Impact—Significant Other Profile (HS-SOP).<sup>20</sup>
- 10) Make the entire clinic family-centered with buy-in from all stakeholders: executives, managers, clinicians, and front office staff. Put family-centered care on the agenda of regular staff meetings.

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# THE HearingReview



April 2016

- Family-centered Adult Audiologic Care: A Phonak Position Statement

August 2016

- Family-centered Audiology care: Working with difficult conversations

November 2016

- Family-centered Audiology Care: Making Decision and Setting goals together

December 2016

- How Do I Implement Family-centered Care in My Practice?

February 2017

- Family-centered Care: Working with partners reporting "incongruent" hearing aid outcomes

May 2017

- Family-centered Audiology Care: Emotion and Reason in Hearing Healthcare

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# THE HearingReview



BLOG

**Mythbusters Myth No. 1: I Would Like to Do More Counseling But Time Just Won't Allow for It**



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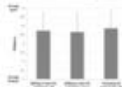
**Mythbusters Myth #2: I Will Be Expected to Be a Marriage Counselor**



Published on December 15, 2017

COUNSELING/REHAB/PATIENT CARE

**Mythbusters' Myth #3: "Many Patients Do Not Want Their Family in the Room"**



Published on January 30, 2018

COUNSELING/REHAB/PATIENT CARE

**Mythbusters' Myth #4: I Have to Discuss the Audiogram**



Published on April 24, 2018

COUNSELING/REHAB/PATIENT CARE

**Mythbusters' Myth #5: "Including Family Members in the Appointment Takes Up Too Much Valuable Time"**



Published on May 30, 2018


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**Family-centered care; an opportunity for...**  
Including family in audiology rehabilitation benefits all involved.

[Read more](#) | 3 Comments




**"No hearing aids on the weekend? - What did I..."**  
A new communication tool for pediatric audiologists - designed to support conversations with families and improve the effectiveness of our recommendations.

[Read more](#) | 3 Comments




**Involving the family in the continuing better...**  
Why family centered care will benefit your patient and your business.

[Read more](#) | No Comments




**Involving the family in the better hearing...**  
Why family centered care will benefit your patient and your business.

[Read more](#) | No Comments



**Do we practice what we preach in...**  
What practicing clinicians think about Family-Centered Care and how this copes with challenges.

[Read more](#) | No Comments





**Training for success: the emerging need for...**  
As the CEO of Summit, a consensus around the urgency to develop the uniqueness of (human) professionals. Our training on Family-Centered Care addresses critical skills such as empathy.


[Read more](#) | No Comments

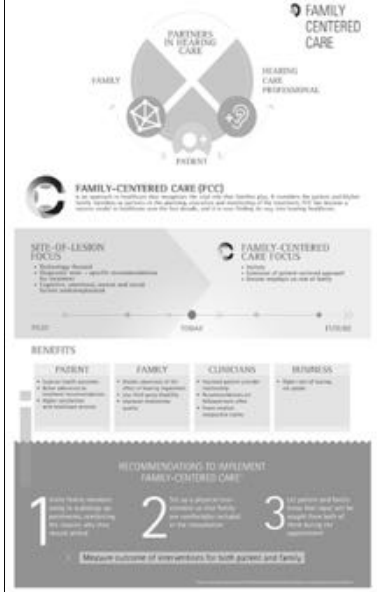
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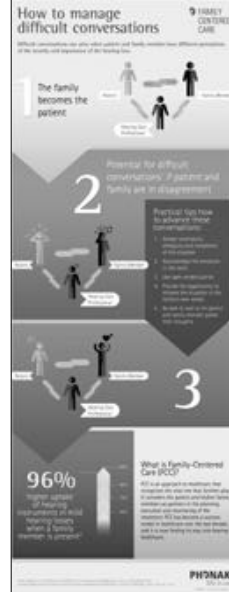


**FAMILY-CENTERED CARE (FCC)**  
It is an approach to healthcare that recognizes the role of the family in the patient's life. It involves the patient and their family in the decision-making process, and it is a key component of the patient's care.

**MEASUREMENT OF FCC**

**RECOMMENDATIONS TO IMPLEMENT FAMILY-CENTERED CARE**

1. Measure outcome of interventions for both patient and family.
2. Use as a primary outcome measure for the patient and family.
3. Use as a primary outcome measure for the patient and family.




**How to manage difficult conversations**

1. The family becomes the patient.

2. Potential for difficult conversations: if patient and family are in disagreement.

3. Potential tips how to achieve these conversations.

96% Higher uptake of hearing aids when family is involved.




**The role of emotions in hearing healthcare**

Emotions and...  
...hearing loss  
...decision making

Understanding the central role of emotions is important to...  
...develop...  
...reinforce...  
...understand...

Partially when discussing emotions with patient and family members:  
50%  
46%

Emotional Communication in Hearing Questionnaire (EHCQ)  
...benefits of effective HCP-patient communication



**Tools for patients and family to address hearing loss together**

Tools to involve family members in the decision-making process:


- The Decision Aid
- The "Emotional" Model of Change
- The Goal-sharing for Families (GSHF)

Joint decision We 96%

What is Family-Centered Care (FCC)?

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## eLearning series on Family Centered Care



<b>Module 1</b>	<ul style="list-style-type: none"> <li>Discusses the theoretical background and benefits of Family Centered Care</li> </ul>
<b>Module 2</b>	<ul style="list-style-type: none"> <li>Setting up the room for success, overcoming practical barriers, busting myths</li> </ul>
<b>Module 3</b>	<ul style="list-style-type: none"> <li>Principles of patient centered conversation, how to apply FCC during the appointment and effective communication techniques</li> </ul>
<b>Module 4</b>	<ul style="list-style-type: none"> <li>Applying FCC during fitting and follow up while applying coaching techniques</li> </ul>
<b>Module 5</b>	<ul style="list-style-type: none"> <li>Identifying reasons for conflict, helping families find common ground</li> </ul>
<b>Module 6</b>	<ul style="list-style-type: none"> <li>Post assessments and evaluation, additional resources, tips &amp; tricks. Setting development goals.</li> </ul>

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 life is on


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**Together,  
we change lives**

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