



2009 Summer Conference Handout

Sunday, July 19, 2009

1:45 – 3:15 pm

***Conversations with my Audiologist
“I am more than just a hearing loss”***

Presenters:

Dave Gordey, MSc, Aud(C) Pediatric Program Manager

Sheila T. Moodie, MCISc, PhD Candidate



Conversations with my Audiologist: “I am more than a hearing loss”

Dave Gordey, MSc, Aud(C) Pediatric Program Manager
 Oticon Canada
dg@oticon.ca

Sheila T. Moodie, MCIsc, PhD Candidate
 The University of Western Ontario, National Centre for Audiology, London, Canada
sheila@nca.uwo.ca




© 2007




Acknowledgements

Mary Beth Jennings, PhD
 Assistant Professor, Dept. of Communication Sciences & Disorders and
 The National Centre for Audiology, London, Ontario, Canada

Kris English, PhD
 Associate Professor
 The University of Akron, Akron, Ohio, USA

Richard Seewald
Marlene Bagatto
Steve Beaulac

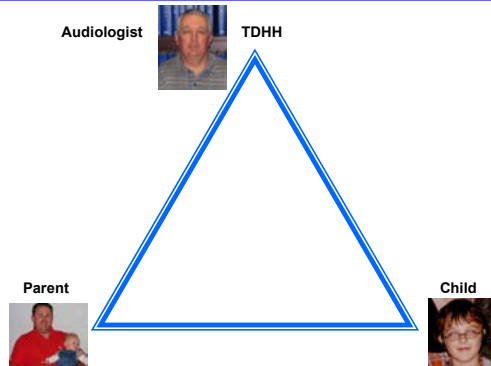
Maureen Clarke




Acknowledgements

- This work has been supported by the Canada Research Chairs (CRC) Program (Sheila Moodie) and by Oticon Canada (Dave Gordey).

Introduction: A Triadic Partnership



Audiologist **TDHH**
Parent **Child**



A Triadic Partnership: Audiologist

- (Shane Moodie) "It's always interesting when they show up to an appointment on their own... and you look around and ask where is your mother?"
- Audiologists working with children are taught to work in the frame of family centered care – and that often means the parents.



A Triadic Partnership: Parent

- Mark Ross wrote in 1975:

“Parents are the more important partners They have more at stake and have the greatest impact upon their children, particularly the younger ones, and their informed participation can be crucial.”



A Triadic Partnership: Parent

- Successful use of amplification is likely to reflect our ability as professionals to communicate this importance to the parents. This will depend on their understanding and their acceptance of their child and the hearing loss."
- First and foremost we must remember that the child is part of a family unit ... and we must work with the parent(s) and all of the challenges that they have in their busy lives.



A Triadic Partnership: Child

The third person in the triad, is really the most important one.

" ... The audiologist may have told my parents, but did not explain it to me.

I am more than just a hearing loss."

(Craig)

The Triad of Care: Challenges & Issues

- A paternalistic, medical model of care can evolve.
- Expectations for the development of self-care are neglected.
- To date, most research focuses on the audiologist-parent interaction



Our Focus on Parents of Young Children with Hearing Loss

- More than 90% of babies with hearing loss are born to hearing parents who had no reason to suspect their child would have any degree of hearing loss (Kurtzer-White & Luterman, 2003).
- The diagnosis is unexpected, and parents feel the future for their child is uncertain and unpredictable.
- Parents report the great need for timely access to understandable information and the need for significant emotional support (Steinberg & Bain, 2001).
- We are focusing a lot of energy with parents – this is great!!



Working with Parents

- Parents today may be more willing to encourage their child to participate in their appointments.....or
- Some parents will manage in an executive-like capacity, regulating what and how their children are provided with audiological information.
- Example from Study

Implications for Clinicians: Working with Parents

- The extent to which children are encouraged by their parents to be independent, will in turn have an impact on the Audiologist's relationship with the child.
- This will affect the child's willingness to take an active part in the appointment and their compliance with audiological care.
- Examples from other medical conditions.

"The Rights of the Child": Implications for Clinicians

- The role of "service user / consumer" has been extended to include children
- The United Nations Convention on the Rights of the Child (UNCRC 1990) gives children rights to participate in decisions that affect them
- Children, even young children, are competent commentators on their own lives (Sinclair, 2004).

Conversations with My Audiologist: Study Objectives

- We undertook a study to explore the reflections of young adults with hearing loss.
- We looked at the audiological assessment and treatment they received through various stages/ages of their lives.
- We examined the personal impact that the hearing care and treatment had on them.
- We believed that we could learn from their stories. It might help us to consider additional methods when working with children.



Conversations with my Audiologist

- 6 individuals (3 males, 3 females) participated in the study
- Average age was 30 years
- Diverse range of hearing losses
- All communicated with spoken language.
- All were born with hearing loss, or acquired their hearing loss at a very young age
- All had the experience of wearing amplification.

Conversations with my Audiologist

- Each subject was sent via email a questionnaire that provided them with several areas we wanted them to reflect on and write about.
- Some sample questions included:
As a child, what did you see as your role (your position) within the child - parent(s) – Audiologist partnership?

Conversations with my Audiologist

- Some sample questions included:

What strategies do you think Audiologists might use to help parents encourage their children to become more active participants in audiological appointments?

Conversations with my Audiologist

- After receiving and reading through each participant's responses, probe questions were written and a follow up face-to-face interview was conducted when possible (n=3)
- You will see some of the participants who were able to be videotaped.

Reflections on Parent's Involvement
in the Triad of Care

Doug: "My parents, for quite a while, **saw their role as enforcing hearing-aid wearing.** Naturally I was uncomfortable as a result. But happily, after some years, I managed to convince them that the hearing-aids were not a good fit, and were not helpful, then things got better from my point of view."

Study Results

Reflections on Parent's Involvement

Krystal: "The audiologist would confer with my parent ... **I trusted both parties to look out for my best interests.**"

Reflections on Parent's Involvement

Amy: "My mom would **tell me to tell my audiologist** my feelings, fear, difficulties that I was having."

Reflections on Parent's Involvement

Kendra: "...in my experience, my parents were somewhat assertive to the point where **they acted as if they knew more about my hearing loss/how to cope with it than I did.**"

"My Mom took care of it."



“My Mom would put them in and out for me”



Reflections on Relationship with Audiologist

Craig: “Often I would hear about new technology from my hearing teacher (TDHH).

The audiologist may have told my parents, but did not explain it to me.

I am more than just a hearing loss.”

Reflections on Relationship with Audiologist

Craig: “After my first experience with my first audiologist (lasted about 5 years), **I felt like I was taken out of the picture** regarding decision –making. For instance, I remember the audiologist talking to my parents regarding my latest hearing test, but not informing me. **I felt like I had a right to understand what my level of hearing was.** Thus, not understanding your hearing loss can really lead to other issues.”

Reflections on Relationship with Audiologist

Mikael: “I always had a pleasant experience with my audiologists. **I was always treated with respect.** Care was always taken to ensure that I, and my parents, were happy before we went out the door.”

Reflections on Relationship with Other Professionals involved in their Care

Craig: “**The hearing resource teacher** (TDHH) showed me on a weekly basis how to look after my hearing aids. She told me what a dry aid kit was and showed me how to clean my hearing aids. She showed me SO much”

Reflections on Relationship with Other Professionals involved in their Care

Probe to Craig: *How did she show you?*
“We practiced sometimes. **She showed me ways to ask the teacher for help without drawing too much attention to myself.** I felt like she was always wanting me to do really good in school.”

Reflections on Relationship with Other Professionals involved in their Care

Doug: “In about grade 6 or 7, a **speech therapist** sent by the board of education talked with me about my degree of hearing loss. **Prior to that, nobody talked to me, just to my parents.** Happily, around grade 8 I managed to push through wearing a behind-the-ear aid at school rather than the rather ineffective board of education “remote” (radio-link) aids.”

Reflections on Relationship with Other Professionals involved in their Care

Doug: “.... At one point I ran into a **surprisingly reasonable** technician who said, ok, just keep it turned really low.”

Emerging Themes

- Relationships
- Self-confidence
- Self-advocacy
- Control
- Access to information
- Responsibility
- Strategies
- Listening
- Respect
- Normalacy

Putting a framework around the childhood stories of hearing loss

SELF-DETERMINATION THEORY

Self-Determination Theory (Grolnick, Deci & Ryan, 1997; Ryan & Deci, 2000)

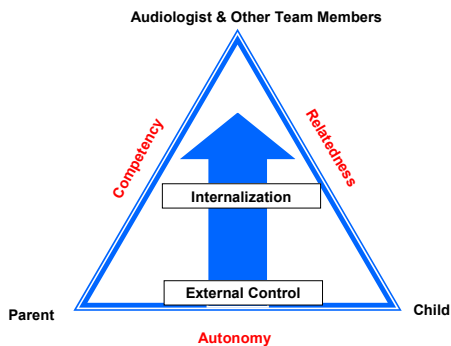
- Children have a **natural** motivational propensity to take in behaviours and to make them their own.
- There are three identified needs that are essential for facilitating **optimal functioning-natural growth, integration, constructive social development and personal well-being:**

Self-Determination Theory (Grolnick, Deci & Ryan, 1997; Ryan & Deci, 2000)

These 3 needs are:

- The need for **relatedness**
- The need for **competence**
- The need for **autonomy**

A Self-Determination Management Approach to the Triadic Partnership



Relatedness: Laying the groundwork for competency and autonomy

- Relatedness can be thought of as the desire or need to have **positive, understanding relationships that will facilitate motivation and growth.**
- It is the starting point for self-determined functioning.

Relatedness with Parents

Amy: “My mom would tell me, to tell my audiologist my feelings, fear, difficulties that I was having.”

Craig: “They encouraged me to have one on one with the audiologist. I was more comfortable explaining concerns one–one. I found parents, up to a certain age tend to influence what is said in the exam room.

Relatedness with Parents

Craig: “They would often drop me off in front of the clinic to go into the appointment alone. They would then arrive at the end of the appointment and let me explain in front of the audiologist what the test results were. That made me feel like I was looking after myself.”

Reflections on Relatedness

With parents and other family members:

Craig: “It really helped that my grandparent wore hearing aids. We shared batteries sometimes, and talked about what we could hear with our hearing aids and what we could not. He told me about stuff that would happen that would make his hearing aids not work. That helped me out.”

Relatedness with Audiologist



Relatedness with Audiologist

Craig: "Start by forming a good relationship with the child. **Be interested in them, their hearing, and more important other things they like.** There is a fine line between encouragement and pressure. I wanted to feel some sense of normalacy – if not with my hearing, maybe with some other part of me."

Relatedness with Audiologist

Krystal: "A good "listening" ear and to inquire about how the student is doing in school – academically and socially."

Mikael: "Always tell the child what you are doing, try to establish rapport with child and parent to establish a high comfort level before beginning testing. Know the little details (what sports they play, subjects they like, sticker they chose the last time they were in) and involve child in conversations."

Relatedness with Audiologist

Doug: "Be less pushy about wearing the aid, I didn't want to wear it since I heard less well after taking it off and couldn't hear well with it in any case."

I think that it would be very good if Audiologists learned to listen to even young children. **I knew at 4 years old that my hearing aids weren't helping me, but I couldn't get myself heard.**

When they started Listening to my views, I began to feel as if the whole process was meant to help me, which simply was not the case early on."

Relatedness with Audiologist

Craig: "*Audiologists need* better listening skills, realize every child is different. I want a relationship that is built on respect."

Relatedness with Audiologist

- When I was a child, and met the audiologist for the first time, they would expect so much information from me. I did not know them, and they are asking me all these personal questions. They need to work on building a comfort level with the kid first, talk to them about something they like. **We are not robots programmed to give answers.** At the end of the appointments, it would be nice to have the audiologist review everything that went on during the appointment and make sure I understand what has happened. I did not like when the waiting room was full, I felt like I was being rushed out.

Relatedness with peers:

Mikael: "The FM system would always provide entertainment because the teachers would forget to take them off during a recess period or when someone was getting in trouble in the hall. During these times my classmates would huddle around me and ask me what was being said. **The FM system was always a cool thing, it helped me a lot, and made me the envy of most of my classmates;** they all wanted one so they could hear what was going on."

Reflections on Desire for Competency

Competency can be described as “a general desire to succeed in achievement-tasks and to perceive one’s own success”

- The process of active engagement to learn about oneself and the environment and therefore to **feel in control and successful.**

Reflections on Competency

Amy: “I wish my Audiologist would have equipped me with words/sayings to tell other children why I wear hearing aids.”

Reflections on Competency

Craig: “I felt like I had a right to understand what my level of hearing was. Thus, not understanding your hearing loss can really lead to other issues.”

“ I asked to be informed and asked for explanations for information given. My grandparents, who raised me also, encouraged me to take care of my own affairs and go into the exam room by myself and consult them after the examination.”

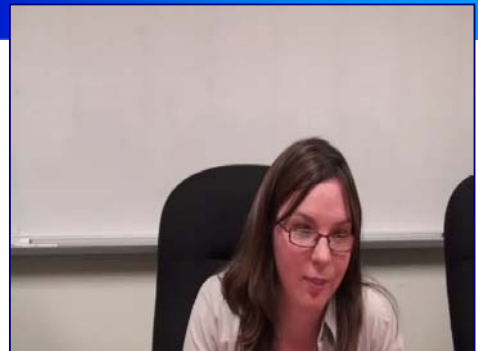
Reflections on Competency

Craig: “I would have liked the audiologist to review any information with me and together we came up with a plan. I think I would have felt like I had some control in making these decisions. Many times, it seemed no one cared about what I thought, that made me mad. I often did not want to go back and see the audiologist.”

Reflections on Competency

Mikael: “My first Audiologist was great...she told me that I was the expert and treated me very well. I think it is very important to empower a child as I remember feeling that I was different and not in control. Now that I’m older she empowered me to be comfortable with my hearing loss.”

Reflections on Competency



Reflections on Developing Autonomy

- Autonomy refers not to being independent or detached but rather to the feeling that **one is engaging in voluntary behaviour, regardless of whether or not the behaviour is dependant on others**

(Ryan & Deci, 2000).

Developing Autonomy

- Experiencing a sense of autonomy and choicefulness in one's actions is critical for people's optimal functioning.

Autonomy and Family Environment

- Autonomy is helped by a supportive, non-coercive family climate
- Parents' promotion of choicefulness has been shown to be a strong predictor of children's well-being, adherence to care and academic functioning (Grolnick, 2003; Grolnick, Ryan & Deci, 1991).

Autonomy

Craig: "I was more in control of the appointments and felt more independent. My grandmother would let me attend the appointments on my own. **She often placed the responsibility on me to tell her when something was wrong with my hearing aids.**"

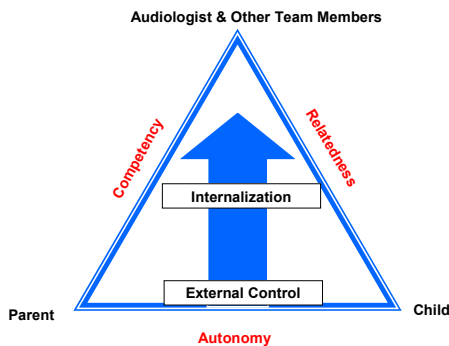
Autonomy

Craig: "The audiologist would look to me for involvement in decisions being made about my hearing. **I would like to be involved in the decision process of choosing a hearing aid. This would give me a sense of ownership and encourage me to take more responsibility for my hearing.**"

Autonomy

Kendra: "I discovered that I understand more about my own needs and sometimes the origins of my problems than my parents and, on occasion, audiologists. **I realized that when my instincts tell me some things, they are usually correct.**"

A Self-Determination Management Approach to the Triadic Partnership: Implications



In Conclusion

- “As young children make choices, indicate their preferences, problem solve, plan, initiate and succeed, they are making sense of the world around them in a way that can ultimately produce feelings of competence, confidence and empowerment.” (Erwin & Brown, 2003)

In Conclusion

- It is part of our job to assist them to grow up ready to succeed as competent, autonomous adults who know we're there when they need us.

In Conclusion

- Self determination theory is a dynamic framework in which the roles of all the players change over time.
- It is a framework that can be used throughout the life span of the professional relationship.
- It focuses on the child and natural development first – then on how to live with hearing loss

More Questions to Answer!

- Interview teens and older children and get a current snapshot of the triadic relationship today
- How does perceived stigma affect perceived self-wellness in the classroom?

Thank you