

# Loud & Clear!



A Cochlear Implant Rehabilitation Newsletter

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## REFLECTIONS ON COUNSELING: Families and Hearing Loss

by Carolyn Edwards

### Past to Present

Many of us began with a narrow perspective of counseling as an opportunity to share our valuable information with families of children who have or are considering a cochlear implant. We were the expert information sources and the clients had opportunities to ask questions. Such a model of counseling is not very satisfying since much of the families' emotional response to the diagnosis and management of the child is ignored in the process.

Yet changes are occurring in the field. Discussion of different aspects of counseling is emerging more and more frequently in our literature. While university programs continue to lag in training counseling skills (Crandell 1997), there is a new focus on counseling for professionals working in the field. Perhaps the focus is appropriate; it may be impossible at the training levels to assimilate both the content and the process of working with individuals. However for professionals working directly with families of children using cochlear implants, it is clear that the nature of our interaction is also



vital to the auditory management of these children.

In its broadest scope, counseling encompasses many possibilities: exchange of information, listening, sharing feelings, the vicarious learning from hearing others' experiences, support, co-empowerment, exploring alternate perspectives, revisiting old patterns, experimenting with new behaviors or completing unfinished business. ***Our willingness to move beyond information purveyors is dependent on our willingness to tolerate the unknown territory as readily as families have been forced into the unknown by virtue of having a child with hearing loss.***

# Attitude and Approach

## The Known or the Unknown

The phrase “I don’t know” is the very phrase by which we judge ourselves incompetent if it emerges out of our mouth early on in our careers and yet it is the mark of growth and maturity as a professional. The ability to set aside what we know and go into a meeting with a family or a child open to all possibilities cultivates receptivity to the issues presented. Knowledge that emerges *after* consideration of the issues is *responsive*; knowledge that occurs *before* all the issues are presented is *complacency and security*.

## Counseling as Exploration

While I can still find myself beginning a meeting with my desired outcomes for a child and family, the moment the conversation begins, the context of this child and family emerges and exploring can begin anew. While an explorer opens eyes and ears to all possibilities, he or she will still make assumptions based on past experience at each step. However the job of the explorer is to check every assumption as he or she proceeds.

I have experienced humbling moments where I discovered that a position that I advocated was actually not valid based on the specifics of the situation. In one case, I adamantly held that an open concept classroom should not be used, only to visit the school and find the noise levels were lower than in many closed classrooms. That particular school had incorporated many good teaching strategies and coordination of timetables to produce a highly desirable acoustic environment. That case taught me that **assumptions are only useful starting premises that must then be evaluated for each situation**. By also encouraging families to question their assumptions, you will support an open environment for decision making.

There are benefits and limitations to the exploration process. The upside is that you stay creative in the process of problem solving and you co-create solutions with the family that work for them. The downside is that you have to give up your attachment to a pre-

conceived outcome; you may not like the solutions or the family may not like your approach. It is important to be sensitive to the family’s responses through this process. Resistance at this stage may mean that the family needs more time to adjust to the changes in their lives; it may be too soon for them to make decisions.

# Communication

In the context of counseling, communication is the gauge by which two people measure each other’s self worth. (Satir 1988) It is the ability to clearly state requests, versus hinting or expecting the listener to mind read. Despite our focus on the words themselves, it is a surprising fact that our attitudes are conveyed primarily through facial expressions and volume, pitch and intonation of voice. The actual words themselves may be a small part of our communication.

## Whole Body Listening

Our first notion of listening comes from the physical: our two ears. In fact, our ability to listen is mediated by so much more than auditory recognition of the incoming input. We listen with our minds, our hearts and our shared humanity. The depth of our listening determines our ability to respond to another person. In each moment we determine what is required to respond - our minds, our hearts, our shared experiences. Listening is a measure of our humanness and our capacity to be touched by another human being. That



is our growth in our development in counseling. The depth of possibility in counseling increases as your relationship with a family lengthens and trust and rapport increases.

I remember a program planning meeting for a young boy with hearing impairment with the school staff and his father. His teacher was describing the various learning problems that the child was experiencing and the father interrupted to ask if we had seen his son's science project which was displayed in the library where we were meeting. He then described how well his son had done on this project. I was puzzled for a moment by the apparently unrelated comment. Then I wondered if he was feeling discouraged by the teacher's feedback so I asked him directly. He said yes; he also needed to hear the positive aspects of his son's progress in order to hear the concerns more easily. So we proceeded to speak about his son's strengths *and* the areas of concern and the father participated more readily in the conference. If I had simply responded to his comment about the science project, I would have missed his actual communication underneath his statement.

## To Listen or Not Listen

Listening with our complete attention is more difficult than one imagines. At one workshop I attended, the instructor asked everyone to listen to a partner for 25% of the time, 50% of the time, 75% of the time and finally 100% of the time. While the experiment was artificial, it did illuminate how often we may have another conversation going on in our heads about some unfinished business while listening to another person. Rather than attempt to force yourself to listen, your attention or lack of attention is a signal to



a change in the underlying dynamics of the communication. The point at which your attention wanes is often a useful clue to something that is being left unsaid by yourself or the other person.

It is important to bring your particular behaviour for stopping listening into awareness. I am now aware that when I have stopped listening, I lean back in my chair. With that awareness, as soon as I notice the physical behavior, I lean forward and re-engage in the conversation to find out what I am resisting. Each of us, professionals and clients, has our own particular characteristics associated with stopping listening. It is essential to become aware of ways you disconnect and to watch for those signs in the families or children you work with. For example, when families stop listening, they may be overwhelmed with information or with their emotions, they may disagree and be unwilling to voice their disagreement or they may agree and yet feel discouraged about carrying out the suggestions. Talking directly about the breakdown in communication

permits some possibility of support and alternative actions.

## Shock Points and Our Responsivity

We must be prepared for the shock points in our counseling and address those shock points directly. In the early years of my career, I was afraid of those moments so I passed on the information so quickly that I didn't have to acknowledge or deal with the impact on the family. I have seen many professionals whom I have supervised do the same. I remember going with my parents to visit my mother's oncologist for a final consultation on the outcome of the chemotherapy treatments my mother had been receiving. The physician indicated that no further treatments were possible. From that moment on, my parents heard nothing else and yet he continued to talk for fifteen more minutes. That was an unacknowledged shock point.

Our challenge is to present the issues clearly and concisely so that the parents or the child are able to confront challenges such as limited progress in listening skills, other learning difficulties, limited follow through in programming at school or home or limited success with the technology. ***When we skirt the issues or address them indirectly with the families, we are poor models and encourage the same indirect response from the families, with no resolution.***

## Content and Emotion

Providing information is a necessary part of our work to educate families in an area in which initially they have little or no information. Focussing on content can provide a safe beginning to build rapport and relationship between yourself and the family or the child.

However it is also important to notice if all of your sessions focus only on information management. Be sure to evaluate if the focus on content effectively contains or deflects expression of feelings on your part or the family. I have seen myself and other professionals use content as readily as our clients to avoid addressing feeling. That is the area of growth for all of us. When we model containment of feelings, we set a tone for our clients to do the same. If you have found yourself doing so, share that with the client and you may open the door to a deeper level of communication and sharing.

Often I will talk to clients about emotion as E - motion, energy-in- motion. When we allow our emotions to express themselves as pure energy, uninhibited, ultimately the energy changes and new sensations and desires emerge. One of our greatest fears is that if we allow an emotion such as sadness or anger to surface, it will never end. Paradoxically, it is because we do not allow ourselves to express that emotion that it continues on.

## Response to Change or Response-ability

Most of us as human beings do not invite change into our lives as a natural part of each day. The reality is that we fall into pattern and that pattern is comfort and security. We do anticipate some natural progression in our work or personal life but when unexpected events change the course of our lives, most of us resist that change at the outset. The way we resist change takes many forms. We can stay in denial or surprise, we can blame others or we can fight against the change. Resistance may

come in the form of delaying - give me more detail, flooding others with the details, intellectualizing, moralizing, OR impulsive action - everything is suddenly fine, I need a solution fast, verbally attacking others without warning OR sustained confusion or denying the impact (I'm not surprised). Over time, as we accept the changes that have occurred, we work to align ourselves with the changes and find a flow, and change becomes an ally rather than the initial enemy.

Listening to families' and children's responses is essential to determine where they are in the process of change. Resistance by families is the outward expression of fear: - I am afraid - of being vulnerable, of having to change, of losing control, of not knowing what to do, of being different and being rejected because of the difference...Each of us has our own fears based on our life experiences, and yet the underlying fear of the unknown is understood by all of us.

## Addressing Resistance

**When someone is resisting change, they cannot hear us and often they cannot hear themselves.** We may be aware or unaware of our resistance; we can feel the fear and don't know what it is. It is more effective to address the actual behaviour at the outset than the fear itself. For example, the behaviour may be the inability to attend the scheduled appointments, the lack of questions, the inability to follow through with agreements to work with the child, the desire to talk about the same concerns repeatedly or the child's rejection of support. The underlying fears will often emerge out of those discussions.

Often professionals have confided to me that they are afraid to speak and confront the obvious and yet the reality is that there is no other place to begin. "I notice that you don't want to attend sessions any longer. I feel frustrated because I'm not seeing any change in Emma's listening skills. What are you feeling?" or "When you stay silent and don't say anything, I feel alone in the planning and I wonder if we are on the right track." Notice that what is important is for professionals to risk speaking honestly about the impact of the family or child on themselves rather than avoidance or deflection to another topic. The former necessarily will create change while the latter will hold the status quo.

## Honor Resistance

Resistance is our response to the fear of loss of control or vulnerability. Chungliang Al Huang and Jerry Lynch in their book *Thinking Body, Dancing Mind* describe fear as a clue to assess the risk you are facing and prepare for it properly. They describe fear as a friend to acknowledge and embrace so that you can open to the knowledge that you need to in order to align with the changes. Those fears will emerge each time there is a transition - from one device to another, from pre-school to school entry, from third to fourth grade when reading skills are firmly established, from elementary to high school and so on.

Honor resistance when it arises. Resistance is a teacher for both professionals and families. Brooke Medicine Eagle (1991) once described how she made decisions - "If it's not a yes, it's a no." I have revised that for myself to say - "If it's not a yes, it's a no or I don't know yet." Said differently, when you are

hesitating or when you are refusing an option, honor that decision. It may be a signal that you need more time or more information or more support or more finances than you currently have. The degree of resistance on the part of professionals or families is a good barometer of the efficacy of intervention strategies. Resistance is usually a clue to slow down, listen more carefully and ask different questions.

### Paradoxical Theory of Change

*Only when you accept who you are is change possible. This is the paradoxical aspect of change (1987).* Otherwise you

are always trying to change to something new by rejecting who you currently are. When children with hearing loss want to feel their similarities to normal hearing children, they will not make the transition without first accepting their difference. Similarly parents of children with cochlear implants must come to accept their child as hearing impaired before any new possibilities can emerge with the advent of the cochlear implant. Otherwise the children will always feel a “less than” aspect of hearing impairment rather than the acceptance of the hearing loss, and hence the acceptance of them as a person.



## Co-Empowering Parents

### The First Meeting

There are a multitude of ways that we can co-empower parents beginning with the first meeting at the clinic or school. Even where we sit in the room sets a tone for separation or connection. Sitting behind a desk versus sitting beside the parents creates a different energy for your interactions. This is not to dictate positioning; it is only to say you will have to work harder to create rapport from behind a desk.

### The Cast of Thousands

I am often surprised how little attention is given to the location of the seats for the parents in clinical or school meetings, despite the fact that there are often between five and ten professionals in the room facing one or two parents. It is a daunting experience from the parents’ perspective; therefore we need to design the layout to create an empowering rather than a disempowering position for the parents. Choose where you would want to sit in the room to empower yourself and then give those seats to the parents.

### Parent Participation

Often at a review meeting, all of the clinical or school staff share their reports and the parents are asked to comment at the end. My recommendation to professionals is that they solicit the parents’ concerns before sharing their own. There is something

that changes the interaction when parents have the floor first; the professional then becomes a part of the team rather than the director. By hearing the parent first, you already can sense which issues are figural for them and that is telling in and of itself. If your issues are quite different, you may want to address the fact of difference at the outset and explore first how that came to be.

At one school meeting, one of the parents indicated that he had written a report on his child to present to the group as part of the process. How wonderful that he honored his own role in his child’s development to do so. Since that time, I have suggested a formal parent report as a possibility to other parents and staff. It is important to prepare parents for this role in advance so they have time to consider their response. We would never ask another professional to present a report at a meeting without prior notice; and the same must hold true for our parents.

### Multiple Viewing Points Offer Perspective

I often share the story of the three blind men, each touching an elephant at a different part of its body. Each of them perceived a different aspect of the elephant and none of them perceived the totality of the elephant. As professionals and parents, the same is true when we collaborate about a child. None of us can

see the complete child. It is important that we communicate our concerns to each other and that the group's recommendations incorporate our multiple viewing points in order to comprehensively address the child's needs. One plus one is more than two.

## Ways to Support Parents

Offering opportunities to learn through experience is an extension of the counseling process. Simulation of hearing loss using earplugs is one of the simplest and most effective ways for parents, extended family, school staff and classmates to experience firsthand the difficulties faced by children with hearing loss. Table 1 describes additional ways to support families during the diagnostic and programming phases of intervention.

## Co-Empowering Children

Children are appropriately the passive recipients of service in the preschool years. We provide them with the auditory devices, we teach others how to troubleshoot and take care of the devices and we engage the child in listening and language experiences. However it is possible to support the development of self advocacy skills from school entry, beginning in simple ways and becoming more sophisticated as the child is cognitively, linguistically and socially ready to do so.

Remember to discuss various suggestions with the parents and with school staff during the counseling sessions so that everyone is able to support the child's development of self worth and, ultimately, self advocacy.

## Making Choices

Children in the first few years of school are often not ready to speak up for their own needs. We can teach them how to make good choices for themselves by setting up two opposing choices, a good choice and a poor choice for a given situation. For example, you can ask them which seat in the circle would be better for them - the one beside the teacher or the one farthest away from the teacher. By showing them the difference, they will learn how to make an educated choice, and in later school years, be ready to advocate for their auditory needs.

## The Child as Expert

Often the educational audiologist or the teacher of the hearing impaired will do a class presentation about hearing loss and the child's cochlear implant. It is vital to set up the child as the expert on his or her device at the end of the presentation, rather than the professional. Then classmates can come to the child with more questions and the child can ask for support as needed. One day I had to leave the class before all the questions had been answered so I turned to the child with hearing loss and

Table 1: Ways to Support Families

SUPPORT	RATIONALE
Family observation of testing	Family has direct experience with testing so they can explain to other family and friends
Earplug or audio-tape simulation of hearing loss *	Family can develop some understanding of hearing loss from own experiences of simulation
Link to parent group or sibling group	Family can develop their own support with other parents
Link to grandparents group Direct discussion with extended family	Support parents when other family members are struggling with diagnosis or management
Link to another parent/child with similar issues	Parents can determine their own needs and issues learn from other parents
Link to school team	Parents become the contact for the school rather than the professional team
Determination of case manager	Parents can dialogue with one person who can coordinate what needs to be done
Support materials provided: <ul style="list-style-type: none"> <li>• Children's story books</li> <li>• Children's guide to hearing aids and cochlear implants</li> <li>• Teacher guide to hearing aids and cochlear implants</li> <li>• Earplugs</li> <li>• Handout on listening checks</li> <li>• Posters</li> </ul>	Parents can provide materials to school team, or to extended family members and friends
Multilingual materials offered	Parents have access to information in their own language or the language of their extended family

\*For a detailed outline of a simulation experience, see Edwards 1995.

said, “Ask Paulo, he’s the expert”. I left with all of the children happily chatting with Paulo who was feeling quite energized. I realized that I had been setting myself up as the expert when I did class presentations, unintentionally disempowering the child. In my desire to support the child by doing the presentation, I had forgotten the segue to the child, assuming that the child was willing to do so. I changed my approach from that day on. Watch for moments where you can put the responsibility back in the child’s hands.

When students with hearing loss enter high school, I have often asked them to draft an introductory letter to the guidance department stating the support services they wish to request. Drafting the letters serves as a good preparation for meeting with high school teachers, and encourages them to hone their discernment of their needs in preparation for self advocacy.

## Preparing the Child for Experiences

Having the child practice what are they going to tell their friends at school about their hearing loss or their cochlear implant can give them strong support and preparation for their school experiences. Note the issues raised by parents or children during counseling. Role playing is a very effective way for children to experiment with situations that are new or problematic for them and children may find new perspectives out of the experience. One child that I saw was in 7th grade and was refusing to wear his FM system. I invited his best friend in to talk with him and then I asked his best friend to play the student with hearing loss and the student with hearing loss to play his best friend. In the process of the

discussion that ensued in these roles, the child with hearing loss discovered that his friend just wanted to help him and was upset when he didn’t hear the teacher talking to him. He decided to start wearing his FM system again.

Involving children in the management decisions from the beginning is essential to their development of self advocacy skills. Pose questions to the student such as:

- Where do you want to check your amplification system?
- Who would you like to help you?
- When it is noisy how will you let me know?
- When you don’t understand, will you come up and ask me or
- Will you give me a code signal to let me know?

Such questions help children discern what they need to become part of the solution.

## Harriet the Spy / The Child as Investigator

For children who are denying the effects of their hearing loss, it is helpful to have them interview their friends or family. Through the process of questioning their friends, children often discover for the first time that others have been compensating for their inability to hear clearly.

When children are rejecting the use of an FM system in the classroom, I ask the teachers AND the children to fill out observation forms to describe classroom conditions and considerations for FM usage. With that information, the student can make that choice with myself and the teacher about strategies and options.

## Personal Growth and Development

Finally, ongoing self evaluation allows you to assess current skills and set new goals for your own development. Table 2 details different aspects of the counseling process that may be helpful in your evaluation.

Counseling is a lifelong development of character and skill. It is a continual evaluation of your capacity to listen, respond and co-empower others. As T.S. Eliot is often quoted, “We must not cease from exploration and the end of all exploring will be to arrive where we began and to know the place for the first time.” If we can hold that possibility in each counseling session, we will be present for parents and children and offer the creativity shaped by all the parents and children before them.

Table 2: Self Evaluation of Counseling Skills

To achieve:	Do I?
• Simplicity & clarity	Truly listen to client without jumping ahead
• Use of appropriate examples/metaphors	Demonstrate an ability to express own feelings
• Amount of information appropriate for client	Show sensitivity to client’s issues and timing
• Timing of information appropriate for client	Provide opportunities for clients to share feelings as well as content
• Awareness of the client’s emotional responses	Support client’s feelings
• Response to the client’s emotional response	Offer experiences for clients to develop more skills in stating own needs
• Accepting and naming client’s resistance	

For further information, the author recommends the following resources/websites:

1. Luterman, D. (1984), *Counseling the Communicatively Disordered and Their Families*, Little Brown and Co.: Boston, (A sensitive exploration of counseling that is relevant today as it was when it was first written).
2. Clark, J.G. and Martin, F. (1994), *Effective Counseling in Audiology; Perspectives and Practice*, Prentice Hall: New Jersey. (A collection of articles on various aspects of counseling in various populations and various settings).
3. Schneider, M. (1996), *Do You Hear Me? Laughs for the Hard of Hearing by the Hard of Hearing*, Thinking Publications: Wisconsin. (A collection of cartoon, jokes, stories that helped a hard of hearing adult cope with his hearing problems through humour).

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