



Cochlear Implant Success And Families: We Can't Do It Without You!

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An acquaintance says that parenting is like serving in the Peace Corps: "It's the toughest job you'll ever love." She was referring to her own experience with two normal-hearing children, yet the challenges of raising a child with special needs surely intensify that statement. Experience with families of profoundly-deaf children suggests that parenting these children really is the "toughest job you'll ever love."

Families are absolutely essential to the success of children with cochlear implants. In this issue, we explore the important contributions that parents make to fostering their child's development with the implant. We review the relationships that develop between parents and their child's clinicians, sometimes creating barriers to full family participation. When these barriers are crossed however, a powerful and unified team of family and professionals may be created to support the child with a cochlear implant. Specific suggestions are provided for involving families in meaningful ways in the complete cochlear implant experience.

Families are Essential to the Implant Experience

What are the unique circumstances of a cochlear implant that compel families to be at the center

of the intervention process? First, the majority of children receiving cochlear implants are under the age of five, and the average age at implantation is rapidly declining. It is widely recognized that intervention with young children is best carried out within the context of the family and that *the younger a child, the more critical a family-centered approach*. Public Law 97-457 (Education for handicapped children from Birth

improvement of a child's potential are listed along with a statement of the major outcomes.

Second, the cochlear implant is a *tool to enhance communication*. Deafness is a barrier to communication and the cochlear implant is viewed as a communication aid. Because communication is first established, later developed, and continually refined within the family setting, it is in the home and with family members that the true benefits of the implant may be realized. Parents typically understand their child better than anyone else and can also draw their child out to maximize communication.

Third, one of the extraordinary potential benefits of a cochlear implant is that *a child is no longer completely dependent on a teacher or therapist in order to learn*. Rather, many aspects of language can be learned incidentally, from the natural environment, in large part, the way that normal listeners learn spoken language (See Loud and Clear, Vol 1, Issue 1). This dictates that communication be a part of real-life conversations, descriptions, events, and family discussions. To limit communication to the learning that occurs in school or therapy is to underutilize the benefit that a cochlear implant can uniquely provide.

Table 1

The Most Important Decisions CI Parents will make:

1. To have high expectations for their child with a cochlear implant.
2. To give their child autonomy and responsibility.
3. To be confident in their own ability to parent their child who uses a cochlear implant.

(After Moeller & Condon, 1998)

to 3 years of age) mandates that young children have, not an Individualized Education Plan (IEP), but an *Individualized Family Service Plan (IFSP)*, highlighting the importance of the family in the intervention process. A multi-disciplinary team should assist in the development of the plan with the parents' participation. Family strengths and needs related to the

Potential Barriers Between Clinician and Families

It would seem intuitive that clinicians take full advantage of the benefits of families and the power that families have to aid in the progress of their implanted children. But do we? What are some of the barriers that prevent this from happening? One factor relates to the initial diagnosis and the approach that clinicians use with parents. Hersch and Amon¹ have identified four strategies that clinicians sometimes employ at the time of initial diagnosis of deafness. The strategies include: the "Hit and Run Approach," the "Minimize-the-Problem-Approach," the "Objective (Technical Jargon) Approach" and the "Action Oriented (Keep-Them-Busy) Approach". The characteristics of each strategy should be self-evident. These counter-productive strategies arise from the clinicians' lack of comfort or experience in dealing with parents during this very difficult time. As Matkin² notes, any one of these approaches to counseling may undermine the relationship of the audiologist with the parents and, in turn, may result in delays in intervention during critical

learning periods. Use of these strategies may put up the first barrier between clinician and parent, particularly if the parent looks back with anger or resentment at the way the clinician handled this difficult issue.

Matkin³ described some of the complexities of the relationship between a clinician and a parent of a deaf child. He notes that the clinician's desire to share information and educate the parents about hearing loss may, in fact, hinder the parent's ability to draw upon resources. If the clinician, Matkin explains, does something for parents that *they* need to learn to do, the clinician promotes dependence and inadvertently contributes to the parents' feelings of inadequacy. This may lead parents to abdicate certain aspects of parenting to a professional. (For example, "Our therapist disciplines my child so much better than I do; I can never get Sally to mind the way she does.")

Important Parental Decisions

The first actions parents take after a diagnosis of deafness are decisions: decisions about communication methodology, educational choices, amplification, to name a few. But, as Moeller and Condon⁴ point out, some of the most important decisions parents make may not be these technical ones, but rather: 1) The decision to have high expectations for the child; 2) The decision to give the child autonomy and responsibility and 3) The decision to be confident in their own ability to parent (See Table 1). The father of a recently-implanted CLARION two-year

old shared his concept that clinicians, as important as they are, should be thought of as *coaches* for the parents. This is an intriguing concept when one considers the role of a coach. Coaches teach and share expertise, give both positive and negative feedback, sometimes have to use tough love with their team, applaud and encourage, but *they don't actually play the game!* They are not out on the playing field winning, but rather cheering others on to victory from the sidelines. Isn't this, in fact, quite similar to the role of a therapist?

Suggestions for Involving Families in the Cochlear Implant Experience

1. Emphasize to prospective cochlear implant families that a cochlear implant represents "an opportunity, not a cure", as the team at Johns Hopkins has stated. The implant is a tool whose success requires all the support and commitment a family can muster.
2. Place families at the center of their child's communication learning process, not as bystanders but as active participants. Therapy should be family-centered whenever possible, with the parent attending and participating in activities. The ultimate goal of such sessions is to help the parents learn how to stimulate communication and incorporate listening into all aspects of their family life. Talented clinicians are able to include one or both parents in every therapy session with young children. The clinician demonstrates an activity, then



Table 2

Ten Probes from the Infant-Toddler Meaningful Auditory Integration Scale (IT-MAIS)
 Zimmerman-Phillips, Osberger, Robbins (1997)

1. Is your child's vocal behavior affected while wearing the hearing aid or cochlear implant?
2. Does your child produce well-formed syllables and syllable-sequences that are recognized as "speech"?
3. Does your child spontaneously respond to his/her name in quiet with auditory cues only?
4. Does your child spontaneously respond to his/her name in the presence of background noise with auditory cues only (i.e., no visual cues)?
5. Does your child spontaneously alert to environmental sounds (dog barking, telephone) in the home without being prompted to do so?
6. Does your child spontaneously alert to environmental sounds in new environments?
7. Does your child spontaneously RECOGNIZE auditory signals that are part of his/her everyday routine?
8. Does your child discriminate spontaneously between two speakers with auditory cues only?
9. Does your child spontaneously discriminate between speech and non-speech stimuli through listening alone?
10. Does your child spontaneously associate vocal tone (anger, excitement, anxiety) with its meaning, based on hearing alone?

quickly "passes the baton" to the parent, who continues the activity with the child. Once at home, parents can apply the principles of an activity but modify it to make it meaningful and appropriate for their child and family. As Simmons-Martin and Rossi⁵ point out, the goal of an early intervention program is not to tell parents how they "ought" to be. Rather it is to guide them in discovering how they can use their own potential to create a home environment that furthers the child's whole development and *that is also satisfying to them as parents.*

Remind families that the development of an effective communication system between themselves and their child is the single most important milestone to achieve. If a

family has chosen sign language as one of the components of their child's communication program, direct them to sign language materials and curricula that encourage family participation^{6,7,8}.

3. Involve parents in evaluating their child before and after implantation. The younger the child, the more critical the parent's role in assessment. With some instruction, parents can be taught to take an accurate spontaneous language sample at home, a technique still considered the most revealing diagnostic information for language assessment. Some evaluation tools, such as the Meaningful Auditory Integration Scale (MAIS)⁹ and Infant-Toddler Meaningful Auditory Integration Scale¹⁰ are scored via parent report

and therefore rely upon families to supply diagnostic information that will guide therapeutic management. Parents' responses to the ten probes on the IT-MAIS (see Table 2) might be used, along with other data, to determine device benefit, cochlear implant candidacy, effectiveness of communication mode, or educational placement. Clinicians who use such parent report scales note that, over time, many parents become extremely capable in observing and interpreting their children's auditory, speech and language behaviors.

4. Hook up families with other families of cochlear implant children. Some of the best advice parents receive may be from other parents who have been through the same experience. A parent of a more experienced CI child may have a solution to a problem that eludes the clinician. "Oh, we had that problem with our son, too. What we found that worked was....". It is comforting for parents to know that they are not alone in what they are going through, and that real-life, workable solutions are available. A cautionary note: Sharing information with other families is helpful. Dictating that one family's experience should mimic another's is unwise, as each child and each family's circumstances are different.
5. Evaluate the individual strengths of each family and help them see how their gifts can best benefit their child. Don't assume that only two-

- parent, middle income families have the resources to effectively raise a child with a profound hearing loss³. A father of one implanted child felt awkward doing language "lessons" at the table but was a marvelous carpenter. He and his 4-year old child created language experiences doing wood-working and tinkering activities in the garage.
6. Let parents know where you are headed in therapy or teaching both in the short and long terms. To convey a long-term view of auditory and language development, provide the parents with some readable resources that document the skills they are working toward. Being overwhelmed by too many small steps makes families myopic – without the therapists' knowledge of the broader scope of communication development, families may feel progress is slow or non-existent. For short-term progress, set a few definable goals and establish a short-term deadline, such as three months. At the end of that period, evaluate the child and with the help of the parents, decide whether the goals have been reached or not. The more clearly parents understand what the child is working toward, the more likely they are to address those skills and the more fairly they'll be able to judge whether the goals have been met. Be honest about a child's progress. Not reaching a goal should be viewed as an opportunity to choose more appropriate

strategies ("Okay, so we know that technique is not very helpful; let's try another strategy"), and not as a sign of the child's or parent's failure.

7. Use teaching and therapy approaches that contain a strong parent component, such as Koch¹¹, Estabrooks¹², Sindrey^{13,14}, or John Tracy Clinic¹⁵. These authors value family participation and convey in their written materials their confidence in parents' abilities to rise to the occasion for their children.

This sounds remarkably

The Parenting Facts of Life

1. There are NO perfect parents.
2. Mistakes are as much a part of parenting as kids.
3. The best parenting is done right now.
4. Parents aren't always popular.
5. Parenting is too important to be taken too seriously.

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similar to the approach we all use with our children. And so it is – with a few exceptions. One mother of a young child with a cochlear implant put it this way. She said, "Parenting a child with a cochlear implant is very much like parenting a normal-hearing child, except that the low moments are lower. "On the other hand", she quickly added, "the high moments are much higher!"

REFERENCES

1. Hersch, B. Amon, C. (1973). An approach to reporting the diagnosis of hearing loss to parents of a hearing-impaired child. Cited in J. Northern & M. Downs: *Hearing in Children* (pp. 167-170). Baltimore: Williams & Wilkins.
2. Matkin, ND. (1988). Key considerations in counseling parents of hearing-impaired children. *Seminars in Speech and Language*, Vol. 9, No.3, 209-222.

3. Matkin, ND. (1998). The Challenge of Providing Family-Centered Services. In Bess (Ed.), *Children with Hearing Impairment, Contemporary Trends*. Nashville: Vanderbilt Bill Wilkerson Center Press.

4. Moeller, MP, Condon, M. (1998). Family Matters: Making Sense of Complex Choices. In Bess (Ed.), *Children with Hearing Impairment, Contemporary Trends*. Nashville: Vanderbilt Bill Wilkerson Center Press.

5. Simmons-Martin, A, Rossi, KG. (1990). *Parents and Teachers: Partners in Language Development*. Washington, DC: A.G. Bell.

6. Gastason, G. *Beginning Level Curriculum Tapes* (SEE 2 signs). Modern Signs Press (800) 572-7332.

7. Stewart, D, Luetke-Stahlman, B. (1998). *The Signing Family*. Washington, DC: Gallaudet University Press.

8. Moeller, MP, Schick, B. *Sign with me: A Family sign language curriculum*. Omaha, NE: Boys Town Press.

9. Robbins, AM. (1998). Meaningful Auditory Integration Scale (MAIS). Indiana University School of Medicine. In Estabrooks (Ed.) *Cochlear Implants for Kids*. Washington, DC: A.G. Bell.

10. Zimmerman-Phillips, S, Osberger, MJ, Robbins, AM. (1998). Infant-Toddler Meaningful Auditory Integration Scale (IT-MAIS). Advanced Bionics Corporation. In Estabrooks (Ed.) *Cochlear Implants for Kids*. Washington, DC: A.G. Bell.

11. Koch, M. (1998). *Bringing Sound to Life: Principles and Practices of Cochlear Implant Rehabilitation*. Baltimore, MD: York Press.

12. Estabrooks, W. (1998). *Cochlear Implants for Kids*. Washington, DC: A.G. Bell.

13. Sindrey, D. (1997). *Listening Games for Littles*. London, Ontario: Wordplay Publications.

14. Sindrey, D. (1997). *Cochlear Implant Auditory Training Guidebook*. London, Ontario: Wordplay Publications.

15. *John Tracy Clinic Correspondence Course for Parents of Young Deaf Children*. John Tracy Clinic; Los Angeles, CA 90007. (800)522-4582.

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