

How to Obtain the Absolute Best Medical Outcomes for Children Using Oral Education

The goal of everything I write in these pages and at the website www.deafchildrenspeak.com is to help parents and professionals obtain the “absolute best medical outcome” for every deaf / HOH child. There are certain things that apply to every child going through the oral process. When all of these items are maximized to their full potential it becomes an extremely powerful habilitation plan to obtain the best results.

Just like every car needs the oil changed, every car needs the tires changed and every car needs frequent tune-ups, in my mind every child who is deaf / HOH can benefit from very specific guidelines and procedures.

The following are excerpts from Chapters 2, 4, and 7 of *A Father's Love*, which can be downloaded FREE OF CHARGE at the above website.

I am a father of a profoundly deaf child who in my opinion has obtained the absolute best medical outcome possible by following the guidelines and procedures listed below. This young girl can follow any open set question with no visual cues, is above age level in language, has perfect articulation, and has the ability to blend in with the hearing world with absolutely no one having any idea she is profoundly deaf. I am hoping for the best results for your child. In my opinion, that means the correct procedures must be followed from the very beginning. This is why most of my efforts are concentrated on the very young population of deaf / HOH children aged 24 months and younger. Do keep in mind that these guidelines will be beneficial for the next three to five years as you go through this language and audition journey with your young child.

The medical community has been trying to answer the question of “the best method” for years. Study after study after study is done to find out “the best way to teach deaf children.” If criteria such as audition, articulation, language abilities, hearing thresholds, and other items are taken into consideration, the procedures below are the answer to “the best method.” For families who choose oral speech, these methods only need to be followed.

The following list has worked wonders in our family. It may or may not be complete. But please look at this list and ask yourself what would happen if every single piece was in place to help your young child? This list is extremely powerful when maximized to its full potential. Above all put your entire heart and life into this process for the next three to five years and excellent results will follow.

- 1) For severe to profoundly deaf children, early cochlear implantation between the ages of eight and fifteen months of age. You need to have a very well qualified cochlear implant surgeon and pediatric audiologist on your team. This also raises the point of early diagnosis. If you even think your child is having a problem hearing please have a hearing test done earlier and not later.
- 2) A parent driven to give their child everything needed to succeed.
- 3) A parent who spends every waking hour learning more and more about language development and the oral habilitation process. This would include going to numerous conferences, reading numerous books, attending the speech therapy sessions, and talking to many parents and professionals.

- 4) A good auditory oral school or a program that resembles what the school would provide. Enroll your child as early as possible, preferably before twelve months of age. Most schools and Early Start programs will want to start parent education and formulate a program for a child as early as possible.
- 5) A school district /Early Start program which adheres to the IDEA law and can see that deaf children can learn normal speech and language. A district willing to fund four or more years of education. This could be as much as \$50,000 (based on 2006 dollars). A district willing to work with you and understand the vision that you have for your child. In a lot of circumstances all it takes is to let people see the success of other children who have gone down the oral path, and it may change a school district's / Early Start administrators' mind in regard to funding a particular program.
- 6) Never take one professional's opinion. Find out for yourself by asking numerous questions of numerous professionals and decide on your own gut feeling what is correct. (This author is available to help weigh the pros and cons of any of the numerous life-changing decisions in this process.)
- 7) Purchase the Ausplan book or a similar language development book and be in sync with the speech therapist. Reinforce all therapy in a natural setting at home. Know where your child is in acquiring normal language and know what the next step is. This ability to be able to track your child's progress and pinpoint where they are on the language hierarchy model is so crucially important. (If you do not know this you cannot spend the numerous hours needed at home to reinforce what is being taught in the speech therapy sessions.)
- 8) About two to three years into this process provide a mixture of oral training and mainstream classes. Provide your child with age appropriate language models including fully hearing children to converse with.
- 9) Get your deaf child around as many hearing children as possible. Enroll your child in numerous preschool classes to help with their auditory skills, such as music, art, playgroups, etc. Their language and social skills will be enhanced by being around other children. Young normal hearing children are such great language and speech models. Some auditory oral programs even make it a point to have a full-time hearing student in the classroom to help model and facilitate language.
- 10) Be thankful, pleasant, and truly appreciative of everything every professional is doing for your child. Buy gifts, give cards, and let these people know they are helping change your child's life for the better. These talented individuals are giving your son or daughter the gift of speech that no one can ever take away. Show your appreciation.
- 11) Have a family support network of at least one grandparent, brother, sister, uncle, or aunt who is dedicated to this process for the four years it will take. This means driving your child to school, the therapists, the doctors, and babysitting as needed. For a single parent or a married couple to put in the time and effort needed in this process is very difficult. This is why one additional truly dedicated family member is so very important.
- 12) Do your homework and take every IFSP / IEP meeting seriously. Know the IDEA law and put a positive spin on why the local school district / Early Start program should fund three to four years of oral education for your deaf child. It is so vitally important to consult with professionals who have gone through numerous IFSP / IEP meetings and understand the IDEA law. Using the right terminology and constructing your arguments in a manner that is backed up by the IDEA is

so very important. Make the process cost-effective for the school district.

- 13) Flextime for one parent. To have a job which gives you the ability to go to the speech therapy sessions, the doctor appointments, the IFSP / IEP meetings and truly be involved in your child's habilitation plan. Trying to go through this process with a boss counting every single minute you need to take off to be with your child just does not work well. You need a boss who wants to help you help your child and give you a flexible schedule. The exact verbiage of how to ask for flextime is listed in Chapter 2 of "A Father's Love."

You as the parent are in the driver's seat. You must make the right decisions at the right time for the absolute best outcome for your child. This may seem odd, with numerous professionals who have years and years of experience dealing with deaf children. But in the beginning you will be a baby needing to be fed information. As time goes on you must be a lion who knows what they want and goes after it. You are the quarterback with a team of professionals all working toward the best outcome for your child. It is your responsibility to make sure that every professional is in sync with needed information and that these people talk to each other and the team work seamlessly for your deaf / HOH child.

Things the Parents Need to Do at Home

The following is what is needed in the beginning of the oral process to help your child speak. You will learn what needs to take place at home to give your deaf child the best possible outcome. Like you, I wanted my daughter to order her own food, ask for directions, converse on the phone, and have a "normal" social life. I did not want her to be secluded to the 1% of society who knows ASL. I wanted her to converse articulately with the 99% of society who use spoken language.

The very first thing that you need is a good quality oral program for your child. Do not let the school district / Early Start program decide for you. You have the right to a private oral school which the school district will pay for if they do not have an "appropriate" program in place. You can locate most of the oral schools in the U.S. at www.oraldeafed.org Call this organization and request some of their excellent videotapes / DVDs, which have amazing cochlear implanted children who speak nearly perfectly. If you are not close to a school, find a good auditory oral / verbal therapist in your area. In addition to going to an auditory oral school and therapy, you need to do the following at home every day with your deaf child to facilitate speech.

- 1) Point out every sound, i.e., the phone rings and you say "I hear that, that is the phone" and point to your ear. If she is eating, say "You are eating apples," etc. Everything, all the time, narrate what your child is doing and what they are playing with. "You are playing with Elmo, Elmo is red." Narrate what you are doing. "Look, Mommy is cooking. I take the pan and put it on the stove..." Repeat the words dozens and dozens of times throughout the day. Whether it be the phone, door, birds, car, vacuum cleaner. Whatever the sound is, point to your ear and say "I hear that, that is the _____."

Keep in mind that children need to learn to listen before they can speak. This goes back to proper therapy. A lot of time needs to be spent on listening before they can graduate to spoken language.

- 2) Cut out ALL background noise as much as possible. I love music and used to listen to music every day. Over the past four years I have drastically reduced how much the stereo is on because of the competing background noise. You need to make a few sacrifices in this area and divide the day into two distinctive parts: the time you work with your child, and the time you watch TV, listen to music, vacuum, etc. If the family has the TV on 24 / 7 in the background you must make a sacrifice in this area so you can have quality "quiet" time with your child. Have the washing

machine and dishwasher going when you are away from home or the same time you watch TV. Make everything a quality listening experience.

- 3) If there are other children in your family have these children play with your deaf child as much as possible. These hearing children will provide an age-appropriate language model that your child can learn from. Let them play games, talk about games, talk about the weather, fight, yell, and do all the things young children do. Don't sit there and have all your children glued to the TV set. The more quality speaking your child gets from siblings will really benefit their language development. Television is good if used properly to play age-appropriate language-rich DVDs and videotapes.

It is very important that our children be in play groups and other social events with hearing children. Try to have your child around hearing children as much as possible. This will help with speech and language.

- 4) Speak to your child all the time. Again, look directly at their face so they can see your mouth. Explain everything to them. Be within 3 - 4 feet when speaking and just talk, talk, talk, in English. This is what these kids need—a huge input of quality language so they can record everything in their auditory memory. Your therapist will be working on auditory-only exercises and you will soon be able to speak with your young child with no visual cues at all. When the time is right the language will come out and just keep flowing out.
- 5) I would be cautious about using any sign language. The problem is kids will use this as a crutch. The philosophy in oral training is to force our children to use their voice. To let them know that their voice has meaning. Let them know when they do use their voice that you understand, and always reward them with a huge amount of praise for using their voice.

The process is to give oral speech a chance before any signing is introduced. Some people will call signing a “bridge” to help facilitate oral speech. This may be true with some children but in general, I do not agree with signing. To take a child who has been implanted at or before 12 months of age and put them into a TC (Total Communication) or signing program in my opinion is medically wrong unless that child has other severe medical issues.

You may have professionals steer you into signing in the very beginning when you do not know better. BE CAUTIOUS. I would only encourage this if you want your child to know sign language with the possibility of their audition and articulation suffering. I would rather be the master of one modality than mediocre at two languages. The key here is that perfect spoken language and excellent audition is what we are concentrating on.

- 6) Keep names simple, one name for each item. Many items have numerous synonyms, but choose one name for each item. Stick with it until they fully understand that name. (A pair of shoes is SHOES, not sandals, boots, slippers, tennis shoes, etc. They are all shoes for the first six months. Same with plates, cups, etc.)

Make a list of 40 - 50 items and write down one name for each item and have the entire family use this one name. As time progresses and your child understands more, you can move onto the next synonym. Speak only one language to your child for the first three years post-implant. Do not confuse these children with a second language. In our case and because we do live in the United States, English is our primary language, Spanish our secondary language. These children can be excellent bilingual speakers but the exact mix needs to be researched. I did not want my daughter to be the test case of when to start a second language. There needs to be more research done on this particular subject; please check with your therapist.

We introduced Spanish at three years post-implant and went through the same hierarchy of language that was learned with English. One word and one name at a time. Overhearing conversation and having the opportunity to give input in a second language is also good. In our case I stick strongly to the three-year rule and would encourage others to do the same.

Full contextual language is very important also, and the key is to build a strong vocabulary and receptive language abilities with the parent and therapist explaining things in full context.

- 7) Play proper language-rich video tapes and DVDs. Let your child play with educational auditory toys that require good listening skills. These toys will ask a question and then your deaf child will need to make an appropriate response. Read every night if possible. Play children's music CDs / tapes in the car, sing songs, and talk, talk, talk.
- 8) Turn on the implant or hearing aids within 30 minutes after your child wakes up. Keep them on all day long. Check the implant / hearing aids daily to make sure they are working properly. Know how these devices function and know how to troubleshoot and fix any problem that may arise. In general when it comes to cochlear implants they have a 10-year warranty on the surgically implanted device and three years on the external components. Listen to the microphone, make sure it is on the correct program, make sure the batteries are fully charged, and check for proper function every day. Check all wires for crimps, shorts, etc. Once a week use a Dry and Store dehumidifier unless you live in a humid climate, which may require use more often. Check with the manufacturer for proper care and maintenance.
- 9) Make sure your child has an appropriate program to learn oral speech and that the teaching environment has qualified professionals. Make sure the acoustics will accommodate learning with a noise-free classroom.
- 10) On weekends get out and explore the world. Go for a hike, a walk, go to the zoo, the grocery store, even around your neighborhood. Look at every item, explain what it is and give it a name. Make a fun game out of it even if you have other children—explain that we are building the vocabulary of our young deaf / HOH child. Not too much too fast, but just the right pace so your child can absorb every word and phrase.

The first five years of a child's life are so crucial for proper language development. These things cannot wait and you just can't start too early. As I did with my life and my daughter, this is a one-shot deal. I can set four to five years of my life aside and concentrate on my daughter because I have lived my life, I am an adult. What's four or five years to me? Nothing. But for my daughter it is the most important time in her entire life. What is done now will shape her language forever. There will be a day in the next two to three years that you do not have to work as hard, you can relax because your child will be caught up with other children their age and you can treat them like a regular kid. It is not like this sacrifice has to be forever, just a few years. This author is willing to help with any advice or questions you may have.

Keep faith that your child will speak and listen and it will all pay off. Just ask me, it is a miracle all the things that our daughter can now do.

Must Have Language Tools

Here are a few must-have items that will help any child develop language.

- 1) Baby Einstein Video / DVDs. (Good language learning videos that children can watch.)

- 2) Videotapes of your child's oral training therapies. Kids love to see themselves on TV. They can watch and learn over and over again.
- 3) LeapFrog Oral Language Toys and DVDs. (Buy toys that your child can learn from, not just take up time. These toys ask questions and need a response. Explain everything when playing together.) The DVDs will explain letters, phonetics and even simple math when your child gets a little bit older.
- 4) Picture books with clear colorful pictures. (So you can point to each picture and name it.)
- 5) The Ausplan book, this is a must-have book provided by Children's Hospital Oakland's Audiology department (510-428-3885). This book goes through every step of language development for cochlear-implanted children. You will refer to this book over the next three to five years and know exactly where your child is and what the next step will be in their habilitation process. You will be in sync with the speech therapists and most importantly you will be able to know where your child is on the speech, language, and audition hierarchies.

These are the steps that a parent needs to take to give their child the best opportunity for success. You are in the driver's seat, and at times, you may be in a position to need to disagree with the professional recommendations for treatment. You will feel confident that your viewpoint has merit because it has been researched and you have data to back it up. Keep in mind that an excellent working relationship with all parties concerned is so very important.

Do not be the one who sits back and is removed from this process. We all have jobs to do, families to care for, and homes to take care of. Ideally both mother and father should have similar knowledge in this process so they can talk about and bounce ideas and questions off each other.

In addition to the preceding list, you will need an experienced cochlear implant surgeon who has operated on hundreds of other children. If the experience is not there then demand a new surgeon. Do not be afraid to ask your doctor, "How many of these cases have you done? How many cochlear implant surgeries have you performed? What is the end result that you have experienced from other patients in this particular situation?" Definitely do not be rude or sound as if you know any more than they do. You need always to be gracious and polite. You will be dealing with the doctors and the other professionals for the next three to five years so do not get going on the wrong foot. Just be clear with what you want for your child. "I want my child to hear and speak very well. I have spoken to parents who have children that speak and hear great, and I want the same for my child. I will do whatever it takes to make this happen. We are committed as a family." When your doctor or caregiver hears this they know you are on board. And believe it or not, you are one of the very special parents that really, really cares about the process and is committed to work with these fine people. They will bend over backwards for you as long as they know you are on board and you always show your sincere appreciation for what they do.

You also need an experienced pediatric audiologist who has diagnosed and mapped numerous children with their implants. Again do not be afraid to demand a different person if the experience is not present. Ask other people for referrals. In a lot of circumstances the audiologist is set up by the surgery center or sometimes the surgeon is recommended by the audiologist. Talk to other parents and find out what they think about a particular doctor or audiologist. Keep in mind you need a pediatric audiologist who has a great deal of experience with cochlear-implanted children, not a general practitioner.

Last but not least is how to pay for all of this fabulous care that your young son or daughter will be receiving. (This subject is covered more extensively in Chapter 7 of my book.) Here are my thoughts and experience in this area:

Most funding that you will need for the education of your child will be obtained from the text within the IDEA law. Please purchase a good book which covers the IDEA / IFSP / IEP process such as the Nolo Press series. The goals for your child and the services provided will be agreed upon at each IFSP / IEP meeting. Know what you want before each meeting, have professionals with you and be ready to back up every point as needed. Make oral education cost-effective for the folks holding the funding dollars. Our children can in many circumstances be mainstreamed by kindergarten or first grade with very little ongoing support. This is different from an ASL-taught child, who may need interpretive services throughout their school years and even into college.

Use the legal resource team at the Let Them Hear Foundation www.letthemhear.org to help fight any insurance denial for an implant. If you are forced to pay cash for any procedure, demand the same rate that the insurance company would pay the doctor. In many cases this could be 40% to 50% less than what they will charge a cash-paying customer. Ease the doctor's mind by having cashier's check(s) made out to each party and give these checks to the appropriate parties on or before the day of the uncovered procedure.

Put your entire life into this process for the next three to five years, look seriously at these guidelines, and know that educating yourself is one of the most important things in this entire process.

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