

# A Father's Love

Teaching a Deaf Child to  
Hear and Speak...

Perfectly

By James Hall

This book is dedicated to my daughter.

“You are my Angel who brightens  
every day of my life.”

Gabriella,  
I Love You

## About the Author

Mr. Hall has spent the last four years on a journey that was full of unanswered questions. He turned over every stone and spent countless hours of research to find out how a deaf child could acquire speech. Mr. Hall is the father of a five-year-old girl who was diagnosed as being profoundly deaf at twelve months of age.

By working with numerous professionals, becoming an expert in language development, insurance, the IDEA law and the IEP process, he persevered with one goal in mind, perfect speech for his deaf child. By always knowing the next step in this process and building a reference library of essential books, Mr. Hall has been called “a highly educated parent” in cochlear implants and language development by numerous licensed therapists and educators.

It is with great pleasure that this author can bring the detailed step by step process that resulted in a “cure” for his child.

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## Introduction

This book is written at the end of a journey that for me never really had an end. Four years of my life and my family's life have been dedicated to the outcome of our little girl. Little did we know that our daughter had a future and an outcome that no one could have predicted. Going through this process of teaching a deaf child to listen and speak was a task that I never imagined myself taking. Never did I imagine that a deaf child could communicate so effectively and have a completely "normal" life. It does not come easy. The biggest and most important questions will eat at you day and night until you find the "right" answers.

I have for years wanted to help families save themselves from the endless unanswered questions and endless anxiety and doubt that comes along with teaching a deaf child to speak. When you are just a parent and have no formal training in speech acquisition the questions are endless, and the decisions you make as a parent will affect your child for the rest of their life. EVERY decision has to be correct. Every decision will either help or hurt your child. You CANNOT make a mistake. There is no time to change it.

This book is written from my own personal experience; that is all I can offer. The education I have received spending the last four years going through this process is exactly what this book explains. The target audience are parents of newly diagnosed children, or children who have been diagnosed in the last few years. If your child was diagnosed four or five years ago, this book may give you some great information, but the ages I am concentrating on are newborn to six-years-old.

I consider myself a self-taught expert on the subjects of cochlear implantation and language development. I do not have a medical degree or a formal education in these subjects. I am a parent who has spent the last four years of my life learning everything possible on these subjects. Going to numerous seminars, spending endless hours with my daughter's teachers, and attending two hundred-and-fifty therapy sessions has given me a great deal of knowledge and understanding of language development. I have spoken to numerous doctors, speech pathologists, audiologists, and even the cochlear implant companies' head engineer who designs these miracle devices.

For the past four years Gabriella has attended one of the best schools in the country on language development. She also has the backing of one of the best surgery centers around. The main surgeon at this center has implanted hundreds of children, even children as young as six months old. The relationship between her school, the surgery center and our family is seamless and the education is priceless. I have read numerous books and found the "right" answers to every question I had. What does the "right answer" mean? There will be many opinions from various highly respected professionals, but what is the "right" answer? I did not want opinions; I wanted answers.

In the beginning, I wanted someone to sit me down and tell me how my daughter can learn to speak from A to Z. I wanted to know the different options of what was available, and the pros and cons of each. I never received this step-by-step information, so I needed to find out for myself. In this process there will be a whole lot of questions. I have done the research and have been down this path so I am hoping this book can answer many of the questions that may be going through your mind. My goal is that this book becomes a road map to help parents give their children the language and speech that we

all desire, the ability to break down a world of silence. So what about the title *A Father's Love*? This is what happens when you dedicate your life to the outcome of your child and are drawn into the deep emotional bond that gets even stronger as you go through this process. A bond that develops when you look into your child's eyes and pray that one day they will speak and hear. A Father's Love is putting your entire life on hold and making every decision in your life based on your child's needs. There will be other jobs, other houses, other cars, other vacations, and the opportunity to make more money in the future, but now and only now is the time to change a deaf child's life. There are no second chances, there is no room for mistakes. Take it seriously.

Even though I am a father and I have a beautiful little girl, this book is written for fathers and mothers. It is also written for grandparents, aunts, uncles, and any person who is a caregiver for a deaf child learning spoken language. This book is written for the couple who looks into the eyes of their deaf child and says: I want my child to speak, I want my deaf child to hear. I will give everything I have to make this happen and nothing will stand in the way. I am here to help you. The couple who needs the new car, the promotion, the new house, or the new clothes before putting their child's needs first, I probably cannot help. As parents let's help our children reach for the stars and use their beautiful voices. Let's look at what these very talented children can do and let's give them the tools to succeed.

A Father's Love is what happens when you look at your child and pray that they will one day speak - one day hear the birds, one day appreciate the sound of running water, music, and of course, speech. There is an unstoppable emotional bond that happens between you and your child when you give everything you possibly have for the next three to five years, telling yourself that no matter what the outcome is I will love my child just the same. A Father's Love is dedicating every minute of your free time to becoming "the expert" in language development and cochlear implantation that you need to be. The professionals cannot educate you like you need to educate yourself. Don't misunderstand me - there is no way our daughter could have reached the heights she has reached if it were not for some of the most caring, loving and professional experts in this field. The problem is that case loads are large and time is limited. A 20-minute appointment or a forty-five-minute therapy session should be spent on your child, not your education.

After about 12 months I felt pretty empowered by my knowledge of spoken language and cochlear implantation. This did not alleviate the need to ask many questions, but the questioning was at a level that would move my family and my daughter to the next step in this process. The basics were far behind me. If you are going through this process and leaving everything in the hands of "professionals" or in the school district's hands and you really do not know what is going on, there is a BIG problem. Please seriously ask yourself how knowledgeable are you in this process? Do you really know the next step and terminology of your child's language journey?

Looking at what information to include in this book, I sat down and looked from the parents' perspective and included everything needed from the very first day of diagnosis until that child is reciting full stories. With this said, I would like to explain the contents of the following chapters in this very special book.

Chapter 1 explains in detail the emotional setback and feelings after you have received the devastating news that your child is deaf. The question to be answered is what to do next? This will explain the very

next step after you have gotten up, brushed yourself off, and are ready to face the world to help your deaf child.

Chapter 2 explains what parents need to do to take responsibility in their child's life. What sacrifices need to be made to give your deaf child the absolute best chance of success in oral speech and language.

Chapter 3 explains how a cochlear implant works, and the difference between cochlear implants and hearing aids. Also this chapter explains the benefits of early implantation and bilateral implants. This chapter goes into detail of how to decide if an implant is the right choice for your child.

Chapter 4 explains what to do in an overview format. This chapter goes into detail of what programs and resources are needed to give your child the absolute best chance of great oral speech. This is a checklist of everything needed to go down this wonderful language journey.

Chapter 5 explains the different parts of language that every parent needs to know. Yes, speech pathologists specialize in the fine details of language, but in order to be in complete control of your child's future you must know their strong points and their weak points. You also need to know the correct terminology and how to help your child in every area that is weak. This chapter is crucial to get exactly what you need in your IFSP / IEP meetings.

Chapter 6 explains "The Plan." This is a step-by-step real-world account of every service that our daughter Gabriella received over a four-year period to obtain perfect speech and language. This chapter goes into detail of how Gabriella went from hearing nothing to hearing absolutely everything. Because this is based on four years of services I feel this could be the perfect roadmap to help any deaf child obtain excellent speech and language.

Chapter 7 answers the questions of who will pay for the \$40,000 - \$80,000 of cochlear implant surgeries? Who will pay for the \$50,000 of speech and language services if your child needs to go to a private school? Discussion of the IDEA law and the IFSP process will give you great information and rights that need to be known. The insurance companies need to realize that YOUR child deserves and needs an implant. Many secrets of the insurance industry are given.

Chapter 8 explains in detail the medical history of our daughter. It explains exactly when she had her first hearing test, her first implant, her medical condition, etc. This will give you a basis of knowing where your child stands from a strictly medical viewpoint.

Chapter 9 is a listing of numerous websites, books and organizations that need to be contacted. This is a detailed list of every organization ready, willing, and able to help your child speak. Please look at this list and contact every company on it.



# Chapter 1

## The Diagnosis

The audiologist walked into the room and said “please sit down.” She then turned to us and said: “I am sorry to tell you, but your daughter is profoundly deaf.” (The tears burst out and the very first question started right here.) My wife said “What?” The audiologist answered, “Well what this means is that after testing across all frequencies, Gabriella cannot hear anything better than 90 decibels.” (Then question #2.) “Will she ever be able to speak?” (Question #3 is right around the corner and the questions never end for at least three years.)

“Mr. and Mrs. Hall, here is what we need to do. I will order the strongest hearing aids made, plus I am giving you the number of a surgeon who specializes in cochlear implants. Oh by the way, the hearing aids probably are not covered by your insurance plan and they run about \$2,500. Make an appointment with my secretary in a week and we will fit your daughter. I am sorry and have a nice afternoon.”

Walking out of the hospital the entire world looked different. Everything just stopped. Every sound meant more, every word was precious. We looked in our daughter’s eyes and after suspecting it for over three months it was confirmed, she could not hear a word we were saying. Our little one was just twelve months old. Mentally I went down a thought process of how will we ever communicate with our daughter? How will she ever speak to anyone? What type of job will she hold? Will she need our help for the rest of her life? Will she need an interpreter forever? How will she communicate her most personal thoughts to the hearing world? How will she ask for help? Will she feel lonely, isolated, alone? All these questions came up just on the short 20-minute drive home. Then the big question came... What do we do now?

## The Next Step

Before even thinking about what to do next, the overwhelming feelings of helplessness and sadness were in our hearts for days. Putting our little girl in her crib at night we prayed for a miracle. A miracle that the doctors were wrong, the hearing test was incorrect, that she would wake up in the morning and be able to hear perfectly. This all must be a big mistake. What have we done wrong? This is our one and only little girl. We would pray that Gabriella could hear the birds singing, the leaves rustling under her feet, the sound of a nursery rhyme. Little did we know that miracles do happen, but sometimes not as quickly as one would like. Our miracle took four years to materialize. This book will describe in detail the journey and the procedures that my wife and I went through to help our daughter hear and speak as well as any normal hearing child. You as parents have the ability to do the same. The motivation needs to be in place, the services need to be in place, the expertise needs to be in place, and most importantly, never doubt what these very special children can do.

In most families one partner is overwhelmed with grief and the other partner just wants to find the answers to “fix the problem.” Don’t misunderstand me, grief and anxiety were everyday feelings, but the helplessness of not knowing what to do was even worse. Since I am a man and the provider for the family we could not both fall into an emotional trap and do nothing. Our daughter was relying on us and asking us to provide the absolute best medical care, the best technology and support available. Not every

family has the resources to provide “the best.” I understand that, but parent support and parental training will fill the gaps, and always throughout this book, this author is willing to help any way possible. Our children deserve it.

A few days later the phone call was made to the cochlear implant surgeon. “Well, Mr. Hall we can fit you in on the 25<sup>th</sup> of October.” But that is three weeks from now, isn’t there anything sooner? “I am sorry, the doctor is completely booked.” The phone was hung up and a feeling of uncertainty and helplessness came over me. Looking at my daughter I thought: don’t these people understand, I can’t wait three weeks, Gabriella needs help now. What will I do for the next three weeks, there are too many unanswered questions going through my head everyday. Is this a bad dream? How will we ever pay for any of this? The phone book came out and looking under “speech pathologists” and “deaf education,” we made numerous calls. Then the realization came that one of the first calls needed to be to our local school district’s special education department.

Every child with a hearing loss falls under the IDEA (Individual Disability Education Act.) Deafness is a disability that will have you working very closely with the special education department of your local school district. I cannot stress enough that a good working relationship with the school district is crucial for your child’s success. Some districts understand that deaf children can learn oral language and speak very, very well and other districts will push TC (Total Communication), ASL (American Sign Language), and other modalities because they are just ill-informed or very cash-strapped.

If your school district is not working with you and time is slipping away, then move to a new district. Put your house up for rent and move. Time is crucial; you cannot waste your child’s future spending months and months fighting the district. Demand that your child be an oral speaker with no TC and no sign language. You also need experts who understand the oral process for deaf children.

There are two main modalities, auditory oral and auditory verbal. This book and our experience is with the auditory oral process. The auditory verbal process is also a very good methodology but in our case we “fell into” a school who taught auditory oral. Both modalities have the backing of case law, the IDEA, and the Federal Government. (Yes, get educated quickly; you must become an expert and an advocate for your child.) Within the Individuals with Disabilities Act is the IFSP (Individual Family Service Plan) and the IEP (Individualized Education Program) procedures. In general these are formal agreements between the parents of a deaf child and the local school district on how to provide an appropriate education to the student. In this case your deaf son or daughter. The IFSP process covers ages 0 – 3 years and the IEP process covers ages 3 – 21 years. IFSP meetings are held every six months and IEP meetings are held every year. You can request additional meetings if needed. No matter whom you are receiving services from, check with other professionals to get their opinion on anything that you may be missing or overlooking that your child may need. Yes, having money is very helpful in this process but even the poorest families can provide the needed services their child requires if they are diligent, educated on the process, treat people with respect, and read this entire book. Why do I say treat people with respect? There is no way Gabriella could have reached the heights she has reached if we did not have numerous people who really wanted to help us and our daughter. By treating people right and going out of your way to help the professionals they will go out of their way to help you and your child.

## **Tell Them that You Love Them**

Rarely are professionals told how much their work is appreciated. Rarely are they invited to a child's birthday party, given a Christmas present, or given a hug. They will put you and your child in a whole different class of other parents who just want and want and expect everything from the school district. You will learn that these people are changing your child's life. They are helping your child speak and hear. If you do not have the professionals on your side you have absolutely NOTHING. We are trying to get from point A (deafness and sign language) to point B (a fully hearing, speaking, and functioning child). In the middle are numerous professionals, speech therapists, doctors, audiologists, and special education personnel. It is your job to be in the driver's seat and know exactly what your child needs. Get advice from every professional and then make the best decision possible.

When there is a great relationship formed with your "team members," as they are called, you will feel comfortable asking pointed questions and fully understanding the responses. Again you must get educated on the process and fully understand the next step in normal language acquisition. Our children follow the same exact path to acquire language that a hearing child does. The only difference is our children are given a lot of help emphasizing everything in this process. A hearing child may learn words from just overhearing those words in normal conversation. Our children must be told that word hundreds of times until they make the association. Please do not fool yourself and think that by putting one or two cochlear implants in your child they will pick up everything naturally and learn clear spoken language. You must know how spoken language is acquired and how to work with your child every day to help them acquire that language. Please refer to the resource section for one of the best books in my opinion, written on language acquisition.

In the resource section there are websites, books and companies that will help you. Learn a little from everyone and I cannot stress enough that you as the parent must make decisions that may contradict what the medical community or experts are telling you. I could fill an entire chapter in regard to taking numerous opinions from numerous people and then deciding what was best for our daughter. Most people who have no formal medical training at all would feel very uncomfortable doing something different than what an expert is telling them. But you will soon find out that three experts may very well have three different opinions. You as the parent must be knowledgeable enough to take these opinions, make sense of them, and make the right decision.

There are excellent books on the IFSP / IEP process, books on language development and books on cochlear implants. (You must start a reference library and have the needed information to face the battles and questions which lie ahead.)

As mentioned earlier, the IFSP covers ages 0 – 3 years and is written every six months. The IEP covers ages 3 – 21 and is written every twelve months. These documents are usually 5 – 20 pages long and cover many subjects in direct relationship to your child's progress and future goals. The goal of all parties concerned is to get a deaf child to enter a mainstream classroom as early as possible so that the child can learn in the same manner as their hearing peers. This helps the school district because there will be one less "special ed" child who costs a lot more to educate than a general population student.

This author is willing to show any school district the abilities of a cochlear implanted child and the perfect language a deaf child can master with the right training. This is not a battle; it is a matter of educating the people who have the ability to change your child's life forever.

Our goal was to have Gabriella attend a mainstream kindergarten with no additional help at all. Yes, a sound field or FM system may be needed but additional services or interpreters would not be needed at all. The school district seems to be very pleased with this compared to the years of help needed for other deaf children using Total Communication or American Sign Language.

Even though money cannot be a deciding factor in the IFSP / IEP process, all school districts must adhere to the bottom line. If you are not getting a satisfactory response from your district, then the fair hearing process may be your only option. Keep in mind that this parent does not want to drain the school districts' resources. I want to help all children. I want all deaf children to go through primary school and college with no support from anyone. This is a cost savings for the school district, the parents, and the federal government. Everyone wins.

## Chapter 2

### The Parents' Role

This chapter concentrates on the parents' role in this process. What parents need to do to take their child from hearing nothing to hearing everything. The following information concentrates on what my wife and I did with our child and what I feel is a perfect habilitation plan for any deaf child.

Let me start with myself. I am the type of person who hates opinions, I only want facts. My whole viewpoint in this entire process was to find the best way to educate my daughter based on people's past experience and medical research. To me if medical studies are done and results are derived this is pretty factual information. This is what I wanted. Unfortunately it just was not clear-cut; opinions seemed to dominate fact. (With this said, Gabriella has been part of various medical studies to help advance the question of the "best" way to educate deaf children.)

I have an occupation which has allowed me a lot of flex time to care for my daughter. I feel for any parent who has a 9 to 5 job with a boss who just does not understand. Yes there is the Family Leave Act which gives you three to six months off, but this habilitation process will take between three and five years. If you have a "regular" job with a boss watching your every move, you must sit your boss down and explain the following.

"Mr. Boss, I love working here, I really enjoy my job and my company, but something has come up in my personal life that I must tell you. My newborn daughter is completely deaf. The good news is that there is hope and a way to teach her normal speech and hearing. I am asking for your support. Through a four-year process deaf children can learn to hear and speak normally. Without this four-year process, my daughter will never hear or speak normally. Can you help me? I am asking for flex time over the next four years. I will still work 40 hours per week, I will put absolutely everything I have into my working hours. I will not let you down. You have the ability to give my deaf child excellent speech, can you please help me? Can you give me flex time?"

If the management says no to your request, submit your resignation letter the next morning. Write a well-drafted heart wrenching letter that lets the company know that they are heartless. (Keep in mind you may need a reference from this company so just show your displeasure with their decision, do not make personal attacks on any individual.) They may even reconsider their decision. Keep in mind that you are bigger than this, you are stronger than this, you will succeed, nothing will stop you from providing what your child needs.

I will emphasize again that one parent needs flexibility in their schedule to go to doctor appointments, meet with the school district, watch their child's therapy sessions, etc. Unfortunately our society is not set up to accommodate these issues with long-term rehabilitation. We live in an all-or-nothing society that will give you a month or two off or absolutely nothing. But to have a flexible schedule over three to four years is what you need to make this process work perfectly. It is like a jigsaw puzzle, putting every piece together to give your child the absolute best chance to succeed. Here is a macro view of what is needed to have every piece in place for the utmost probability of success:

- 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 represents 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. (The following chapters will go into detail about the type(s) of program needed.)
- 5) A school district which adheres to the IDEA law and can see that deaf children can learn normal speech and language. A district willing to fund four years of education. This could be as much as \$50,000 (based on 2007 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 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 three years into this process provide a mixture of oral training and mainstream classes to give your child language models and 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 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.

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 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 uses spoken language.

The very first thing that you need is a good quality oral program for your child. Do not let the school district 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](http://www.oraldeafed.org) Call this organization and request some of their excellent videotapes / DVDs, which have amazing cochlear implanted children who speak near perfectly. If you are not close to a school, find a good auditory oral / verbal therapist in your area.

The first few months after activation is just dedicated to learning to listen with the implant. These kids need to make sense of what they are hearing and it is our job to point everything out. Hearing children "listen" for 12 months before their first words come out and our children are no different. The first step

is sound awareness and step two is sound discrimination, which will come after the first few months. Do not put the cart before the horse. Give your child plenty of time to listen before you expect any speech. This is the difference between a therapist who has experience with cochlear implanted children and one who does not. There needs to be a lot of time spent on listening, and the therapist needs to fully understand the hierarchy of oral language for implanted children.

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. Then when the time is right it will come out and just keep flowing out until they are talking in full sentences.

- 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 them 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. Use signing as an absolute last resort. Some people will call signing a “bridge” to help facilitate oral speech, I do not agree. 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. You will have professionals steer you in this direction 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 oral speech and articulation suffering. I rather be the master of one modality then mediocre at two languages. The key here is that perfect spoken language 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.

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.

- 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 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, check for proper function every day. Check all wires for any 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.

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 done forever, just a few years. This author is willing to help with any advice or questions you may have.

It really made me upset in the beginning when I asked three people their opinion of what to do and they all said something different. So I set out to find on my own what was best for my daughter. We as parents must be the driving force in this process, not the teacher or school, but us. I hated it when people would look at me and say "You need to do what you feel is right for your child, every child is different." I thought "Damn it you're the professional, why don't you know what to do?"

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 below 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. (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.)
- 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. 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.

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 up your point of view. 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.

## Chapter 3

### How a Cochlear Implant Works

Miracle, that is all I can say. This device has revolutionized the way deaf children hear. With this in mind, the following pages will discuss hearing loss, the workings of cochlear implants, and the differences between implants and hearing aids. Cochlear implants have been approved for use in adults since 1988 and children since 1990. Most people do not understand how cochlear implants work and the great hearing these devices can provide deaf children.

### Hearing Loss

You may have heard the term sensorineural hearing loss in the doctor's office but not really know how it affects your child. This type of hearing loss is one that damages the tiny hair cells in the cochlea. Since the hair cells are damaged, it does not allow the electrical impulses to reach the hearing nerve. In general, the physical parts of the ear are in working order, such as the bones, eardrum, and other membranes, but the hair cells are damaged in the cochlea. The hearing nerve itself in most cases is in good working order, but everything stops at the cochlea because of the damaged hair cells.

A conductive hearing loss on the other hand is one where the physical aspects of the ear are damaged. The tiny hair cells work fine, and in general this type of loss can be corrected in a lot of circumstances with surgery.

Cochlear implants have been around for over twenty years. It was not until the electronic age that the programming and sophistication of these devices came to a point that children who are profoundly deaf can now hear whispers and respond to open set commands at levels as low as 15 - 20 dB. These devices, with the addition of the right oral program and dedicated parents, are an absolute miracle. To start with, we should get a good understanding of the audiogram and "speech banana" that many audiologists refer to. Because you are the informed parent, when a professional asks you how well does your child hear? Do not say "oh they were diagnosed as having a severe hearing loss" or "I am not sure, you can talk to the audiologist." The answer needs to be: "Johnny can hear between 70dB – 80dB in the low frequencies and 85dB – 100 dB in the higher frequencies unaided. With hearing aids he is between 40dB – 60dB across all frequencies. I will get the audiologist's report to you."

The audiogram is marked in decibels (dB) and Hertz (Hz). The graph plots out from 0 dB (the softest sound) to 110 dB (the loudest sound). The frequencies range from 125 Hz (the lowest pitched sound) to 8000 Hz, (the highest pitched sound). So a child with a 70 dB loss cannot hear anything quieter than 70 dB. Our speech, or the speech banana as it is called, ranges from about 15 – 50 dB. So in this case the child with the 70 dB loss cannot hear any speech at all. A child with a 40 dB loss is missing out on a great deal of speech and will most likely have a hard time following conversations in an auditory-only manner.

There are very helpful charts and diagrams which give you a visual picture of the speech banana and what devices make different decibel and frequency levels, e.g.: lawn mowers, birds, pianos, speech, jet engines, etc. Please ask your audiologist for this or print a copy from the internet.

## **Cochlear Implants**

Cochlear implants are designed to help with sensorineural hearing loss at levels which are generally severe to profound on the audiogram. If your child's level is less than severe or a combination of moderate / severe, a hybrid cochlear implant may help. Cochlear implant devices have three main parts which consist of the internal device, the microphone, and the sound processing unit.

The internal device is surgically implanted under the skin in a shallow pocket the surgeon makes in the child's skull. Then the electrode array is fed inside the cochlea, "wrapping" around the hearing nerve. These devices are generally encased in titanium for durability. The internal device is theoretically supposed to last a lifetime and never needs to be replaced. If the device is replaced the surgery is called an X-Plant and in most circumstances the child will hear as if they have a brand new implant. In reality there is a very small failure rate and technology is always changing so these are things to take into consideration. The microphone "picks up" audible sound and transfers it to the speech processor where it is turned into electrical information. This information is then transferred to the internal device via a headset and magnet. This electrical information is then transferred to the internal electrode array to stimulate the hearing nerve directly. This is a replica of what thousands of tiny hair cells do in a hearing person's cochlea.

There are numerous mapping strategies that your audiologist can use on the external device. Most implants have up to four programs available and every electrode can be set to stimulate as much or as little as needed. The program is always checked by taking the child into the sound booth and testing all frequencies and sound levels. As mentioned before, speech recognition and discrimination is possible at 15dB – 20 dB with these miraculous devices. To translate this into real sound, I can whisper at an extremely low level and my daughter can discriminate any word presented to her with no visual cues. Keep in mind that you cannot just put these devices on and think your child is cured. It takes years of speech therapy and a formal habilitation process in the auditory oral or auditory verbal manner to achieve this with a deaf child.

## **Hearing Aids**

Hearing aids are generally used with people who have mild to severe hearing loss. As the cochlear implant completely bypasses the damaged portion(s) of the deaf person's ear and stimulates the nerve directly, a hearing aid in essence makes the volume much louder and feeds that volume through the damaged ear. Hearing aids have their purpose in certain circumstances. The key with either device is to have the child hear the entire speech banana with clarity. I cannot emphasize enough that once a child is diagnosed as being deaf or hard of hearing, the hearing aids must go on immediately even if they will receive a cochlear implant in the next few months.

Today there are top of the line digital hearing aids that can be programmed and sound very good to the recipient. Hearing aids need ear molds and can "feed back," which to me always presented a problem. With this in mind purchase the best aids you can afford. Do not short change yourself or your child with inferior hearing aids. If your child does receive a cochlear implant, donate the hearing aids to your audiologist or charity of your choice. Take the tax write-off and feel good that you are helping a child

hear who may not be able to afford a pair of hearing aids. In our circumstance the hearing aids were a temporary fix until the cochlear implant surgery date. With this said, every sound a child hears will go into their auditory memory for future recall, so give your child the benefit of sound as early as possible.

Let's talk a little bit about how the brain hears and stores information. The auditory memory as it is described by many professionals is a function of the brain that stores auditory sound. The child must hear numerous sounds, words, phrases, etc, the more the better. Just keep feeding it in. (Feed in information and words in a systematic way following the natural progression of speech. This is why the correct books on language development are so important). Receptive hearing comes before expressive speech, and a child will be able to follow simple directions before they are even able to speak their first word. As mentioned in future chapters, it is crucial that the speech therapist and program you are in take a lot of time on listening and following auditory commands before anyone even expects one word from your deaf child.

After the sounds, words, and phrases are fed in for months, then when a child hears a sound such as a door and replies "door" you know you are on the path to a speaking child. The brain stores everything auditory in the "auditory memory," clear sounds and words in, clear sounds and words out. This is why I am such a strong advocate of cochlear implants because the clarity that the child receives is phenomenal. Doctors will tell you "If your child is getting good benefit from the hearing aid(s) continue to use them." What does good benefit mean? In a lot of circumstances good benefit could mean that your child is hearing at 30dB – 40dB. Is this sufficient? To me the answer is no. I want my child to hear at 15dB with the absolute clearest sound possible.

## **Bilateral Cochlear Implants**

Bilateral cochlear implants are more prevalent today than they were in 2004 when our daughter received her second implant. Personally I could not stand the fact that my daughter had one good ear and another ear that could only hear 45 - 50 dB across most frequencies. With the second ear only hearing 45 - 50 dB with a hearing aid on, I had no idea if this was helping or hurting the clarity of sound to her brain. I was born with two working ears, I love music, and enjoy hearing everything around me 360 degrees. I wanted the same for my deaf child.

In our case we were denied a second implant by our insurance carrier. I did not understand. Doesn't it make good medical sense to have two good working ears? In the appeals process with the insurance company, there were ten people sitting in a room, not one was an audiologist, ENT or surgeon, they were all MD's and administrative people. This was my opportunity to explain why my daughter needed two implants. They would say things like "One cochlear implant is all that is needed to acquire speech." (This is an absolutely true statement.) I then asked these people to cover one of their ears while I was speaking, and then I would ask if it is just as clear as hearing with two ears? They would say, "Oh no, but the standard of care is for one implant." A few days later a form letter would come which stated we were denied for bilateral implants. Sometimes fighting the system works and sometimes it does not, but always try. (The Let Them Hear Foundation has a legal resource team that can help FREE of charge in this particular circumstance. We were not fortunate enough to have their expertise available in our case.) We ended up paying cash for the second implant. Today things are different, and many insurance companies cover both implants and there is case law that now backs up bilateral implants.

So there we were all insurance appeals exhausted and I would look at my daughter, look at her audiograms, and it was very clear to me that the cochlear-implanted ear could hear much much better than the other ear with the hearing aid. So the questions became, Keep the hearing aid on or take it off? Is it helping or hurting her hear? After speaking to numerous people, all I wanted in the end were two ears that could hear equally well. So on November 5, 2004, Gabriella received her second cochlear implant.

Keep in mind that the second implant had very little to do with her ability to gain speech. Children can gain excellent speech with just one implant. The reasons went much deeper. Studies have shown that bilateral implants help in noisy environments; they help with localization of sounds and word recognition. My reasoning followed the fact that when Gabriella gets to the age of riding a bicycle or driving a car, I want her to hear where the cars are coming from. When a dog barks I want her to know where the dog is so she won't be scared. I want her to appreciate the full range of sounds all around her 360 degrees.

Gabriella received her second implant 11 months after her first implant. By altering her auditory oral therapies and taking a methodical approach to teaching her new ear to listen, both ears could hear identically well within four months. The process of how to work with a newly implanted ear must be dealt with by a therapist who has experience in this area. Do not leave it up to trial and error to someone who does not know how to do this. There are many factors to take into consideration such as how long is the time between implants, how well the new ear is hearing, and how much auditory stimulation that ear has had in the past.

In our case, Gabriella had a hearing aid on her second ear from the time she was diagnosed to the day she had her surgery. Out of a fifty-minute therapy session, our therapist would work with the new ear for twenty-five minutes and then the old ear for twenty-five minutes. We would leave just the new implant on her ear for one hour every evening. The rest of the time she had both implants on. When you fully understand the hierarchy of receptive and expressive language and fully understand the steps that every child takes to acquire speech, you will see that the newly implanted ear needs to "catch up" with the old ear for both to hear the same. (The hierarchy of receptive and expressive language will be explained in greater detail in future chapters.)

Many children these days are getting both implants in their initial surgery, which to me makes a lot of sense. It is more cost-effective, there is no alteration in the habilitation process, and they get great sound in both ears at a very young age. I would strongly recommend having both implants put in during one surgery if your medical team feels it is appropriate.

These days children as young as seven months of age are receiving cochlear implants. This is not the norm but our surgical team has performed these types of operations on young babies. Again, this is a very medically oriented question to answer, when your child should be implanted. The sooner the better as long as your doctor feels that your child is healthy, strong, and ready. My personal opinion leans towards 11 – 14 months of age. Again, I am not a doctor but any later than this they may fall behind in their language skills.

The question of whether a hearing aid helps or hurts their listening in the un-implanted ear is one that to me is still unanswered. It is true that the auditory nerve needs to be stimulated to keep it healthy and vibrant, but what about the hearing? I just did not want to put any more thought to it so two implants was the decision our family made.

### **Care and Maintenance**

Ever since Gabriella had her first implant we have been very careful about protecting her from falls and electromagnet static that could damage the internal device. As hard as we tried, she still is a very young child and young children do fall. Running in the house “bang” against the door jamb on the implanted side, our hearts would drop. Walking on the sidewalk and she trips over her feet and falls to the ground. Once she even fell off the bed. She must have fell or hit her implanted ear at least six or seven times. Every time we tested her at home to make sure her hearing was still OK. Each time we felt like inadequate parents, but, kids will be kids. Thankfully these devices are very strong and no damage occurred. My advice is just to be very conscious to protect your child from hitting their head. As children get older and walk better, falling down will happen less frequently and sometimes even never.

The external devices need care and maintenance too. Just like a car, if you never change the oil or never change the spark plugs it will stop running or sound very strange. The external devices need to be checked daily that all cords are in good working order and that the batteries are fully charged. Weekly, make sure that the microphone is working properly. Use a dehumidifier as recommended for your geographic area. Read your care and maintenance section of the owner’s manual and call the manufacturer or your audiologist with any questions. Quality sound 24 / 7 is what we are after.

### **Assisted Listening Devices**

Because our daughter was implanted early she did not need any assisted listening devices such as a telecoil, FM system, or a loop in the movie theater. She hears fantastic with just her implants. We are confident that she will never need a captioner, interpreter, or any additional help to make it through her school years and life, just her two implants. Currently she is using a sound field system in her kindergarten class and I would recommend this in the first few years of school or even possibly an FM system. There will be an age when the child can tell you what they need. The miracle of the cochlear implant is that they will need very, very little as time goes on.

Keep in mind that I am talking about our child, and every child is different, but do not get too concerned about all the talk from “professionals” about assisted listening devices, interpreters, etc. Again, this is all based on age of implantation and an excellent oral program. In our case Gabriella wore hearing aids beginning at 10 months of age, which really helped, and she received her first implant at 14 months of age. The important thing is to get what your child needs to hear the absolute best no matter what it is.

### **Cochlear Implant Manufacturers**

There are two main companies that make cochlear implants, Cochlear Corporation and Advanced Bionics. There are a few smaller companies but these are the two leaders and have the largest market share in this field. Our daughter uses the Cochlear Corporation device and all of my experience revolves



around this implant system. I am very familiar with the Advanced Bionics product and have seen numerous children do very well with them.

It is strongly suggested to research these devices, go to seminars, talk to parents, call the manufacturer, and review their websites and literature before your child's surgery. Honestly, I was so busy doing other things such as dealing with insurance companies, hearing aids, doctors, etc, that I really didn't put any thought into which device to use. I felt whatever the surgeon recommended should be fine. In reality both devices are excellent. The companies will tell you that there is a difference between the two, and I am sure there is, but most surgeons feel that you can not go wrong using either device. Do your research and then talk to the doctor doing the surgery and ask what they prefer and why. As I mentioned before, this conversation with the doctor will mean nothing unless you have a basis to understand what they are going to tell you. Be the informed parent.

### **The Surgery and Mapping**

The implant surgery takes about two to three hours to perform. Most experienced surgeons will tell you on the scale of things that it is a minor surgery that is not very difficult. (At least this is what our surgery center tells us, which is one of the best in the country!) Your child is put to sleep and for young children they spend the night in the hospital. For older children and young adults they actually go home after the surgery. Personally, I would prefer my child stay in the hospital to be monitored and cared for until the next morning. After a few weeks and the healing process is complete, you will go to the audiologist for the mapping session.

The mapping session is the moment of truth and can be a very emotional time. This will tell you the success of the implant surgery and how many electrodes are functioning correctly. The audiologist hooks your child to a computer system, and on the screen each electrode comes up. The audiologist can adjust the sound level on every electrode until the mix is perfect and your child hears properly. Initially the detection of sound is all that anyone is really looking for. The audiologist will stare at her computer screen and talk to the assistant, while you sit and pray. Electrode #1 a little more stimulation, a little more stimulation, then... your child's head turns rapidly and the audiologist says good. Yes your child has detected sound in that electrode. This process is repeated numerous times until every electrode is mapped. Your child can hear and the tears of joy start to flow. Usually there is a series of about three mapping sessions in a two- to three-week period, with the volume increasing each time.

This is just the start of the habilitation journey. Every deaf child needs to be in a good language program to acquire speech, the younger the better. Children as young as six months of age and younger can enroll in an auditory oral / verbal program. If you have not done so already, this is where you become the expert and find the absolute best program for your child's situation. You must work with the school district, insurance company, the program director(s), and many other people to find the right program. (In our case we went to an auditory oral school, which I highly recommend. Our school also had a strong emphasis on auditory-only listening and cognitive skills.) I cannot encourage you enough to read this entire book and talk with parents who have success stories in oral language about their child. The correct oral program for your child is in my opinion the most important factor on whether a deaf child gains good quality speech or not.

## Chapter 4

### What to Do

Helping parents find their way through the maze of choices and opinions in this process has always been my desire. By helping parents make the right decisions, I know the children will benefit with good quality medical care, schooling, and speech. Forthcoming is some of the most important information and detailed description of what to do with a deaf child who ultimately wants to speak and communicate just like his hearing peers. As you will hear a hundred times from numerous people, “every child is different and there is no guarantee.” All you can do is try your best and provide exactly what your child needs.

Everything written in this book comes from my own personal experience with my daughter over the past four years. This is just one father’s experience of this incredible journey of speech and language. (Notice I did not say “one father’s opinion” because everything written is a fact and is what actually happened.)

My experience revolves around the auditory oral process and the 100% oral approach. Gabriella was diagnosed as having a moderate hearing loss at ten months of age, and profoundly deaf at twelve months of age. She had her first cochlear implant at 14 months of age, and her second implant at 25 months of age. We worked with the local school district’s special education department immediately after diagnosis. They could only offer a Total Communication program and after doing research we found The Jean Weingarten Peninsula Oral School for the Deaf, which is a non profit auditory oral school. Gabriella started at this school at eleven months of age and graduated in June 2007, a total of four school years. Because school years are only nine months long this was a total of 36 school months.

### Looking, Listening, Speaking

After the joy of delivering a perfectly normal baby, full-term, we knew nothing could go wrong at this point. The doctors ran all the tests and mother and baby were doing great! A young man hooked our baby daughter up to a machine and after hemming and hawing for a few minutes and having problems getting one ear to pass the newborn hearing screening test, he finally said she passed. We were overwhelmed with joy! At this point, I do not know if this young gentleman misdiagnosed our daughter or not, but I am thankful that many states do require this test for all newborn children.

Coming home from the hospital was a precious experience. There we were with this beautiful newborn little girl. All she wanted to do was cry and drink milk. A few months went by and then the hands and legs started moving in and out somewhat at their own rhythm, and I was wondering is this normal? Out came the infant guide book and this was a normal reaction of the muscles in the baby’s body. I didn’t know because I have never been around a newborn for any period of time, I was a new father!

With every little thing that happened we had to talk to another parent, the nurse, or even read about it. We were going down this road of being parents totally blind because this was our first child. Most of our friends had children five to fifteen years old. They were good to talk to about general things but the day-to-day specifics we left to the advice from the nurse at our local hospital.

After about seven months I would notice that Gabriella's eyes would follow most everything but she seemed somewhat tuned out when it came to sound. She did react to sound, but not on a consistent basis. Having nothing to compare it to we read the infant guidebook again and asked her pediatrician. "How do you check for the senses, sight, smell, hearing, etc." The pediatrician replied "Oh your baby is fine I can see she is looking around, she responds to touch on her body, everything looks fine to me." "But what about the fact she is not cooing and making noises like the book explained to us." The doctor replied, "Different children speak at different times and your daughter looks fine, now go home and have a good afternoon." We heard the same thing from two different pediatricians who basically said "don't worry everything is fine." Two more months went by and we had a scheduled vacation planned. In my mind I said OK, let's go on vacation, we will come back and if my mind has not changed about our daughter's hearing I will march into the doctor's office and demand a hearing test.

Vacation was wonderful, we had a great time. After being at home for about a week we had another appointment scheduled with the pediatrician. This time I had my list of concerns in my hand and after getting past the initial examination I turned to the doctor and said, "I feel Gabriella needs a hearing test because of..." The doctor agreed and off we went to the Audiology Department. Ten-month -old children cannot readily tell you "Oh I hear that, but I did not hear that." They are more difficult to examine and obtain a good audiogram from because they cannot tell you what they hear. The testing must be done by a qualified pediatric audiologist, someone who has tested and diagnosed numerous infants previously. If a person of such caliber is not doing the testing, demand to be referred to a hospital specializing in children. One wrong diagnosis at this point could be devastating to your infant's long-term progress.

Behavioral response testing is what is used with young children. Sounds are presented and the experienced audiologist looks to see if the child reacts to the sound. Whatever the diagnosis, please get it confirmed with another test and another audiologist. So there you are with the testing results. Now the next step is to get sound to your child with the absolute best hearing aids that are made. Emotionally the entire world is crumbling around you, your precious little child has a hearing problem and you know this leads to numerous other problems throughout life. Why you? Why your little child? No one can ever answer this question. All you can do is work with the cards that life has dealt you and move forward. The moral of this story is to stay alert, question doctors' opinions when they do not correspond with your gut feeling, work with experienced professionals, and demand, don't ask, for the best care for your child.

Early diagnosis is the key to great speech. I know there are people reading this section who may have received their child's diagnosis at 24 or 36 months of age for whatever reason. Do not worry. There is nothing you can do to change that. What you can do is to put everything you possible have into the next three to four years and help your child communicate. As I said earlier I know adults who are profoundly deaf and have only been using hearing aids their entire life and they have great speech. The reason why is hard work, and very little reliance on sign language. This book lays out the best case scenario and what to do from my own personal experience. In my opinion we have been blessed with a number of factors that really helped our child: a school district who believed in our vision of oral speech; a loving grandmother who cared for our child when we could not; an excellent auditory oral school; and one of the best surgery centers in the entire U.S.

This is easy to say when you live in a large metropolitan area that has these facilities. I know there are many places in this great country that have very few facilities to help deaf children acquire great speech. The knowledge in this book and hard choices on your part will make the difference in your child's life. Don't forget what I said, to sacrifice for the next three to five years will change a deaf child's life forever. This methodology of great oral speech is a sacrifice for us parents. Children given the proper care and training can accomplish anything. Just ask me because I see it every day with my daughter. It amazes me to this day that I can be driving my car, looking straight ahead at the road, and carry on a substantive conversation with my deaf daughter who has perfect articulation and syntax.

### **A Checklist to Follow**

I am going to list everything that should be in place to help your child obtain great speech. Keep in mind that you may not be able to obtain 100% of what is listed, but the more the better. When I was going through this process with my daughter I never had a checklist to follow. I never had any type of roadmap. I went on my gut feeling and thankfully the choices were correct. Speaking with many professionals, going to conferences, and discussing our situation with other parents really made the difference in the decisions that were made to help our daughter. In reality I had no idea of how well our daughter would hear, how clearly she would speak, no idea of how well she would articulate words. I just wanted her to have the ability to communicate with the world around her. Four years later I can tell you that perfect hearing and speech are possible. As parents we must educate numerous "professionals" throughout this process that perfect hearing and speech is the goal and the end result that everyone must be working toward. Self-reliance so a deaf child does not need to rely on anyone to communicate is what all the hard work and money is for.

Early diagnosis and early implantation are the keys. Implantation at or around twelve months of age is ideal. (If your surgeon suggests sooner, definitely consider the recommendation.) If your child has been implanted later just move forward. There is nothing you can do but give them everything else in the following list. Here in the San Francisco Bay area some doctors are implanting as young as seven months of age. This is something that really needs to be discussed with your surgeon. The California Ear Institute in Palo Alto and San Ramon, California, is one of the most experienced surgery centers in this area. I would highly recommend contacting them.

A great relationship with your school district's special education / early intervention department is a must. A lot of children are served by their local school districts and sometimes if other medical issues present themselves they will be served by a regional center. We have experience with our school district and really do not have any experience with our regional center. Both entities fall within the Early Start program for 0 – 3 year-olds. So your services can start from day one. There are time lines that they must follow to move things along quickly. You should be aware of the time lines and know what your rights are. Again, I must emphasize, do not sound like a lawyer! If the time line says 30 days and they need to take 40 days for some reason be flexible as long as they are moving things forward and you are getting services in place.

Your child needs to be in an excellent auditory oral program that emphasizes listening and auditory-only responses. (Look for the OPTION Schools web site in the resource section.) Children can attend such a program as young as six months of age. With the correct program in place there are months spent on

listening and responding via facial cues and then as time progresses absolutely no visual cues at all. The child will be given a choice of three animals and the word or sound will be presented and they will react appropriately. This is so important: listening needs to come before speaking. This is a natural progression with all hearing children. Keep in mind that our children follow the same identical path in regard to speech development as a hearing child. The only difference is that our children are given a great deal of emphasis on every step in the process until they are articulating full paragraphs and using language appropriately.

You want 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 nice 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 few 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.

A family support system that can help you when you cannot be home or you cannot take your child to school. Remember, in this process children start school as young as six months of age. One spouse needs to have a boss that understands that flex time for the next four years is a non-negotiable request. Either you need flex time or you must quit your job. You cannot go through this process with both parents working 9 – 5 and having a boss breathing down your neck counting every minute you take for breaks. It will not work. I understand you need the money and you need the job, but this is a one-shot deal and your child needs you NOW.

Time to find out everything you need to know about cochlear implants and language development. The desire to order every book needed and read it from cover to cover. You also need the confidence to ask professionals hard questions and understand the answers. Start a bookcase and maintain your reference library that you will be building for the next three to five years.

Be part of the community. Go to as many conferences and educational events as possible. You will meet parents, professionals, and children who have experience with cochlear implants. Understand what programs these parents / children are going through and compare them with yours. Volunteer your time,

donate to your school, and let these people know that you are going to help in any way you can because not only is your child going to this school or program but there are hundreds of children right around the corner who will be diagnosed in the next few years. You want their excellent program to continue to help your child and others because giving a child the gift of speech is a great thing.

A thorough understanding of insurance procedures, which would include understanding “negotiated contract pricing,” co-pays, coverage, what is written in your policy, etc. When the insurance company states, “We do not cover that,” tell them to show you in writing where it is not covered. The legal resources of the Let Them Hear Foundation are priceless with these insurance companies. Their track record is amazing and they have won or overturned many denials from insurance companies!

Now comes the question that may represent a small number of people reading this book. What happens if you do not have insurance? Well, from my experience there are a few options open to you. When a mother has a baby the mother’s insurance covers her for the delivery. You need your child’s insurance to take effect the very same day as delivery. This is a completely different insurance policy than the mother’s policy. The reason why is because if your child fails the newborn hearing screening they are designated as having a pre-existing condition which is a huge red flag for obtaining insurance. A few days after delivery your baby will probably have a wellness check from a pediatrician, and your child needs insurance. In general group plans with employers will cover people with pre-existing conditions. People that are designated as low income can qualify for different programs that are available. Last but not least the state of California has a program called HIPPA that will provide insurance if you obtain in writing three denials from insurance companies. This policy is not as good as other policies because it sets limits on yearly payouts that may or may not cover what your child needs. I hope that other states have such a program. The real expertise lies with the lawyers at the Let Them Hear Foundation. Please call them and get educated on your insurance rights.

This is an ever-evolving educational process. To fully understand and learn everything needed could take years, just like it took me. Learn the important things first that correspond with your child’s habilitation process. For example, do not even worry about assisted listening devices or mainstreaming if your child is two- or three-years old. In future chapters I will lay out in detail at what ages Gabriella was enrolled in different programs and how she obtained language. This will be a good roadmap to follow along with the guidance of the Ausplan book. This excellent book covers in detail language development of cochlear-implanted children and covers all aspects, including auditory, speech, and language.

In my opinion the very first thing to have in your arsenal of knowledge is a full understanding of your insurance policy, a full understanding of the IFSP / IEP process and your legal rights, and a good relationship with your school’s special education / early development department. Sit down and talk with your spouse, run it through your mind a hundred times if needed, come to the absolute conviction that yes, I want my child to speak and hear, I want my child to have great articulation, and I do not want my child to rely on sign language to communicate. If you know that in your mind, this author and many other professionals can fill in the blank spaces to make your dreams become a reality.

It has amazed me when different professionals mentioned that they have a case where the parents will not get an implant for their child. They will not enroll their child into an auditory program. I have even

heard of cases where parents will not attend their child's IEP meeting. These parents unfortunately are in complete denial. As parents we have the legal right to do absolutely everything for our deaf children to help them speak. We also have the legal right to do absolutely nothing. I will say it again—take this once-in-a-lifetime opportunity to do everything you possibly can to help your deaf child communicate with their beautiful voice. Become the expert that you need to be in all of these subjects. Do not leave it up to other people to teach your child. You are the quarterback, and just like every great football team you need a group of highly skilled professionals to make it to the fourth quarter and win. People will keep saying things such as “What have you decided to do?” “You should go with the language option your family feels comfortable with.” As a parent you know what's best for your child. You are in the driver's seat, no one else. Good luck.

## Chapter 5

### Understanding Language

What is language? Is language the ability to have someone understand your needs and wants in the most basic and primitive manner? Or is language more complex than this? To have the ability to fully understand where other people are coming from, to understand their innermost feelings behind their words and to be able to react appropriately, is this language? Language is complex and has many different parts to it. The parts that make up complex speech and language are endless: receptive language, expressive language, articulation, syntax, the use of language, auditory processing, understanding abstract ideas, communication, spontaneous expressive speech, age-appropriate language, age-appropriate articulation, the hierarchy of language, etc. We will now examine the different aspects of language, speech, and auditory skills. Along with these very important topics, various other things associated with language and your child's development will be discussed.

This is one father's explanation of what I have learned over the past four years about speech, language, and articulation. A lot of the books written on these subjects are very technical and go into terminology that most of us do not understand. There will be terminology in your child's IFSP / IEP that I am sure you will not understand but it is your job to find out exactly what it means. When you read goal # 3 on your child's IEP and it says: "Johnny will respond appropriately and with proper syntax to two-part questions when presented in an auditory-only manner, four out of five times." Do you even know what this means? What can you do at home to help facilitate this goal to help your child? If the speech pathologist is the only person who can translate this goal and know what exercises Johnny needs to practice, then you have not been paying attention.

It is vitally important to know where your child is on their language journey and where they need to go. Sitting in on as many speech therapy sessions as possible is also crucial. In the very beginning I had no idea of how children obtained speech and language, but with hours of reading, speaking with the speech therapist and attending numerous speech sessions I soon understood how children acquired language. I never was the expert I left this to the SLP's and Teachers of The Deaf. My job was to hold an intelligent conversation and provide good feedback on what we were observing at home. It was not a matter of saying, "Oh Gabriella is speaking a lot." I came into the therapy sessions stating that "Over the weekend Gabriella was joining three words together spontaneously, she reacted appropriately to a two part request auditory only. She even picked two correct items out of twelve in a closed set!" This is the language you need, to help the professionals, you can not talk in generalities they need to know what is going on at home.

Open up your mind and get ready to learn the terminology that every parent needs to understand to help their deaf children speak. I hope this chapter can be of great help to you.

### Receptive Language

Receptive language really means how well does your child take in information and "listen." To go one step further, how well do they follow directions? This is completely different from how well your child hears. Hearing is documented in the sound booth and on your child's audiogram. In a good auditory oral



program the speech therapist will concentrate on receptive language for many months before any words or vocalization is expected. Children will hear numerous sounds, words, and phrases for up to twelve months before they will speak their first word. This is the time frame that hearing children are on, but our children must “catch up” rather quickly. We will inundate our children with lots of words, phrases, and exercises for many months to facilitate their receptive language before we even expect any words or vocalization. This is why getting hearing aids for a child when they are first diagnosed is so important. The more the child hears in the very beginning, the easier it is for them to catch up on their receptive language skills.

### **Auditory Discrimination**

When I was told that one of the goals for my deaf child was to react appropriately to a two-part question in an auditory-only manner, I did not even know what that meant. The person working with us gave us an example to try at home, to then be included in the IFSP. With Gabriella in a different room, we were to say: “Gabriella, grab your Elmo toy and come set him on the couch.” I thought, how is a deaf child going to hear me from a different room and know which toy to get and where to put it? This seemed like Mt. Everest in the world of listening, but I had to go along with what the therapist was saying because if she has confidence that my daughter could do this then I should also.

Auditory discrimination is listening to a word or a phrase and picking out the key word(s) and reacting appropriately to that statement or question. The key words in the above sentence are: Gabriella, Elmo, and Couch. I could have said, “Mommy, grab Elmo and put him on the couch.” Or I could have said “Gabriella, grab your favorite book and bring it to the table.” There are key words to every phrase and as humans we tune into those key words. Hearing children pick this up naturally but our children need a lot of help and repetition. While we are playing with our children we must emphasize words hundreds of times, we must say Elmo, couch, etc., hundreds of times. We must know for sure that our children know these words before we can ask them to bring a toy to different room. Then when the time is right and they are ready for the Mt. Everest challenge you will do just what the therapist asks of you. Your deaf child will set Elmo on the couch and tears of joy will fall from your face knowing that real progress is being made.

The moral here is to keep the words simple, and do not use synonyms until your child fully understands and can react to the first word given. So for example shoes are shoes, not tennis shoes, sandals, boots, slippers, etc. They are shoes. Once your child knows the word shoe and can pick that item out of four or five items, then a little more explanation can be given, such as there are different types of shoes, etc. Everything explained in this book needs to correspond to your child’s hearing ability and speech ability. This is a hierarchy of listening and expressive language. Do not put the cart before the horse. Know where your child is and only work on what is appropriate at that point and time. If you do not know where your child is on the hierarchy then you cannot be effective when working at home. Worse, you can confuse your child with things that are too hard and they will take much longer to learn and may even suffer in their articulation, speech, and language. Be on track; know where your child is.

All children love to play with toys. When they are very young numerous toys can help with discrimination and listening. LeapFrog and other manufacturers make toys that require the child to react appropriately to a sound, a song, a word, or even a phrase. These very special toys need to be in place

from the very beginning. Children will play with these toys for hours, learning how to discriminate different sounds and words. When buying a toy be very conscious of how it will help your child's listening and discrimination skills. You do not want toys that just make noise; you want toys that require your child to decipher what is being said and react appropriately. To go one step further, I purchased a small xylophone for our daughter so she can hear the different tones and frequencies of sound. We would sit there and bang on the xylophone and she was learning that sounds can be soft, loud, high pitched, low pitched, etc.

Getting back to discriminating words, sit down with your spouse and make a list of about 50 items in the home that have one name and one name only. Many items have numerous names and synonyms. You should use only one name in the very beginning. Use plate, not saucer, phone, not telephone, shirt, not blouse, pants, not Levis, etc. The exact words don't really matter. What does matter is that the same word be used all of the time. Type up a list and let your speech therapist know what words you are using and say these words hundreds of times while pointing to those items. Use the words in sentences and always reinforce with a visual, pointing the finger or showing the object. Children's picture books are perfect for this type of teaching. When your child reacts appropriately give a great deal of praise and let them know you are proud of them.

Before you know it you will have five items on the floor and when you say "phone" they will point to the phone, when you say "pants" your deaf child will point to the pants. The therapist for our daughter started off with sounds of animals and would have Gabriella discriminate the sounds of three to five animals. Then when our daughter had the sounds mastered she went on to the words, then the words were put into a question, such as where is the cow? Or, show me the cow. Each morning she would start the session by using the seven Ling sounds and having Gabriella respond to these. These seven sounds when presented will tell the therapist if the child is hearing all of the frequencies that make up speech.

As an informed parent you will understand the hierarchy of receptive language and you will know if the therapist is going through the correct order. Hopefully you get a great therapist from the very beginning, but because time is so precious in this process you must know if your child's speech therapist is up to the challenge of teaching YOUR deaf child to hear and speak.

Single words are used in the beginning and as time goes on these words are imbedded into sentences that can be simple or complex, one-part or two-part. For example, as your child gets older the therapist will use sentences such as "Johnny, can you pick up the green crayon and color the tree?" Johnny has 12 crayons and lots of items on his coloring book. (This is a two-part question because Johnny needs to get the correct crayon and color the correct item.) In an auditory-only manner with no visual cues at all Johnny does exactly what the therapist asks of him.

There are exercises that follow an open set format and exercises that follow a closed set format. In the beginning, while your child is learning to discriminate, a closed set format will be used. For example, if you have five animals on the table and the therapist asks for the dog, this is a closed set because the child has five visual cues to look at and only five animals to choose from. In an open set format the child has an unlimited number of choices and absolutely no visual cues to choose from. A question in an open set format may sound like: "What do people wear on their heads?" Or, "What color are the clouds?" There are no clouds to look at, no hats to look at, absolutely no visual cues at all, and the child could

answer or interpret this question in numerous ways. But when they do pick out the key words and answer correctly, you as the proud parent will know that your hard work is paying off. Keep in mind that the home life is turned into an educational bonanza, learning and hearing numerous words, sounds, and phrases all of the time.

We've talked about words but what about sounds? Being told that Gabriella would be able to hear the birds in the trees or the sound of rain on the windshield seemed like an impossibility for a deaf child. There are hundreds of sounds around us and as parents we must explain and point out every one. The microwave buzzer, the birds outside, the dog barking, the coffee grinder, music, the rain, the knock on the door, the leaves under our feet, the sounds of every animal at the zoo. I could go on forever. Again, do not go too fast. Let your child become comfortable with the basic sounds and move on from there. You are sitting in the living room playing and someone knocks on the door. Say, "What is that?" Look at your child and if they do not say door, then hold your hand to your ear and say "I hear the door." Repeat the name a few times and go answer the door. The same goes for the phone, the microwave buzzer, etc. Repetition is the key to great listening.

### **Expressive Language**

When we are told that our child is deaf or hard of hearing the very first thing that comes to our mind is "I want my child to speak." We forget about hearing, discriminating, and all these other things; we want our children to speak and communicate with the world around them. Expressive language is referred to as everything that comes out of a child's mouth. This could be a gesture for wanting milk, it could be a vocalization, or it could be expressing one's thoughts in an entire paragraph or two of information. There are numerous parts to expressive language just like there are numerous parts to receptive language.

Deaf children learn speech and language in the same exact manner as hearing children. Our children need a lot of repetition and help to emphasize every part of the language hierarchy. They follow the same path, and as parents we must know where they are at all times. Let's look into the finer details of expressive language. This is where the term "age-appropriate" is so important. As a father with one child and no other children to compare language to I had no idea what was age-appropriate for receptive and expressive language with my daughter. My recourse was reading books on language development, talking to the speech therapist, and understanding the tools they use, such as standardized language testing models, etc. I formed a good understanding of where Gabriella was and what the next step in natural language development would be. This brings me back to the very first sentence in this chapter: "What is language?" Many professionals will compare our children to deaf children of the past who did not have the luxury of cochlear implantation at a very young age, a great doctor, and a great auditory oral / verbal program. They will say things like "Your child is doing great." Our question as parents is, "great compared to what?" We MUST compare our children to normal hearing children every step of this process and if one person says, "Oh we cannot do that because your child is deaf" they need to talk with my daughter or speak with me.

A deaf child that is given every tool needed to acquire great speech and language can and should have a great vocabulary, great articulation, and good use of words in the proper order and context. This child should be able to understand abstract ideas, and give a great explanation of the world around them. They

should have completely normal speech and language in three to five years after this process starts. This is our goal, this is our hope, and this is my daughter's reality. I pray that your child reaches the highest stars and never lets anyone stand in their way.

### **Spontaneous Expressive Speech**

Throughout this entire process you as the parent, along with the speech therapist, will be feeding in appropriate language to your child. You will be their model so they will learn what to say and how to react to certain questions. When your child says "mmm" with a cry and holds their hand out for milk you will say, "I want that." Turn the "mmm" into "I want that." Even if you only get the word "I" in the beginning, they will learn. When a person asks, "How old are you?" and your child sits there motionless with no words, you will say "two." (You will work on what is appropriate for your child at that point and time, not a full sentence, just one or two words if that is where they are at in their expressive language skills.) Older children will use the phrase "I am three-years-old." Keep modeling language day and night until the child gets it 100% on their own. Expand language and turn a short two-word statement into a longer three- or five-word response. Normal hearing children pick all of this up naturally but our children need a lot of help in the beginning to form excellent speech and language. So what is spontaneous expressive speech? This is speech that the child uses to get what they want, or to ask questions with no input from any other person. The child starts the conversation with no cues from anyone. For example, if two or three children are playing together and one just comes out and says "Can I have the doll?" this is spontaneous. No one asked her if she wanted the doll. She just asked for it on her own. If the child is on the couch and says "I am cold / hungry" this is spontaneous because no one asked the child if they were cold or hungry; they just came out and said so. As time goes on the spontaneous speech will turn into three- or four-sentence questions: "Mommy, I want to go outside and ride my bike. Then I want to see my friend Mary. Can we go to the park mommy, can we?" This is an exciting time because the next step would be to try and carry on a back-and-forth conversation with a few exchanges.

### **Birth Age and Hearing Age**

In many formal meetings such as the IFSP and IEP, there will be discussion of what is your child's birth age, and what is their hearing age. The birth or chronological age is how old they are and the hearing age is how long they have heard with proper amplification. So a child who is born completely deaf and does not have proper hearing aids or a cochlear implant until ten months of age would have a chronological age of 12 months and a hearing age of 2 months on their first birthday. As time goes on, in most reports the evaluators and professionals will use the hearing age, chronological age, and whether or not your child is speaking / hearing at age level.

The key is to close this gap. In the preceding example the child is 10 months behind in their receptive and expressive speech. As time progresses they will be six months behind, three months behind, and then hopefully age level or even surpassing the speech and language of most hearing children. I know this sounds extraordinary to be deaf and have better communication skills than most hearing children, but it is possible.

## **Cognitive Skills**

Most college-bound children take the SAT to see how “smart” they are. Some people even take an IQ test to show their intelligence. In very young children the term used is cognitive skills. What this means is how smart are they at that point and time. Cognitive skills can change over time so if your child is behind just help them catch up. Very simple tests are used on young children, such as can they stack blocks, can they tell the different shapes, letters, colors, or even stay within a line while using a crayon. As the child gets older things such as vocabulary and use of language are factored into cognitive skills. I feel that a very close relationship with your child’s teacher is crucial. To know what they are learning at school so you can re-emphasize these things at home will just make them smarter and more confident when people ask questions of them.

## **Articulation**

Have you ever wondered why children do not have clear speech from the very first day they put words together? The reason why is because as humans our mouth and brain work together to form sounds. Our tongue, lips, cheeks and teeth must work in perfect order to make clear sounds. It takes time and a lot of practice to formulate all of the sounds in the English language, so children formulate the easiest ones first and then the more complex sounds come over time, upwards of age seven or eight.

Vowels are the easiest to formulate and come first, followed by vowel-consonant or consonant-vowel. Then consonant-vowel-consonant will formulate to end this part of articulation. Keep in mind that specific vowels and specific consonants will come before others. The previous description is of a single-syllable word. As time progresses two-syllable and even three-syllable words will follow. We would not work on an exercise to have a baby pronounce the word “unsuitable,” a four syllable word. We also would not ask a ten year old to pronounce “dog” or “cat.” The speech therapist must know the natural order and age-appropriate skills relating to articulation. When they work with your child for a while their reports and conversations with you will emphasize the child’s full repertoire of sounds, and which ones need to be worked on. Clear articulation is so important and crucial for clear speech. Make sure that you have a speech language pathologist who is keeping track of the full repertoire of sounds and whether your child is making age-appropriate progress.

Oral motor exercises can be used to help facilitate building the muscles in the mouth, tongue, and cheek. Things such as sucking on a straw, blowing a feather, puckering up to kiss, and many other exercises will give your child good oral motor muscles and will help facilitate good articulation. We as parents will never be the “experts” on these subjects, but how can we have a substantive conversation with our child’s therapist or even think about what goals should be on their IFSP / IEP documents without knowing these things and knowing them well?

It hurts me to talk with a parent who has been in this habilitation process for two or three years and they do not have the slightest idea what any of these terms mean. Are they in the driver’s seat? No, the school district, speech therapist, and other people who do great work are in the driver’s seat. Keep in mind that these professionals have numerous other children to look after, too. We and only we as parents know our children best. We must be ready, willing, and able to help them. If you are lacking in these areas, this author and many books listed here will help get you up to speed.

## **Auditory Processing**

A child could have great hearing, great articulation, and even great speech, yet the brain might not be making sense of the words. This is where auditory processing comes in. Some children may have minor processing issues and other children may have no issues at all. In these circumstances the child listens to a question or a statement and makes sense of it, then answers with an appropriate response. These types of questions may sound like: “What should we do if our car runs out of gas?” “What do you need if it rains?” “Who makes a louder sound, a mouse or a lion?” “What would happen if we left the water faucet on in the sink?” Some questions are easy and give two choices (closed set). Other questions require an explanation. In both circumstances it does take some thought and processing to answer correctly.

Auditory processing is very important when we get to the subject of complex language. As language becomes more abstract and ideas are presented and the listener has to think about how the pieces fit together, auditory processing and language comprehension become very important areas to understand. So the simple explanation here is that language comprehension and auditory processing is how well the brain makes sense of what is being said.

## **Complex Language**

Even though our children are deaf or hard of hearing they can and should be given the tools to develop complex language skills, complex language skills that are age-appropriate until they become adults. When Gabriella was first diagnosed as hard of hearing at 10 months of age and then completely deaf at 12 months of age, many thoughts went through my mind. Because I am a very expressive person and love talking about theoretical and complex subjects I thought what a terrible feeling it must be to have all of these great thoughts and ideas in your mind and not be able to express them to anyone. Well, the one person who may understand is a person who knows ASL (American Sign Language); everyone else, forget it. The thought of Gabriella going through life bottled up where every thought must be written down or signed hurt me deeply. I know I would go crazy if I had no one to discuss my innermost feelings and thoughts with. I wanted my daughter to express herself just like I’ve had the opportunity to do my entire life.

This is complex language. We do not just say “I want food.” We say “I would like to have a steak medium-well, with a baked potato, salad with light dressing, and a large glass of iced tea to drink.” It is expressing your needs and wants with pinpoint accuracy and knowing the correct word, synonym, or phrase to get your message across. If you do not have these skills how would you ever tell a husband, wife, boyfriend, or girlfriend how much you love them and what your true feelings are?

Understanding complex language is just as important as speaking it. Being able to listen to a person and respond with pinpoint accuracy is so important. Otherwise the person will think that you are not paying attention. (Little do they know you are deaf!)

Using proper language in the proper sequencing, formulating sentences and having a strong vocabulary are all parts of complex language. Having our children reach these heights just like a hearing child is our goal. Do not let any professional tell you that your child cannot accomplish complex language. With the proper implants at an early age and a great oral program the sky is the limit!

## **The Hierarchy of Receptive and Expressive Language**

The following list will give you a basic understanding of how children progress through receptive and expressive language skills. Keep in mind that our children follow the same format to learn language as hearing children. The difference is that we emphasize every part of the process and help them every step of the way until that beautiful day when we know they have mastered language and can walk on their own. Many exercises and standardized tests will help the professional working with your child pinpoint where they are on this hierarchy. As I mentioned earlier there are a few must-have books that need to be in your reference library to fully understand this amazing process.

Listening always comes before speaking and a lot of time needs to be spent on the auditory skills that all deaf children must acquire to differentiate speech and understand what is being said. I do not care how well a child can speak, if they can not listen to a conversation and make sense of it then they will be lost. What have you gained if your child can speak great but they can not hear great? Listening comes before speaking.

This is one of the primary differences between an auditory program and a Total Communication program. With TC children rely on visual cues and sign language to communicate. They are not given the months of hard work it takes to develop good auditory skills which are crucial to function in a hearing world. Without good auditory skills the language must always be supplemented with visual cues or else the child can not follow along, talk on a phone or converse from another room as so many orally educated children can do.

Please look at the following hierarchy's and understand that this is just an overview of the very complex patterns that all children follow to listen and speak.

## **Hierarchy of Learning Oral Language**

### **Receptive Language**

#### **“Listening”**

- 1) Awareness of Environmental Sounds
- 2) Discrimination of Sounds
- 3) Discrimination of Single Words
- 4) Discrimination of Single Words in a Sentence
- 5) Performing One-Part Requests
- 6) Performing Two-Part Requests
- 7) Discrimination of Two Key Words
- 8) Fully Understanding Over 100 - 150 Nouns
- 9) Fully Understanding 50 - 75 Verbs and Adjectives
- 10) Answering Questions



## Example

- 1) Such as the door, the phone, music, a bell, a dog barking, etc.
- 2) Discriminate oink, oink vs. quack, quack, vs. ruff, ruff
- 3) Discriminate pig vs. duck vs. cat
- 4) Where is the pig?
- 5) Pick up the pig. Color the dog, etc.
- 6) Pick up the pig and put him in the box.
- 7) Where is the black car?
- 8) Phone, car, plate, shoe, cup, rug, couch, table, etc.
- 9) Run, walk, brush, climbing, small, big, long, short, etc.
- 10) What color is the car? What shape is this?

## **Hierarchy of Learning Oral Language**

### **Expressive Language**

#### **“Speaking”**

- 1) Vocalizing Sounds
- 2) Vocalizing a Full Range of Sounds
- 3) Speaking Single Words and Word Approximations
- 4) Repeating and Copying Spoken Words
- 5) Attaching Meaning to Words
- 6) Speaking Two-Word Phrases
- 7) Speaking Three-Word Phrases
- 8) Speaking Four-Word phrases
- 9) Speaking Full Sentences
- 10) Carrying on a Back-and-Forth Dialogue

## **Example**

- 1) Vowels will be mastered first, then consonants
- 2) Making sounds of different length and shape
- 3) I, Me, My, Ma Ma, Pa Pa, Eyes, Baby, Bye Bye, Milk, Bread, Etc.
- 4) Dog, Cat, House, Car, Paper, Pen, Monkey, Sleep, Wash, etc.
- 5) They know what the word means when they say it.
- 6) Come home, Let's eat, Want milk, Play outside, etc.
- 7) Help me please, I want that, Hi little doggie, etc.
- 8) I want to play, Let's go to park, I want take bath, etc.
- 9) Daddy, help me with my shoes. Mommy I want to eat lunch.
- 10) Back-and-forth dialogue with multiple exchanges

## **Chapter 6**

### **The Plan**

At this point I hope you feel empowered with the knowledge needed to help your child speak and listen. Having the right knowledge and doing the right things at the right time will make all the difference in the world. There is no time for mistakes. If you have made mistakes, brush yourself off, and do not feel like a bad parent. Unfortunately the system is not set up with clear, concise answers. In a lot of circumstances there are no clear answers. You must just go with your gut feeling, what feels logical and seems the best decision for your child.

This process is a sacrifice for us parents. It is a financial commitment and a time commitment for everyone involved. But for me, I would rather give my child the gift of spoken language than have any material object this world could possibly provide me, even a million dollars. There is no price to put on changing a child's life forever and letting that child reach their highest dreams. I know every child is different but this book and these actions that are written here will help any deaf child succeed. They may not have perfect speech, they may not have perfect articulation, but you will know in your heart that you have done everything humanly possible to help that child reach the stars.

Forthcoming is a roadmap that I hope can become a standard of care for deaf children. This roadmap is everything that our family has done from the very first day Gabriella was diagnosed with a hearing loss to the day she enrolled into a fully mainstreamed kindergarten with perfect speech and language. I hope that you look at this chapter as a guide and compare it to what you and your spouse may be doing for your child. Again, every child is different and there is no one-size-fits-all plan, but this is exactly what we did.

We have already discussed the extremely important aspects of what to do at home, the parents' role, etc. We will now discuss the type of school Gabriella attended, the type of surgeon and operational procedures she had, the therapy sessions, the hearing tests, the IFSP / IEP meetings, etc. Four years of step-by-step procedures are laid out here. We will not get into the intricate details of speech pathology or the day-to-day activities of her school. There is a listing for Gabriella's school and other oral schools throughout the country in the resource section of this book.

### **Why us**

Walking into the sound booth with my wife holding our little daughter, my life flashed before my eyes. How many times have my parents taken me to the hospital for some type of test? Yes, as a child I was hurt and I needed medical attention, but a few stitches and a week or two of recovery and I was fine. I have always made a full recovery from any medical problem I have had. The very little I knew about hearing loss told me that whatever the audiologist results were, they were permanent. There is no fixing it, there is no "few weeks" and Gabriella will be fine." This is a life-changing test that is taking place and all I could see was a bunch of numbers on an illuminated board and the young lady writing on a piece of paper. All I could think of is why us? Why our little helpless girl? I have experienced everything this world has to offer, let it be me and not our little angel.

After the test the woman told us that our ten-month-old daughter had a moderate hearing loss and would need hearing aids. She explained the different types, analog and digital, and told us to make a decision and give her a call. Even though “the best” hearing aids cost over \$2,000 and were not covered by our insurance we knew we needed to get sound to our little girl. We purchased programmable digital hearing aids and put them on her little ears.

It was suggested that a genetic test be done and we agreed. The audiologist at our local hospital was experienced with children, and, looking back, was an absolute miracle worker. We spoke with the ENT doctor and after a few visits it became apparent that Gabriella did not have a conductive loss, fixed with an operation, but a sensorineural loss, affecting the tiny hair cells inside of her cochlea. These hair cells give electrical impulses to the hearing nerve, and without enough hair cells the hearing nerve would not be stimulated, in other words a permanent problem which really had no quick fix to it.

So we put the hearing aids on and had a few more sound tests to program these very advanced devices. At this time the audiologist and ENT doctor suggested having an ABR (auditory brainstem response) test done on our child. There tends to be a thirty- to sixty-day wait for such tests so we were scheduled at our local children’s hospital to have this done. This one decision by the audiologist and doctor to have this test done was a crucial decision. Who knows how long we would have gone through this process not knowing the actual severity of our daughters hearing loss if it were not for this type of test?

The audiologist explained that the ABR test required that our child be put to sleep. There would be electrodes and wires attached to her head and they would do a very, very accurate hearing test on our little angel to see exactly how extensive her hearing loss was. Keep in mind that hearing tests in the sound booth are very subjective because of the child’s age and the audiologist’s experience. This one ABR test is the tell-all and is very accurate.

Every evening we were subjected to feedback from the hearing aids, we always needed to get new ear molds, and in general these things were a pain to keep on her ears. They always fell off and I had no idea how well she was hearing with these new devices on her tiny ears. Immediately the special education department was contacted for Gabriella’s local school district. We met with a very caring person who set us up with services about three times per month. The Deaf and Hard of Hearing specialist would come to our home and explain to us how to work with our child. Simultaneously I pulled out the phone book and called every audiologist and speech pathologist I could find. Numerous calls were made. I must have spoken to twenty different people. I wanted a speech evaluation knowing that my daughter was behind in her speech. In reality I should have been looking at the different options available to acquire speech instead of an evaluation. I wanted a person who had experience with children and who dealt with deaf and hard of hearing children only. I ran across numerous people and either the waiting time was months to get in or the person did not specialize in children. Then one person said to me “have you contacted the Jean Weingarten Peninsula Oral School for The Deaf?” I said who is that? They explained and then I made the most important call of my life.

The phone rang and a woman answered. I explained that our daughter was just diagnosed with a moderate hearing loss and I wanted a speech evaluation. I explained that she must learn how to speak no matter what it took. Two days later I arrived at the Jean Weingarten Peninsula Oral School for the Deaf and met a very caring woman. I walked in the door and sat down on a couch. I explained to the woman

that my daughter had a hearing loss and I wanted her to speak. I explained that I loved her dearly and wanted her to communicate with the numerous people around her. Tears flowed and the feeling that this school with their expertise was our one and only chance for speech hit me. At the end of the meeting the woman said she will call me in a few days to see if we could be accepted into their school. I felt that if this school did not accept us, there was no other choice. Of course looking back on things there were other choices, but a good auditory oral school has everything in one place. This school was perfect for us. We waited and prayed that Gabriella would hear, we prayed that she would speak, we prayed she would hear the birds and the sounds of nature around her. We did not want our little girl to live in a world of silence.

A few days later my cell phone rang and it was the director of the family center for the Jean Weingarten Peninsula Oral School for the Deaf. She said, "I have good news, your daughter has been accepted to our school." I said, "Fantastic, thank you so much." She then said she wanted to explain how things work there. "We will provide twelve months of educational training and speech therapy at no charge to you. During this time we will work with you and your local school district to reimburse us for these expenditures. There is no guarantee that they will pay us, but we feel it is important that you learn how to work with your daughter. We ask that you try your hardest and work with us to obtain funding not only for this year but for next year also." I said, "Of course, I will do whatever is needed. What do you mean that there is no guarantee that you will be paid?" She then explained about the IDEA law and the fact that every deaf child deserves an "appropriate" education and that some school districts may not be able to offer an oral program for their 0 – 3 year-old deaf children. It all seemed a little complicated to me but our family was extremely happy that we were on a path to help our daughter speak.

## **Our First Year**

Gabriella was enrolled in this auditory oral program at eleven months of age. It was late August and the beginning of the school year. She had her hearing aids and we went to a forty-five minute therapy session twice per week. We met a woman who has worked at this great school for over twenty years and had experience teaching deaf children to "listen and speak." This is the school's motto, and in a few short months I would know why.

Every session, we worked on sound awareness, sound discrimination with animal sounds, vocalization, and listening to very basic things. We would sing a song to see how well Gabriella listened. We would knock on the door and see if our daughter could recognize the sound. The Ling sounds were used in every therapy session. After a few months we were still focused on listening. I thought, when are we going to move on to speech? The Speech Therapist / Teacher of the Deaf we were working with said that Gabriella was over nine months behind on her listening skills and we needed to work on this first because all children will develop receptive language before they develop expressive language, and Gabriella's listening skills needed to be on track. It is a fact she said that the better children listen, the better they will speak. It all sounded logical to me, and I was no expert so I accepted what was said.

The day finally came that our daughter was to have the ABR test at our local children's hospital. I woke up and said numerous prayers and even brought with me a small Bible, knowing that this test would tell us definitively the extent of our daughter's hearing loss. In our minds we truly hoped that this was just a big medical mistake and all the doctors and audiologists were wrong.

The test was performed and about two hours later it was complete. We then went to the audiologist's office and she said to us: "Mr. and Mrs. Hall I am sorry to tell you, but your daughter is profoundly deaf. She has a hearing loss that exceeds 90dB – 100dB in both ears." We were both devastated and saw the world crumbling around us. Feeling the Bible in my back pocket I wondered what good is this thing? As many religious people have said to us, we are working on God's schedule and not ours. Little did I know that there were bigger and better things planned for me. This process has brought me closer to my daughter, has given me the opportunity to volunteer my time, meet some really wonderful people, raise money for her school, and has given me the opportunity to show numerous professionals and parents the medical miracle that has transpired over the past four years. Gabriella's is a medical case that is helping enlighten people to what works in oral education. Little did I know that God had touched me at that time, and gave me the ability to write this book and help numerous parents' help their children listen and speak. Four years later every prayer we have had has been answered, Gabriella can hear the birds, the leaves under her feet, our voices, and she communicates just like a hearing child.

The next day I informed the Director at the Jean Weingarten school of Gabriella's profound deafness. She talked about a cochlear implant and said that this would help our daughter. She also said that the therapy sessions would continue and we were not going to change a thing about her educational process. We then made an appointment with a cochlear implant surgeon at the California Ear Institute in Palo Alto. Previous to the appointment we were directed to have a CT scan done on both of Gabriella's ears. With the CT scan in our hands we went to the appointment and hoped that good news would come.

The doctor looked at the CT scan and anything but good news came. "Gabriella has a malformed cochlea and enlarged vestibular aqueducts, the doctor said." "What does that mean?" we asked. "Well her cochlea only wraps around the hearing nerve 1 ½ times instead of the normal 2 ½ times. This means that the cochlear implant will be more difficult and the results can vary. Also, the enlarged vestibular aqueducts are the reason why she lost her hearing so rapidly; she has had a progressive hearing loss since birth." This news was the last thing we needed to hear about our daughter's medical condition. Then this extremely experienced surgeon turned to us and said: "Mr. and Mrs. Hall, I have implanted hundreds of children, many who have had the same medical condition that Gabriella has. These children do very well. Your daughter is attending an excellent auditory oral school and I have full confidence that she will speak very well. I would like to set up a surgery date." This lifted us up and gave us hope that this experienced surgeon could help our daughter hear.

Little did I know that our insurance would not cover this doctor for surgery but covered his counterpart in San Ramon, CA. We met with the other surgeon and she said the same thing the first doctor said about our daughter's cochlea and enlarged aqueducts. At this point all we wanted was an implant. The surgery date was set for November 25, 2003. At fourteen months of age Gabriella was implanted with the Cochlear Corporation's Nucleus 24 implant device in her right ear. She would still use the extremely powerful hearing aid in her left ear. Our local children's hospital where the surgery took place set up speech services one time per week after the implant surgery. These services continued off and on for a total of about three years, being paid for by a combination of insurance and out of pocket. So in reality Gabriella was receiving speech services two times per week at her auditory oral school and one time per week from the hospital.

## The IFSP

The schooling continued and Gabriella progressed through the receptive and expressive language hierarchies that have been discussed previously. We were attending the Jean Weingarten Peninsula Oral School on a “trial basis” and we did not make a unilateral decision to enroll her there. We were working with the school district and as parents we were investigating the different options available to us to acquire speech. (This is a very important legal concept because if a parent makes a unilateral decision to enroll their child in a setting it may jeopardize their ability to receive funding based on the IDEA law.)

About a month after the diagnosis of hearing loss an IFSP document was drafted. The school district offered various speech and language options, including a summer school program. Gabriella would be placed into a Total Communication setting along with other children as she got older. Immediately she would receive services three times per month. Not being comfortable that all options had been explored, I refused to sign the IFSP document and this was put on hold. Not signing this document is quite all right, but do keep in mind that the school district may refuse services until a formal agreement has been reached.

In January of 2004 and four months after Gabriella was enrolled in the Jean Weingarten School we set up a formal IFSP meeting to readdress the educational process and services. I attended this meeting along with the director of the Jean Weingarten School. We met with the school district officials and explained that an oral education is the “appropriate” training methodology needed in Gabriella’s case. She had a cochlear implant and she could hear very well. Total communication or sign language, we said, is not an option. We explained that it was a cost benefit to the school district to fund an auditory oral program for my daughter. We foresaw her being mainstreamed in kindergarten with very few support services. This would save the school district a great deal of money in the long run. (In reality money has nothing to do with what is appropriate for a particular student. A district cannot refuse services because it costs too much money. In reality all districts want to save money and they will be more accepting if you come forward with a cost-beneficial solution.)

Because the school district did not offer an auditory-only program for children 0 – 3 years-old they agreed to fund six months at J.W.P.O.S.D., including three weeks of summer school. Being at a school such as Jean Weingarten, we worked very closely with the Speech Pathologist / Teacher of The Deaf. We worked on everything that was being taught in the therapy sessions at home. If it was animal sounds we would work on that at home, if it was particular words we would work on that at home, being in total synchronicity with the therapy sessions. This to me seems to be very difficult in a public school setting, but is vital to make this process work. If your school district is not providing the information then you need to attend every therapy session such as we did and know what is happening. This is “appropriate” and needed for the successful outcome of speech and language. You cannot be in the dark.

To facilitate speech and language we purchased picture books to increase the vocabulary and word recognition of our daughter. We would show her a picture, point to it, and say the word, dog, car, boat, tree, etc. We then worked on sound recognition by knocking on the door, pointing to the phone when it rang, pointing to the vacuum cleaner when it was on, etc. We would then point to our ear and say “I hear that,” all the while keeping the home a quiet environment for good listening. When we did need to make noise it was all done at the same time. The dishwasher would be on, the vacuum cleaner would be going,



and the music might be playing all together. Then the noise would stop and the learning began. We tried very hard not to mix the two.

Because we only have one daughter it was easy to give one-on-one time to her. It may seem difficult for families who have additional children to find quality time to spend with your hard of hearing / deaf child. Be creative and think! Have dad play with the older children while mom works on vocabulary. Have all the children play together in a structured way so the little one can pick up natural language from the other children. Go exploring on a Saturday morning to name the flowers, the birds, all the objects in the environment. Explain to the other children that this is to help your little brother and when you name an item it must be clear, loud, and articulate.

### **Time is of the Essence**

You may be asking yourself, who has time to do all of this? When you need to leave the house by 8:00 a.m. and not come home until 6:00 p.m. Who will drive my child to school, work with her, etc. I have been in outside sales for fifteen years and having this type of job has given me the time to make a flexible schedule, work on the phone, work on my laptop, etc. Luckily for me I do not need to travel away from home for my job. I stay local and this really helped. After a few months, I went to my employer and explained the situation with my daughter going to a special school forty-five minutes from my home. I also explained that there were meetings and therapy sessions I needed to attend. I explained that learning how to speak is crucial at this time, my child cannot wait, I cannot put this off. Because I work for a small company who cared for me just as much as I cared for my daughter they said “Jim, we understand your situation, why don’t you take off time if you need to, adjust your schedule, maybe you can work on Saturday. Whatever you need to do we understand, we feel you will do fine. Keep track of your time off and we will readdress this in three months.” So the first year went by with this understanding, amazingly my sales numbers did not drop a bit and the company never questioned my schedule. I was fair to them about the hours I was working and they were very fair to me understanding my situation and the urgency of the matter.

### **Progress Report**

By June of the first school year Gabriella was twenty-one months of age, and seven months post-implant. She had excellent receptive language, months behind her hearing peers but making very good progress. Her expressive language was coming but was slower to progress. At this point Gabriella could discriminate many animal sounds and many words. She could hear all the environment sounds and discriminate various things including the door, the phone, the birds, etc. She loved music and we would give her many toys that played music for her enjoyment, we would sing songs with her and she followed along. Her expressive language consisted of simple words such as me, mine, I, ma, ma, eyes, up, etc. Two-word statements followed the one-word statements along with more two-syllable words as time progressed.

The entire summer was spent exploring the world around us and giving a name to everything that we saw. Because she was working on one- and two-word statements, our description of particular objects were one and two words long. We would talk to her in full sentences and treat her just like any other child but were very conscious of how we named things. For example if we saw a car we said “Look

Gabriella, a car” Then look at her again and say “car”. After a few dozen words were under her belt we would say things like “show me the car, show me the sign, etc.” Receptively she knew many words, she was a very good listener. Keep in mind that we were working on the same part of the language hierarchy that the therapist was working on. We were just broadening her vocabulary, enforcing words, concepts, and phrases that were being worked on in her therapy sessions. Keep in mind that therapy is forty-five minutes long and we are with our children twenty-four hours a day which gives us a lot of time to teach them new things. Gabriella attended three weeks of summer school representing the same schedule she had during the school year. Before we knew it summer was almost over.

## **The Second Year**

Late August came and we started a second year at the auditory oral school across the bay, forty-five minutes away every Monday, Wednesday, and Friday. We were now going three times per week, attending therapy and a classroom environment with five other children. The day class was three hours long with therapy being forty-five minutes within these three hours. We started class at 9:00 a.m. and finished by 12:00 noon. Every morning there was also a twenty-minute music class which ran from 8:40 a.m. to 9:00 a.m. This class gave the children the opportunity to sing songs and play around in a group environment. Four of the children in Gabriella’s day class were hearing-impaired and one child could hear. The hearing child is put into the classroom environment to serve as a language model for the other children.

In September, we had another IFSP meeting to discuss the funding and Gabriella’s progress. The school district visited the therapy and class settings and really did not know what to make of the progress that had been made. Things were slow to begin with but we convinced them to be patient and good things would come. We presented substantial evidence that orally educated children need fewer services and are further ahead of their peers in language and cognitive skills. This in turn helped us obtain funding for six more months.

## **The Program**

In the classroom environment the teacher would work on following directions, word recognition, and communicating with peers. Language was always fed into every student. For example if a child or a teacher asked a question of a student and that child did not answer, the appropriate answer would be fed into the student through the teacher or her aide. The teacher would ask, “What are you doing?” Silence, the teacher then would look directly at Gabriella and say, “I am playing with my blocks. What are you doing?” Gabriella responds, “playing blocks.” A lot of praise would be given for trying or coming up with the right answer. Loud sounds were explored, whispers were explored, many things having to do with sounds, words, and vocabulary were all being taught. Freeze dancing was a very important part of class. The music would be turned on and all the children danced. All of a sudden the music stopped and all the children stopped dancing. This taught the children to listen very closely to their environmental sounds and listen even though there were no visual cues. Experience books were also very important. Whether it was a holiday, a vacation, a particular subject, etc, a book would be made with pictures of the child and a one-sentence subtitle that explained the picture. These books were brought to class about once a month and the teacher would discuss all the books, with all of the children asking questions and waiting for correct answers. If the correct answer did not come then it was fed into their little ears by the

teacher or her aide. Feeding in language all the time was the key at this stage of the process. Children will hear many things and store that in their auditory memory. When the time is right they will search their brains and pull out the correct word or phrase that they have heard dozens of times before.

The forty-five minute therapy sessions were quite different. At this point full sentences were used to ask questions or give directions. Single key words were embedded into sentences. As time progressed two key words were embedded into sentences waiting for the correct response. For example with fifteen crayons in front of her the therapist would ask, "Gabiella can you pick up the green crayon?" Or she would change the sentence and say, "hand me the green crayon, please." All the while the student needs to pick out the key word. As time progressed two words were used, such as "Pick up the blue crayon and color the house." Or the therapist might say, "Can you get the yellow crayon and color the sun?" This is very difficult because there are at least fifteen crayons and at least ten different things to color in the book in front of the student, many variables to make a mistake. Gabiella had a nearly perfect track record as time went on. Her listening skills were excellent.

In regard to speech, the therapist would ask a question and Gabiella would give a response. Sometimes just one word, sometimes two words and on a few occasions three words. The therapist always encouraged the student to expand the sentence into a longer and longer explanation. If the student said two words a three word response would be given back, etc. Production of speech was a main focus along with enhancing listening. Getting the student to feel comfortable talking as much as possible was a very important aspect of this time period. Rewards and encouragement were always given. Many interesting toys were used that the child loved to play with. These toys kept the therapy fun and were part of a reward system for trying.

Sometimes in the therapy session an object was brought into the classroom such as a toy or a picture and the speech therapist would discuss this object with the student, trying to get back and forth conversation going. Even though Gabiella answered in short two- to three-word statements most of the time a dialogue could be established. Vocabulary and articulation were also addressed.

In the first year or two of therapy one parent would usually be present. This gave the child the feeling of comfort and it gave the parent the knowledge needed to help their deaf child at home. Memory was worked on along with numerous other tasks. There are some great books in the resource section that can help with all of these exercises. Most importantly get a good school, a good therapist, and follow along with them in tandem helping your child reach for their next speech and language milestone.

She still saw the other speech therapist one time per week at the local children's hospital. This woman concentrated on articulation and knowing exactly when every speech sound should develop. We would also play games and do different exercises to encourage more speech production. We would color pictures and talk about things, checking for articulation and age-appropriate syntax.

### **Playing with Hearing Children**

I knew very early on that because our daughter was an only child she must be around other children to develop good language and social skills. We always made a point to get her around hearing children as much as possible. She would go to playgroups at the local community center for children eighteen-

months to three-years-old. We enrolled her into Gymboree, or The Little Gym, or even a music class from Music Together. We always had some sort of class scheduled once or twice per week. This schedule I thought would clearly wear any child out. Even though she was playing most of the time it was a matter of rushing from one location to the next. It was nice to just spend time with our little one relaxing and being a family. About midway through the school year we enrolled our daughter into a preschool twice per week for three hours per day. This only lasted for six months and was the only time she was in a preschool which we needed to pay for.

Rushing around from appointment to appointment with so many professionals analyzing my daughter's every word really made me think. Her entire childhood life has been full of doctors, therapists, sound booths, hospital rooms, operations, and many, many tests. Can this child just be a kid, I thought? Is she going to lose her childhood to schooling and language exercises? This was definitely a concern to me but really good progress was being made and there was no turning back. All we could do as parents was give her good quality time with us and other children and let her enjoy as much play time as possible. Thankfully for us Gabriella enjoyed going to school and never grew tired of the schedule. Some children I am sure would not be as patient with the process. As I said before, the process of oral education is a sacrifice, not only for the parents and family members but for the deaf child also. This sacrifice has huge rewards that only become apparent as the child grows older and masters the use of language.

### **The Second Cochlear Implant**

After seeing some great results from the first cochlear implant we were seriously considering a second implant. We discussed this with her surgeon, the speech therapists, and other parents. We went to numerous conferences and tried to answer the question of whether a second implant could help our daughter. The overwhelming answer to us was a resounding yes! For the longest time there was no clear answer on whether the hearing aid in her opposite ear was helping or hurting the quality of sound. We knew that with an implant she would have clear sound in both ears and that is what we wanted. Other benefits became apparent such as sound localization and better ability to hear with background noise present. At this time Gabriella had the Cochlear Corporation's body-worn processing unit. One of these "boxes" was hard enough to keep attached to her body. How would we ever have two boxes attached to her waist? We put some thought into this and every pouch or holster that was on the market just did not work right. Gabriella's grandmother, who is a good seamstress, designed a pouch made of really nice fabric that went over her shoulders and had an "X" in the back with two "pockets" to hold the processing units. The pockets were on her sides, right where her hips were and did not interfere when she sat down. My wife purchased tops that flared out at the waist, and by putting this holster on under her shirt and feeding the wires behind her no one could tell that Gabriella was wearing a cochlear implant. Our daughter has long curly hair so even the microphone and headset were pretty well hidden.

At no time were we trying to hide the fact that Gabriella was deaf. We were just trying to have our daughter fit into society without the stares or awkward looks of kids saying things like, "Look, Mommy, that girl has wires stuck to her head." To be honest I did not care what anyone said or thought. I knew that the cochlear implants that Gabriella was wearing gave her the ability to speak and hear. I will show the world that a deaf child can communicate just like everyone else, I thought. If a parent would say something like "Does your child wear hearing aids, or does your child have a hearing problem?" I would take this as an opportunity to educate this parent on hearing loss and the wonders of cochlear

implantation. When they heard the clarity of Gabriella's speech and saw that we were not using sign language and that our child could follow all directions and questions with no visual cues, the parent then said things such as, "Is she still deaf? She hears and speaks remarkably well." This was my opportunity to tell that parent about the great auditory oral school she was attending, all the while hoping that my little conversation would open up the eyes of the world to help these children financially and emotionally.

After deciding to obtain a second cochlear implant for our daughter we started the insurance process. At this time bilateral implants were somewhat rare and the medical community felt that one implant was good enough to develop excellent speech. This is a true statement. A child can develop great speech with one implant. But just as I told the appeals board at my insurance carrier, "Would you like to go around your entire life and hear only with one ear, or would you rather hear with two ears?" If any person on this ten-person panel had said "Oh, I just want to hear with one ear," I would have torn them up and made everyone feel like an insensitive idiot. No, just like a politician they heard the question and responded, "Mr. Hall, we understand how you feel and you want the best for your daughter, but the standard of care today is one implant, I am sorry." Back in late 2004 we did not have the resources of the legal team at The Let Them Hear Foundation to take on our case. It was either accept this decision, hire our own attorney, or pay cash. Again, time is of the essence and we paid over \$37,000 for Gabriella's second implant. Not every family will have these resources available to them, but thankfully today things are much different and more insurance carriers are providing for bilateral implants.

It was very important to us that the skilled surgeon who performed her first operation worked on her this time. This was too important to leave to a doctor we did not know or had no idea of their experience. So the day came in November of 2004 that Gabriella had her second cochlear implant. Everything went well except for some minor balance problems following the surgery due to her enlarged vestibular aqueducts. After about a month she was her old self and we just needed to wait a little longer for the all-important mapping session. After each surgery we would have an appointment with the surgeon a few days afterwards. She checked that the wound was healing properly with no infections.

We felt very thankful that the doctors and hospitals worked with us and charged us exactly what they would receive from the insurance companies. For some strange reason when people pay cash without insurance they are charged more! I could never understand this. It made no sense to me. The understanding was to pay for everything the day of the operation with cashier checks made out to the appropriate parties. The hospital would not have to wait ninety days to get their money from an insurance company; they were getting paid in full the same day. There were certain fees waived and certain prices reduced because we had a great working relationship with the hospitals and doctors up to this point. We were so thankful that a few months later we donated \$1,000 and engraved a beautiful brick that sits in front of the main entrance to the hospital.

### **Training the New Ear**

So now at twenty-five months of age our daughter had two implants. By twenty-six months of age all mapping was complete and she was off and running. The next unanswered question came to me, how do you teach a child that has a second implant to use it properly even though she is pretty far along receptively with her first ear? Numerous phone calls were made and a lot of people were spoken to. All I

heard was either the hospital or person does not deal with bilateral children or if they did the child received their implant years after the first one, or maybe the clinic only works with adults, etc. People even went so far as to say that no formal studies have been released yet. I did not have time for formal studies. I needed answers now. We had an experienced therapist at Gabriella's school, but as always I needed to know absolutely that we were doing the right thing. I wanted to understand and speak with people who worked with children that had both implants within twelve months of each other and received their first one very early.

Somehow I got in touch with a speech language pathologist in Colorado who said they had worked with a few children just like our daughter. My ears opened up and I said, could you please explain to me what the therapy program is and how you work on two ears that are on two different levels receptively? She said, "During the forty-five minute therapy time half of the time is spent on the new ear only. You need to take a step back and only work on receptive goals that she can master with her new ear. Keep in mind that you may need to go back to what you were doing in therapy six or twelve months ago. Move up the receptive hierarchy scale and within six months both ears should hear identically. Oh, by the way in the evening at home use only the new implant for one hour every evening. This will get your daughter to rely on this new implant just like she relies on the old one." I was absolutely floored, a precise direct answer given to me with the utmost confidence that this is what needs to be done. I thanked the woman and asked if I could call her occasionally with questions and she said sure. To our surprise after about four months both ears could hear the same. This was due to a relatively short period of time between the two operations.

This entire process needs to be a team approach between parents, doctors, therapists, schools, etc. Because it is a team approach and we parents are so vital in this process I had very open communication with all professionals involved. I told Gabriella's main therapist what the woman in Colorado told me and I asked her opinion of it. Some people may feel that you are questioning their professional ability but in reality this is our child and we are going to search for the right answers just like the professional would. No matter what I brought to the table at any time I felt the different professionals respected my opinion and understood that this was a team approach and this parent has a strong education in this subject. So my opinion definitely does matter. Try not to work with egotistical people who will guide you down the wrong path. Number one, you must get educated and other people will definitely respect your opinion.

### **Another Important Decision**

As a family we could see the progress our daughter made with her first implant. She was doing so well. It was vitally important to us that she have the same success with her second implant and that her speech and language continued to mature. The hard decision came that one of us would quit our jobs for up to twelve months to provide the ongoing learning and teaching experiences needed to help her speak. In March 2005 I explained to my employer that I needed to quit my job to help my daughter facilitate her language. I said everything was going great and if they had a position for me in the future I would love to talk to them about it. They were understanding and wished me the best.

So there I was, Mr. Mom, with a thirty-month-old daughter still in diapers and as cute as ever. We spent the next ten months exploring the world and talking a lot to each other. I was the only male at most of

her playgroups or music classes. I looked on the internet for a fathers' playgroup for children but all I found were playgroups for woman who have children. Gabriella and I went to the zoo, we went to the ocean, we saw planes take off at our local airport, we looked at all of the insects, the birds, the flowers, we shopped together naming every fruit and vegetable, we played games together, we watched children's videos together, we looked at picture books together, and I was always explaining things to her in full context so she fully understood. She was at a level where just short answers were not enough. She was very inquisitive and wanted a good explanation of things. Many words, phrases, and explanations were used to enhance her vocabulary, speech, and language skills.

Driving to school in the morning took forty-five minutes. We had a collection of children's songs that was played and we would sing along. She knew the title of the songs just by the first few bars or words. It was amazing. She would say, "Old MacDonald" and I changed the tracks on the CD player, she would respond, "no, no, no," or "yes that one Daddy," by just hearing the first few notes! Then we would sing along together. One of our favorite games in the car would be to look out the window and talk about the weather and name as many different objects that we could find. I would say "What do you see out the window?" She would respond "a sign, a car, a doggy" I replied to her "I see a yellow sign, a blue car and a big doggy" always expanding what she would say. By doing this for a few months she caught on and was more descriptive in what she was seeing. As time progressed and the years went on we would always work on expanding her language. By the third year of school I would ask "what do you see out the window?" She responded, "I see a yellow school bus, I see a man riding a bicycle." These are six- and seven-word sentences. Fantastic! Now let's conjoin the sentences and make one long grammatically correct sentence. "Gabriella, you could say 'I see a yellow school bus AND a man riding a bicycle,'" emphasizing the word AND. We are now talking about a twelve-word grammatically correct sentence—always helping the child understand the next step to expand their speech and describe their environment.

Three critical sets of DVDs that must be used at home in this process are the Baby Einstein DVDs that help facilitate vocabulary and words. We fell in love with anything that LeapFrog produced, including their toys and DVDs. They have one tape that explains the alphabet, one that explains words, and one that explains math. When children are three- to four years of age I feel it is the right age to present this information to them. Another critically important set of DVDs is anything produced by Richard Scary. This gentleman produces the cutest cartoon videos that are very educational. These DVDs explain opposites, large, small, different shapes, counting, etc. On top of learning the child gets tuned into listening to full sentences and responding with answers. I cannot emphasize enough how much our daughter loved all of these videos / DVDs. She has learned so much and this has also helped her language prosper. All children are different but anything produced by Walt Disney is also a big hit in our house.

### **The Transitional IEP**

As a child approaches three-years-old they move from the IFSP process to the IEP process. Everything changes at age three. The IDEA law is broken into two distinctive areas which cover children from 0 - 3 years old and 3 - 21 years old. With the transitional IEP there is a series of meetings to introduce the new team members and make formal evaluations of our daughter's progress. Everyone at the school district was saying how well Gabriella was doing. She was doing great, but in reality this was the wrong thing to say. When the school district responded in this manner we became concerned that they were

going to pull the funding for the following year. We were trying to increase Gabriella's school and therapy time to four days per week starting in September. She did great on any tests given to her but we knew her weak points were expressive speech, spontaneous speech, peer-to-peer communication, and some articulation issues that needed to be addressed.

The meeting ended and the real question was: will the school district still fund JWPOSD in September when Gabriella has her first IEP meeting? This would truly be our worst nightmare, to have Gabriella pulled out of such an excellent school where she had done so well. The end result of the meeting was that she would be getting funding through September 2005. The summer came and I spent time researching everything I could about the IDEA law. (This law was revised and changed by Congress in October 2007. Make sure you are looking at the current version.) I talked with lawyers at AG Bell and numerous other people who have dealt with a school district who pulled funding prematurely. We had a great working relationship with everyone. Never were there any heated moments between our family and anyone else involved in this process. We respected everyone's hard work and truly appreciated their efforts. This was evident with Christmas gifts, cards, and a true sense of Thank You So Much! As I mentioned earlier if you do not have the team members on your side, this process becomes very difficult.

### **A Big Blow**

For about three months our daughter would consistently pull off her right side implant and refuse to wear it. She would always wear the left side but had a real problem with the right side. When children are young and they cannot tell you exactly what they are hearing this becomes a real guessing game. We told this to her audiologist and she suggested having an integrity test done. So we showed up at the hospital and met the Cochlear representative who was to perform the integrity test. First she tested the left ear and everything was fine. Then the Cochlear rep performed a test on the right ear. After a good five minutes of staring at the computer system and going "hmmm," the rep turned to us and said, "There is a problem with this implant." My wife started to cry and we both said, "What is the problem?" The rep performing the test told us that "the results are not consistent with company standards." She went on to explain that there was an intermittent problem and the internal device was not working correctly. I turned to her and said, "Everything works fine, and Gabriella can hear great with the right side implant." Since we were around our daughter every day we knew how well she could hear with both implants. I could not buy into the fact that there was a problem with one device. She hears great with the "bad" implant and can discriminate any word(s) with it.

As the weeks went on we did a lot of testing on the right side implant and it continued to work great. The company's official line was that they wanted to re-implant our daughter. (The problem with re-implantation is that there is no guarantee that the new implant will work as well as the old one. The child could have the same hearing after re-implantation or the hearing may be worse. We did not want to take this chance.) After speaking to Gabriella's surgeon and many other people, we took a "wait and see" attitude and decided to re-implant if the device no longer functioned and Gabriella could not hear from it. God had answered all of our prayers up to this point and I knew this would be no different. So we had a lot to pray for and be thankful for even though the "computer" said there was a problem with one of Gabriella's implants.



All throughout the month of April Gabriella was tested in the sound booth. She was tested for discrimination and every other test you could imagine to see the functionality of the right side implant. Every speech language pathologist working with her said she could hear great, she discriminated great, and she followed auditory-only questions. So I repeated again we were not going to re-implant this device! The end result of all this testing was that her right and left implants worked great. Her audiogram showed that she was hearing between 15 – 25 dB and could hear all frequencies and respond to voice in the 20 dB range. Gabriella could even differentiate the words “pat,” “hat,” “mat,” “hop,” “hip,” “bike,” and “mike.”

I felt that we needed some solid answers to what was going on. As I mentioned before there is sometimes no “right” answer. You must just go off of what your gut tells you. Well, my gut said that her implant worked great and the medical community was just wrong. I then spoke with the senior engineer at Cochlear Corporation. I explained my daughter’s test results and told him that she heard great with her “bad” implant. He mentioned to me that they have had teenage patients that had integrity tests that were “way off” just like Gabriella’s, and they never reported a loss of hearing and they never got re-implanted. The tests were just wrong. The engineer stated that the tests could be wrong due to the “physiological makeup” of our daughter’s ear. Also he said something about the chemical composition of the fluid in her ear having something to do with it. I told this information to Gabriella’s surgeon and she said she would call the engineer and find out exactly what was going on. The surgeon called and spoke to the head engineer at Cochlear. The decision was made not to re-implant and just keep an eye on the right side. To this day the right implant works great and she can hear fantastic with it. In August 2007, the three electrodes that were outside of normal limits were turned off and our daughter still hears great. The remaining electrodes take over the full spectrum of sound so there is no loss of frequencies.

## **Progress Report**

By the end of June 2005 Gabriella was thirty-three-months old. Nineteen months post-implant on her right ear and seven months post-implant on her left ear. She is now saying spontaneous three-word sentences and has a vocabulary of 175 - 200 words, lots of two- and three-word combinations. We are still working on spontaneous five-word sentences, verbs, more expressive speech, and ongoing dialogue. The ongoing dialogue is rated by how many exchanges a child will take. We are also working on “what,” “when,” and “where” questions. Gabriella is singing complete songs on her own like “Row, Row Your Boat,” “Old MacDonald,” “The Wheels on the Bus,” etc. She knows all of her colors, shapes, letters, and numbers. She now counts to twenty and knows the entire “ABC” song from start to finish. Getting around and being exposed to normal hearing peers as much as possible was a big reason for taking time off from work. This is what’s needed as children grow older and become more confident in their language abilities. At this point more complex receptive language is introduced and the expressive language will follow. For example, questions would be asked such as “what barks?” “What is red and grows on trees?” “What do you wear on your head?”—descriptive questions used in an open or closed set format.

We were still visiting her other speech therapist at the local children’s hospital, but only one time per month. After some testing and an hour of therapy the therapist said to my wife and me that “Gabriella is currently at age level for receptive language, and is getting much closer to age level on her expressive language.” I had heard the same thing from other therapists, but to be honest I did not really believe it

because I did not want to shortchange Gabriella on the therapy she needs. I also did not want to remove her prematurely from her great auditory oral school. It is amazing to think that the “professionals” are telling us that she has the same capabilities of any other child with normal hearing. Both of Gabriella’s ears hear the same and her newer implant only took four months to catch up to her old one.

### **The Third Year**

The summer went past us and Daddy was working on potty training and everything else a three-year-old child needs. We attended three weeks of summer school at JWPOSD. We went to Disneyland and did a lot of adventures to expand the world around this bright little girl. In September we had our first IEP meeting and after doing months of research I felt prepared to handle any objections the school district might throw at us. Every IFSP / IEP meeting was attended by either the principal, director, therapist, and/or teacher from the Jean Weingarten School.

The meeting started and my wife and I had three school personnel with us. The school district had their director, their SLP, a psychologist, and the teacher of the “Communication Handicap” class they wanted Gabriella to attend, a total of nine people in this meeting! We reviewed the previous goals and discussed test results and our daughter’s progress. We also discussed where Gabriella was lacking in speech and language, and her future goals. Would we get funding for next year? Would the school district want to pull funding and rely on their in-house program? This was a big concern and at the end of this meeting we would find out the answers to these very important questions.

Because we felt Gabriella needed four days at JWPOSD and the school district thought three days were more appropriate we had to compromise. In reality our daughter was doing great and three days at the private auditory oral school, I am sure, would have been fine. I did not want to look back and think Gabriella did not get exactly what she needed. After some very careful consideration and speaking with my insurance carrier I agreed to three days funded by the school district, one day privately paid, and one day per week at the school district’s “language” class. This is now a full five-day schedule for this three-year-old child.

### **The Program**

Our daughter’s program now consisted of four days of auditory oral class, 9:00 a.m. to 2:00 p.m. Monday through Thursday. Within this time period she was pulled out for a forty-five-minute therapy session each day. In the morning from 8:40 a.m. to 9:00 a.m. she attended her music class with approximately twenty-five other children who wore cochlear implants. On Fridays she would attend her local school district class with other three- and four-year-olds. Because the district only had a Total Communication class and did not have an oral class for deaf children she was placed in a class with other hearing children who were behind in their language skills.

There were many things being worked on and addressed in the IEP process. We wanted Gabriella to socialize more with other children and use spontaneous language. She always did great around adults but for some reason with other children she was very apprehensive. Her ability to retell or paraphrase a story with more than just short three- to five-word statements was being addressed. It seemed like you always had to “pull” the next statement out of her; she just would not want to be very expressive. Her abilities

were fantastic. We noticed in many situations at home she was very expressive, very talkative, and loved to speak. But for some reason at school she was much more “quiet.” So in reality it really had nothing to do with her ability, but the use of language in a natural setting. This was the terminology we were all using to address this particular issue.

Class consisted of talking about the weather, talking about what the children did over the weekend, exploring bugs, flowers, books, pictures, etc., very open-ended descriptive explanations of the world around them. There was an assistant to help feed in language as needed when the children became stuck. This class consisted of a total of four deaf children with cochlear implants and one hearing child, all the same age. Again, the hearing child is in the class to model language for the other children. This entire process consists of raising the bar ever higher so the deaf child can move on to the next level in natural language acquisition. If they are working on five-word statements then we modeled two five-word statements conjoined together with “and,” “or,” “but,” etc. If they understand the name of various items we will expand their vocabulary by explaining other synonyms. Discussions of how items are grouped together would be covered such as what items belong in the food group, the clothes group, the toy group, etc. Even tricky exercises were done such as “what item does not belong” and why? All of this would be taught in the classroom in a natural setting. It is also important to teach children when and how to use language. Manners were worked on, such as taking turns, saying please, asking a child if they can play together, etc.

### **Therapy time**

Four times per week for forty-five minutes Gabriella would attend therapy. Fortunately for us this school provided excellent therapists with all the right certifications and education. Most therapists who do this type of work are either Teachers of The Deaf, or Speech Language Pathologists.

With this being the third year in therapy, the language skills were beginning to blossom. The therapist would work on descriptive questioning, memory skills, three-step commands, synonyms, ongoing dialogue, recalling information, groupings, auditory-only responses, etc. For example, here are some of the questions that would be asked: “What can you tell me about this picture you see?” “What did you do over the weekend?” “What else can we call a dog?” “Which group does the lemon belong in?” All of the questions in these examples are open-set and the child has to recall from previous experience the correct answer. The child needs to respond in full grammatically correct sentences such as, “A dog can also be called an animal,” “The lemon belongs in the fruit group,” etc. To work on expanded sentences and ongoing dialogue the therapist may put a toy or some other object on the table and ask “What can you tell me about this toy?” As the child says a few things in short sentences the therapist will add “and,” “what else,” “what about,” etc., always trying to get a few conjoined sentences together and a longer description of a particular object. Occasionally another child was brought into the therapy room to facilitate peer-to-peer ongoing dialogue.

Around November of 2005 we noticed a little bit of stuttering with Gabriella’s speech. It progressively became worse over the next two months. I mentioned this to her therapists and each person had an opportunity to look at Gabriella while she was having a hard time with speech. It seemed that her spontaneous sentences were the culprit, especially with words starting with *I*, *W*, *K*, *T*, *Y*, *A*, and *D*, being the worst. Some examples of the sentences that Gabriella had problems with were, “What are you

doing?” “I want to go outside.” “Can you help me?” “Are you playing with a game?” “Do you want to play?” etc. This was actually diagnosed as being a “partial word repetition dysfluency.” Most professionals felt that this was a temporary issue due to her mind working faster than her mouth. Over the next eighteen months she did self-correct, and her stuttering went away.

As a new year was upon us I looked for a job and felt that our daughter was on her way to gaining great speech and language. Looking back, the time I spent with Gabriella over those ten months was truly amazing. She is such a lovely girl and I enjoyed every minute with her. We did a lot together like going to the zoo, to the park, feeding the ducks, looking at the hills and the trees, and having picnics. And at every turn of every day I tried to get her around fully hearing children to play with. Gabriella and I played at different music classes where I was the only man there. I took her to children’s play groups where there were ten mothers, and me. Never did I feel out of place because I had my daughter with me. This is a time I will look back on in my life and remember all of the fond memories of being able to be with my daughter over such a long period of time.

The nice thing about the school she attended was that even if I could not be in the therapy room with my daughter, there were windows and headsets for a parent to listen and watch. This gives parents exactly what they need to formulate the correct type of questions and dialogue at home. Taking what is being taught in school and helping your child become an even more proficient speaker at home is the role of the parent, and in my opinion the only way this process can work perfectly.

### **Volunteer Work**

Looking at the great speech that my daughter was acquiring and all of the hard work that everyone at the school was putting into it, I wanted to know that this school would be around for every parent and child who came after us. They have been doing this great work for over forty years and they need to be here at least another forty years! That is why I volunteered every year to help with the school’s November benefit auction. Never in my life have I volunteered for anything, but raising money for this particular school was extremely important to me. I could see the miracle that was happening with our deaf child and I wanted every family to have the opportunity to get the services their child so desperately needed. Opening up the world’s eyes to the wonders of cochlear implantation and early intervention services was very important to me. Many people to this day do not understand what deaf children and deaf adults can achieve, but my daughter was living proof. Every time I saw a child at her school I was hoping that that child could do as well as my daughter.

The key here is to give back to the people who are giving your child a voice. I have seen too many instances where parents may be working two jobs, or they may be busy. I understand. The problem is that some parents do not look at what is really important. They do not write that check for \$100 or \$200, even though a dinner and a night out on the town could easily cost this much. What is really important? These same parents could take one day of vacation and volunteer for eight hours. Who needs three weeks of vacation? What is one day? Nothing. Look into a child’s eyes who is acquiring speech and you will know that your time and your money might be the difference between that child and possibly even your child receiving the services they need.

## Home Sweet Home

My experience relies on having a very close relationship with everyone involved in this process: my daughter's school, her therapists, her audiologist, her doctors, etc. I am only writing this book from what I have learned throughout this four-year process. We have only one child, a great family support system, and we did have the insurance and means to supply everything needed for our daughter. But as I said previously, one of the absolute most important factors is what the parent does at home and how diligently they obtain services for their child, services the child is entitled to under the IDEA law. As Americans we pay a lot in taxes, and I did not feel "guilty" about having the federal government and local government finally step up to the plate and help my family. As a parent you must be your child's best advocate and KNOW what that child needs. Do not just go off of what other people are telling you. Three people may give you three different answers. I am hoping this book can be a "roadmap" of needed services for any cochlear-implanted deaf child. Again, your child is probably different and their program may vary.

Chapter two explained in detail many things that need to happen in the home. Please follow these guidelines and as time goes on you can talk with your deaf child just like any other child. Do not look at this process as constant work, or that you are putting your child through constant drills. Here is the simplest way I can explain this three- to five-year transformation of having a deaf child "listen and speak" just like a hearing child. If you can remember this it will be easy to explain to other people the process your child is going through. Deaf children with the proper amplification and early diagnosis learn speech and language identical to hearing children. They go through the same hierarchy of language and learn just like any hearing child. The difference is that our children and the professionals and parents that work with them take every single part of the receptive and expressive hierarchy, break it down, and emphasize each of those parts for months, until the child becomes proficient. Then we will move on to the next step in language acquisition, always reaching for and expecting proficient language and speech from our children, consistently reaching for the next level. A hearing child will acquire language through listening to other people. Our children must be told the same words and the same phrases hundred of times until they master them. In the beginning they need visual cues and as time goes on, auditory-only even with some background noise present should be no problem for these kids. Repetition is the key to learning.

Understanding language acquisition and knowing exactly where your child is on this scale is crucial. This is the basis of every IFSP / IEP meeting, and the services that are needed, and what you should be doing at home. If you do not know this as a parent how can you help your child? Do not leave this to other people. You are a team member just like everyone else—in my opinion the most important team member. The parent's role is to play quarterback and facilitate the entire process. It is a lot of work but at least you will never look back and say to yourself "maybe I could have done more." I knew this question would never enter my mind because even if my daughter had the worst speech and language skills of any child, I would know in my heart that I had done everything possible for her. I would love her just the same and be so proud of her for the accomplishments she did achieve.

As the quarterback and facilitator of this process it is important to keep all team members knowledgeable of any medical reports, hearing tests, IEP meetings, etc. You are the purveyor of important information and as you learn things from each professional the information must be passed on

to help the next person do their job most efficiently. The time will come when your knowledge will be at a level that these professionals respect your opinion and what you are trying to accomplish for your deaf child. For example, I strongly felt that in year four my daughter needed fewer auditory oral services and more mainstream experiences. This was completely different than what the school suggested but I respected their opinion and they respected mine.

We knew her right implant failed the integrity test, but because my wife and I were around Gabriella every day we knew her implant worked properly. We strongly felt that re-implantation was not the answer at that time. You need to research everything that comes your way and let other people know what is behind your strong opinion for doing one thing or another. Please do not get too confident; we are parents, after all, and do not have a formal education in these matters like the professionals we are working with. We are working with one child and they have experience with numerous children. They will guide you in the right direction and do what needs to be done over the course of habilitation that your child needs. You will get different opinions from different people and as the parent you need to sift through this information and come to the RIGHT decision. Only one chance—time is too precious. Good luck. This author and this book are here to help

### **Progress Report**

By the end of June 2006 Gabriella was forty-five-months old. Thirty-one months post-implant on her right ear and nineteen months post-implant on her left ear. In my mind she was age-appropriate in language, speech, and articulation. Even though the professionals had told us this months before, I now agreed with them. It is hard to know what is age-appropriate when you only have one beautiful child. We conversed with Gabriella just like any other forty-five month old, working on imaginary play, abstract language, conjoining more sentences, ongoing dialogue, etc.

With the help of the various videotapes and DVDs she watches at home she understands the entire alphabet phonetically, she counts to fifty, knows every color, shape, and understands opposites, up, down, below, inside, out, etc. She knows the world around her and comprehends how things work, such as the weather. She can spell about fifteen words and can read most of her children's books. To this day we do not understand how she learned to read because she reads whole word and does not sound out each syllable.

Auditory-only comprehension is the norm for our daughter at this point. A conversation can be carried on with no visual cues, and questions can be asked even with background noise present. Not once have I ever been anywhere and noticed anyone acting as though she had a speech, language, or hearing problem, because at this point she does not.

### **The Fourth Year**

Summer went by and we spent another three weeks at summer school. I was so excited at how well our daughter was doing. If she had gone 100% into a mainstream preschool I do believe she could have adapted well. Just so we did not take any chances or make any mistakes, one more year at JWPOSD was what everyone thought would work best. After another IEP meeting we all agreed on three days at this special school plus two days in the Head Start preschool program at our local school district. The real

question was should there be three days of mainstream experience per week or only two. Either one would have worked out fine, but we settled on only two days per week of mainstream preschool. We all knew that a fully mainstream kindergarten was the next step after this school year. The journey was getting close to being over; we could see light at the end of the tunnel.

## **The Program**

Our daughter's program consists of three days of auditory oral class from 9:00 a.m. to 2:00 p.m. Tuesday, Wednesday, and Thursday. Every morning a twenty-minute music class is held so the children can sing and act a little silly. There are four cochlear-implanted students and one hearing child in her class. During the school day she is pulled out for forty-five minute therapy sessions. On Mondays and Fridays she attends her local school district in the Head Start preschool program. This program has twenty students ranging in age from three to five years. So, as far as age is concerned our daughter fits right in. This is a fully functioning mainstream preschool with no special services provided to Gabriella because she is deaf.

Up to this point we have not used any assisted listening devices because with two implants our daughter hears very well. We did demand that a Teacher of the Deaf from her JWPOSD school attend the Head Start program for five sessions to make sure that the acoustics, instructional style, and comprehension of the language were adequate. We knew as long as our daughter heard everything she would do great. For whatever reason Gabriella still kept very much to herself. She did not socialize much, and she initiated very little expressive language with the other students in her mainstream class. With adults it was completely different. She was a little chatterbox. Even at home when she had a friend or two over that she knew well she would be very expressive and kept up with the back-and-forth dialogue.

At JWPOSD class and therapy revolved around social interaction, demanding what you want, understanding feelings, comprehending stories, abstract language, asking for clarification, etc. On many occasions two classes were joined together for a total of ten students. This helped with the realization that on the outside most class sizes are twenty kids and the comfort of a small class would be a thing of the past. At this point the teacher might read a lengthy story and ask the students various questions about it. This required excellent listening and reasoning skills. The obvious questions were then asked: "Why did he do that?" "What do you think would happen next?" "What should Johnny do now?" and so on. The fact that these kids go through so much training where there is an absolute right and wrong answer gets them to feel uncomfortable with taking a chance if they are not certain of themselves. The basis of these exercises is to explain to the children that sometimes any answer could be correct. It is OK to take a guess, and sometimes three kids could all have the right answer. There does not always have to be just one correct answer. Listening to the question, sorting out the facts, and taking a stab at what the child feels is correct is OK. Reassurance and praise is always given for trying.

One great thing about the JWPOSD is that they spend a few weeks on a particular subject and they dive deep into it. For example, every summer school session had a theme to it, every holiday was recognized, and during Thanksgiving, for example, the kids spent a lot of time on food. The oceans were explored, the forests were explored, the bugs and animals were explored, too. Learning was truly fun and not just a chore. The therapist would construct their therapy session around whatever the theme being taught for

that time period was. Each week a letter to the parents was emailed to inform all parents what theme they were working on and suggestions of things to do at home to carry on that particular theme.

Stepping back and feeding in less language in class was important. It was now time for the children to talk among themselves without support from the teacher. As the children were playing if they did not react to a student's request the teacher might pose a thought provoking question so a problem solving skill could be adapted.

### **Therapy Time**

Inferencing, along with abstract language, problem solving skills, sequencing, and retelling a story would be some of the skills worked on in therapy. The teacher would pull out a picture book with no text in it and say, "let's make up a story. I will talk about the first page then you talk about the next page." So the therapist started the explanation of what she saw in the first picture. The student then would take that and expand on the story. They were just making up a story and it could go in any direction. The key was to get a lot of expressive language and storytelling going on. Recalling information with questions such as "what did you do over the weekend," was worked on. Then the all-important "Really? Tell me more about what you did."—no ideas or suggestions from the therapist. The child can talk about anything they want to as long as it pertains to the question. If it does not pertain to the question the therapist took a step back and said "Is that what I asked you?" Explanations and staying on subject were always emphasized.

At this point Gabriella was much more conversational. Class time consisted of expanding language, correcting language, having fun, and learning the rules of conversation. Giving a series of choices so the child could decide for themselves was another skill which was worked on. Cause and effect were covered. Language is very dynamic, and even though a child can speak well, certain questions must be asked—can they think for themselves, can they problem solve, can they understand abstract concepts, do they follow the rules of conversation, is their speech grammatically correct? One of the most important things to always keep in mind would be is their articulation mirroring that of a normal developing hearing child? Clear articulation with normal speech sounds at various ages will ensure very clear speech.

### **Head Start Program**

On Mondays and Fridays our daughter would attend a fully hearing preschool provided by the school district. There were twenty children in this program, which ran from 9:30 a.m. to 12:30 p.m. This was our opportunity to tell how well Gabriella would do in a mainstream environment. Also I never wanted her to leave the comforts of a five-student class with a lot of one-on-one instruction and get thrown into a class of twenty students with background noise. There needed to be a transition period and this was it. Looking back, I would have preferred that the teacher use a sound field system in this classroom for optimum signal-to-noise ratio. We did not feel it was needed at the time, so we did not ask for one. FM systems in my opinion tend to be very problematic and they need to be functioning just right all the time. Sound field systems are simpler and actually help every student in the room.



## A Four-Year Degree

June 2007 was approaching fast. The excitement of Gabriella leaving this excellent program was overwhelming. We were so proud of her accomplishments up to that point. She was still a very young child and yet she had four years of school behind her!

The empty feeling of not being associated with the Jean Weingarten program any longer was a little hard. I knew as time went on this school would be on my list of charitable donations and I would always be available to help any parent coming up through the ranks who needed a word of advice or encouragement. This had been four years of intensive training, at times never knowing where the next hurdle would be, never knowing what the end result would be, and never knowing if Gabriella would truly speak and converse in an intelligible manner. By year three these concerns were behind us and at the end of year four we knew she had normal speech and language. She could hear great and understand any question posed to her.

So the last day of school came and Gabriella read, (and I mean literally read) a thank you letter to all of her teachers and therapists. This truly felt like our daughter was graduated from the most prestigious college in America with a 4.0 GPA. She was graduating, and the entire world was in front of her to concur. I could not have felt prouder had she been graduating from Stanford, Harvard, M.I.T., or Cal Berkeley. This was her success and it was as good as any education any college could ever give. I then went to the front of the room and said a little speech and presented the school with the following plaque:

Walking Through These Doors We Only Had a DREAM

Day By Day We Saw PROGRESS

The Caring Staff Brought us HOPE

In The End We Found LOVE

Thank You J.W.P.O.S.D. For The PRECIOUS Gift of Speech

Love Always,

Gabriella Hall and Family

June 2007

To look beyond every capitalized word the meanings in my mind are profound.

Walking through the doors of this school looking for answers and explaining that our ten-month-old child had a hearing problem was full of uncertainties. However, I knew that we were in the right place.

At that point in time and for about two more years, we could only DREAM that our daughter would speak normally, never knowing if this was even possible.

In the beginning, progress was slow. But as time moved on so did the amazing progress we saw our child make. At about twelve months post-implant a language explosion happened and she was learning new words all of the time. She would put two words together, then three words, then four words. The PROGRESS was always apparent and we knew she would continue to move forward.

Every time we were let down through a hearing test, a medical report, or an IEP meeting that did not go right, the staff picked us up and said “it will be fine, keep moving forward.” The biggest “HOPE” we ever saw was just after our daughter was diagnosed as being profoundly deaf. We were invited to watch some cochlear-implanted four-year-olds in their classroom setting. These children were talking, asking questions, responding to questions, and following the conversation with great articulation. We had HOPE our child would one day speak just like these beautiful children.

Being around the most caring people who truly want your child to succeed fosters a great deal of respect and LOVE. I can say that we LOVE the many people who have helped Gabriella along the way, for truly putting everything they have into their work and the success of our daughter. We have friends for life and are forever thankful that we met such dedicated professionals.

Speech is truly PRECIOUS. Being able to live an independent life without interpretation, being able to choose any career you may want, being able to order your own food, and even hear that whizzing car that may strike you is truly PRECIOUS. Speech and language leads to the ability to open up your personality to anyone willing to listen, the ability to convey your deepest thoughts. Not in a basic rudimentary way but in an exciting thought provoking way that truly gets your words across to the listener.

The empty feeling of leaving the school and not being around the many people we had grown to trust and truly care for was hard. These people have given our daughter the gift of speech and we will always be thankful. In my mind, this school and numerous schools just like it throughout the country must continue on with their work. If the public knew what is possible with cochlear-implanted deaf children the money would pour in and every child would have a fighting chance to gain great speech and language. But the public doesn't know, and many schools struggle to make ends meet. I am hoping with your help and my help we can make the program I just explained in this chapter the standard of care for deaf children who want to acquire great speech. I encourage everyone reading this to please donate your time and money to the organization(s) you feel are close to your heart. Oral deaf education is close to my heart and one day I hope to open a school such as JWPOSD in one of the most scenic and remote corners of America.

Our local school district was an instrumental part of this entire process. There are people in the special education department that we highly respect, and we hope that they can help every special needs child just like they helped Gabriella. We have all learned a lot in this process, without having truly known what the end result would be. For their unwavering support and dedication throughout this process we provided the following plaque to our school district.

Thank You For...

Having the DESIRE to Help a Child in Need,

For

Having the VISION to Change a Child's Life,

For

LISTENING to Other Professionals,

For

Breaking Down a World of SILENCE,

For

Giving a Little Girl the Precious Gift of SPEECH.

With sincere appreciation of all your LOVE and SUPPORT,  
we thank the entire staff of the S.L.U.S.D.

Love always,  
Gabiella Hall and Family  
June 2007

Every capitalized word on this plaque has a deep meaning to me and my wife. We truly can not explain the gratitude we have that these professionals could listen to others and have the vision we had in our minds. It was truly amazing to watch this vision materialize in a matter of four years. No one knew the end result, but thank God that the pieces were in place, the program was in place and we now know what the outcome can be for a child given the right tools to succeed.

### **Progress Report**

By the end of June 2007 Gabiella was fifty-seven-months old. Forty-three months post-implant on her right ear and thirty-one months post-implant on her left ear. By all measures, Gabiella has normal speech and language. She does great in background noise, can follow any question auditory-only, can respond to faint whispers, and is very inquisitive about the world around her. She is a little timid around other children but in the right setting she is very expressive and carries on a conversation just like or even better than most five-year-olds.

Her testing in the sound booth shows that she is hearing between 20 dB – 25 dB across all frequencies, with 15 dB speech recognition. Her open-set word recognition is 92% in the left ear and 96% in the right ear. She can distinguish many rhyming words and rarely makes a mistake in this area.

We have included her in various medical studies to help the researchers find the “best” way to educate deaf children using early intervention. On to mainstream kindergarten, we have an IEP meeting in September, and look forward to a relaxing summer.

### **Mainstream Kindergarten**

Another summer of the Little Gym, parks, games, and playing with other hearing children. We wanted to put her in a swimming class over the summer but because she cannot hear a thing without her processors, how would she understand the instructor? She reads lips pretty well but could only really distinguish conversations if people were looking right at her. Knowing a little bit of sign language in this circumstance would be very beneficial.

Getting ready for the IEP meeting, the school district performed many speech, language, and cognitive tests on our child. We all met in early September. Gabriella’s therapist from JWPOSD attended, along with our local school district’s principal, SLP, psychologist, classroom teacher, and caseworker. We wanted a sound field system, a deaf and hard-of-hearing specialist to monitor the new class, weekly speech therapy, and ongoing progress reports. What Gabriella qualified for was a little different. Her testing results indicated that she was in the 84<sup>th</sup> – 97<sup>th</sup> percentile for speech, language, and cognitive skills, with an age equivalence of 6 yr. 3 mo. – 7 yr. 2 mo. This is a full one to two years ahead of her hearing peers. She did not qualify for any speech services through the school district’s special education program. (We had some language skills that we felt needed to be worked on in therapy, but we would just need to address these at home.)

Formal approval for a sound field system and a number of visits with the school district’s deaf and hard-of-hearing specialist were granted. This was to ensure that Gabriella was hearing everything, comprehending the language, that the background noise was not too loud, and that she socialized and conversed with her peers. The progress reports were just the standard reports that any child would receive. This was not exactly what we felt was needed in Gabriella’s case, but up to this point who could complain? We felt very fortunate to have our daughter in a mainstream classroom being treated just like every other child with no special services.

My wife made a point to help the teacher one day per week so we could also see how our daughter was getting along. As the years go on to first, second, and third grade sometimes hearing-impaired children get lost because the language becomes more abstract and less hands-on. Staying focused on her education and making sure she does not get behind as the years progress is very important. I do feel fortunate that being in the special education IEP process has given us the ability to have a close relationship with the school district and the progress of our daughter’s education.

### **Looking Back**

If someone had said to me four years ago, “Your daughter will have perfect speech and language even though she is deaf,” I would have thought they were crazy. I have never seen a deaf person with perfect speech and language, and every deaf person I have ever seen uses ASL. Sure, I thought, speech is possible, but perfect speech, I don’t know. I just wanted my child to communicate. We have been blessed with a medical miracle and now I hope I can turn to you and say perfect speech is possible with

the right program and the right technologies. No matter what the end result is, put your entire life and heart into it and whatever the outcome, be happy. Look on the positive side. I have seen many children on TV and in the hospital literally fighting for their lives with leukemia, brain tumors, heart conditions, etc. Our deaf children are healthy and happy. The only thing is that their ears do not work properly. Please be thankful for what you do have. When you see a family or child that is fighting for their life and suffering from some dreadful disease, please give a word of encouragement or a donation to help that family.

Please understand also that I have the highest respect for all deaf people no matter what language option is used. Many deaf people would not want to have cochlear implants and that is OK. Many deaf people may not have had the option to get implanted, or attend an oral school, I understand. But for my family this was the right choice, and I am thankful that medical technologies have come such a long way.

## **Chapter 7**

### **Who Will Pay for This?**

\$55,000 for auditory oral training, \$45,000 per cochlear implant, \$10,000 for private speech therapy and second opinions, \$5,000 for mappings and hearing tests, \$3,000 for doctor appointments, \$200 per year for parts and maintenance. Who will pay the \$110,000 - \$160,000 needed to see your child through this process? What is needed and what is available don't always coincide. This book has explained what is needed; now we will look at what is available and how to get it.

The IFSP / IEP process is based on the IDEA law and states that "every child is entitled to a free and appropriate education." This law also uses the concept of a "least restrictive environment." This law and what is written within it will be the driving force behind the services your child receives. Because we are concentrating on young children under the age of three we will concentrate mainly on the IFSP process. Nolo Press publishes some excellent books on the IFSP / IEP process that are essential in your education. Please read these excellent books.

A free and appropriate education basically means that your child, even though they are deaf or hard of hearing, should have the opportunity to learn general curriculum material in the least restrictive environment. The school district or regional center is required by the IDEA law to do whatever is "appropriate" to help that child enter the general curriculum mainstream setting. In the case of cochlear implants it would be an oral education with no use of sign language. Many schools and regional centers do not offer an oral-only program, so they are obligated to fund an outside program. Keep in mind, we are not talking about what is "best" for the child or what the parent feels is the "perfect" program. We are only talking about what is "appropriate." All letters and correspondence on your part need to reflect language that stays within the parameters of your legal rights under the IDEA law. (Please do not sound like a lawyer in your correspondence. A friendly working relationship is what we are striving for.) My experience and my daughter's case revolve around private insurance, our local school district, and the Early Start services provided by the state. I have never dealt with our local "regional center" which is designed to help children with multiple disabilities up to age three. Let's examine each area that affects your child, and the ability to pay for their education.

### **The Early Start Program and the IDEA Law**

Early Start and the newborn hearing screening test are designed to diagnose children with hearing loss and provide services at the earliest possible age. Research has shown that the earlier a child is diagnosed and provided services the better their speech, language, and cognitive skills will be. Once a child is diagnosed the parents should contact the special education department of their local school district. They will start the process to provide a home-based therapist or a classroom setting that will work with your child and teach parent education. This professional will also do an assessment of the child's age-appropriate language skills. We were receiving services three times per month in the home. At eighteen months of age this usually changes to a classroom-based setting. Make copies of all medical reports and hearing tests to help your therapist understand your child's medical condition. All services are provided free of charge.

Having a knowledgeable professional come over every week or two is a good start but is only a foundation for the real work that lies ahead. An IFSP meeting will be scheduled and at this meeting a program will be designed to help your child, again free of charge. When our first IFSP meeting was scheduled I barely had enough time to research anything and did not feel knowledgeable enough to make a decision on my child's future. I refused to sign the document and postponed it until further notice. I needed to find out what programs were available in the private sector to compare to the public sector programs.

There are time frames set to complete the IFSP document, which is a six month agreement between the parents and the school district / regional center on the appropriate program for the deaf child. The parent has the discretion to sign and agree to what is being offered, or present their own case for why a different program would be the "appropriate" option for their child. Knowing that we wanted Gabriella to speak fluently and be able to communicate with the world around her in the easiest possible manner, we knew that the oral-only approach would be the appropriate modality for our cochlear-implanted child.

After a few months, I felt much more knowledgeable about which programs were available to help Gabriella. We then re-addressed the IFSP document in a formal meeting which included the school district personnel and the director from the JWPOSD. We brought case studies, years of experience, and a strong desire to teach our little girl to speak. Even though we were knowledgeable on the IDEA law we did not address it and would only pull it from our back pocket if needed. The meeting concentrated on high language skills, high cognitive skills, cost savings, and being a fully mainstreamed student in kindergarten. (Today there are many studies that show that oral children do much better in school and with fewer support services than Total Communication children or ASL-taught children.) Because an oral-only program was what we felt was an appropriate education, we concentrated on that and talked about the service provider for this type of program. Most school districts, including ours, offer a TC program, so they agreed to fund the JWPOSD school until the next IFSP meeting. (Keep in mind that funding is usually only designated for six to twelve months and can be pulled at any time.)

We always felt that the tuition at an oral-only program and a service provider who had the expertise and experience to teach deaf children to speak were the most important items in the IFSP agreement. Sometimes the school district will offer transportation reimbursement, and I have even heard cases of some medical services being covered through the IDEA. Being fair and only receiving what is necessary is important in building a long-term relationship with the local school district personnel. Medical insurance should cover all medical procedures so it is unnecessary for the school district to address this area of the child's care. In most cases the federal government will treat medical mileage and medical expenses as a tax deduction. We never received transportation reimbursement, and unless you are in a financial hardship I would suggest the same.

The IFSP document covers many areas, such as the child's medical condition, current language skills, home environment, parents' desire to educate, needed services, number of services, and the service provider. One of the most important areas that drives everything is the section on goals for the next six months: if the child is doing very well but has no goals to strive for then why would they need services?

You may get the program you want but not the service provider, you may get the service provider but not the program. The goals may be set too high or too low to show sufficient progress. This is why as parents we must know where our child is and what the next step is in their education. As a layperson knowing very little about oral education and deaf children at this stage of the process, it was crucial to speak with as many professionals as possible for their opinion on the “appropriate” program. (Refer back to chapter six for a guideline on what could be the right program for your cochlear-implemented child.)

If a program or service provider is being offered that you feel is not appropriate for your child, then mediation or a fair hearing process could be your only alternative. Please try to do whatever is needed to avoid this lengthy, time consuming, and expensive procedure. The legal resources at AG Bell along with other organizations could be beneficial for advice or representation if this becomes the only option left.

## **Insurance Companies**

Simultaneously to agreeing on the IFSP document and discussing funding issues you will need to address the best amplification system for your child. From the very first day a child is diagnosed it is crucial that hearing aids go on and an accurate sound booth / ABR test be scheduled. Emotions can be overwhelming at this point but please know that there is hope. My daughter is living, breathing proof.

Many insurance companies do not cover hearing aids and this will need to be an out-of-pocket expense. Do not worry about the cost, and get the best possible aids that your child needs. When the child does receive their cochlear implant you can donate the hearing aid and feel good that you helped a deaf child hear. (Please look into the many organizations that will give loaner hearing aids if you cannot afford your own pair.)

Numerous insurance plans will cover speech therapy sessions and may pay the oral school directly. In most circumstances this is a very limited number of visits and really is only a Band-Aid to the entire habilitation program. In our circumstance the IEP document covered three days per week and our insurance coverage picked up one day per week. We were limited to twenty-five sessions per year, and we used every session for a total of two years.

If you are on a plan with a high deductible it is probably best to switch to one with higher premiums which covers more things. Keep in mind that your child at this point is diagnosed with a pre-existing condition and switching carriers is pretty unlikely, unless you are on an employer-sponsored medical group plan that does not require the recipient to go through a medical review.

Medical billing in general is a mess and you as the consumer must keep track of all your receipts, payments made, etc. These bills will help during tax time, but more important is that when your plan states you did not pay a bill, you owe more money, or you are not covered, you will have proof to back up your side of the story. I have had about \$10,000 of medical billing mistakes overturned just because I was right and the insurer was wrong. To prove my case I needed documentation. Obtain the “plan summary” which spells out every procedure covered and not covered in a thirty- to fifty-page document. This is the formal contract between you and the insurer. Never and I mean never accept anything verbally that you do not agree with. When they say “Oh Mr. Jones we do not cover that,” Or “Gee, Mr.



Jones we only cover that at 50%.” Kindly ask “What page in my plan summary can I find that on?” The person on the phone will have no idea so then you need to go to their boss and get the page number, if they do not have it then go to that person’s boss. Again, we are dealing with a formal contract between you and your insurer. Your obligation to the contract in order to keep it in force is to pay your premiums on time. The insurer’s obligation to the contract is to provide the services as designated in that particular contract. There are no opinions, or “we generally don’t cover that”, or “we feel that...” Ask them to show you where what they just said appears in writing in the plan summary. Sometimes it is written in black and white and you will not have a leg to stand on. Other times the insurer will be completely wrong or misled by assuming something that is not written in the formal plan summary. From my understanding (and again I am not a lawyer) the plan summary changes yearly in January along with your premium increase and cannot be changed unilaterally within the year.

Our insurance carrier had a total of eight words in their plan summary which referred to cochlear implants, and they were: “No amount will be payable for cochlear implants.” I interpreted this as meaning no amount will be payable for the cochlear implant hardware. The insurance company stated that “We will not pay for the hardware, the operation, any doctors appointments associated with the operation, life threatening circumstance from the operation, any long-term care due to negligence, or any injury in the hospital on the day of the operation. In essence you do not have insurance. If anything goes wrong in the operating room, well Mr. Hall you will just need to pay the huge bill out of pocket.” I said, let’s read these eight words together, are you ready? We read them together very slowly and I then asked how they matched their previous statement to those eight words. “Well we feel that...” Hold on, there are no feelings here, let’s look at what is written because I interpret it this way.

I absolutely needed insurance coverage if a catastrophic circumstance occurred in the operating room and my daughter was in the hospital for weeks. I would be bankrupt if I did not have insurance. This is why I pay premiums, and this is why my policy is current and up to date. After three weeks of talking to ever-higher people on the insurance carrier’s staff, including their lawyer, I gave the insurer an ultimatum in writing, either provide underlying coverage outside of the device and operation itself or get sued in a class action suit. They bent and provided a letter stating I had underlying coverage for any unforeseen circumstance in the operation room. Insurance companies will try everything not to provide coverage even though you are covered.

### **Uncovered Benefits**

Let me explain how the insurance racket works. Every insurer negotiates a contracted rate for various services with each hospital and doctor. Outside of the negotiated rate is the retail or cash rate. So when a consumer such as us goes to a hospital for a procedure and we tell the doctor we do not have insurance coverage and will be paying cash they say “O.K. Mr. Jones that will be \$3,000 for that procedure.” Keep in mind the insurer could be paying the hospital or doctor sixty percent or less for the same procedure. You pay \$3,000, the insurer pays \$1,500 and the hospital is happy to wait ninety days for their money! Why does this happen? The default rate for people paying cash is huge so they must charge more. The secret here is to put the hospital’s mind at ease. The first thing you must make clear is that you will not be paying the cash or uninsured rate, you demand to pay the negotiated contract rate that the insurance company would pay the hospital. “By the way I will be paying with a cashier’s check on the day of the procedure so you will not need to wait for your money.” If they do not agree with you go to their boss

and if he does not agree with you, just say “Do you want my business or should I go to a different hospital?”

For my daughter’s operation the anesthesiologist normally charged the insurer \$1,200 and the insurer would pay the negotiated rate of \$400. Which figure are you entitled to? It just depends on how knowledgeable and diligent you are. Believe it or not the anesthesiologist company, which is a private contractor, had the nerve to send me a bill for the remaining \$800 I did not pay! Because I kept all my records and whom I spoke to I presented the cashed \$400 check along with their company’s letter explaining \$400 would be payment in full, and the \$800 was wiped off the slate in a matter of days. Keep your records and notes of everything!

Just like dealing with the school district, be nice, be pleasant, try to make friends and sincerely show your appreciation when someone goes out of their way to help you financially or just with great service. The people working at the hospitals, doctors’ offices, and insurance companies are just regular folks like me and you. Sometimes they have the authority to reduce bills or wipe out money due. You just do not know until you ask. Thank you letters, boxes of candy and a personal visit can sometimes make a huge difference in your negotiations.

I had such a good relationship with the doctors and hospitals and by working with both parties they slashed their normal rates by about \$10,000! My daughter’s operation retailed at \$70,000 (the dummy rate that no one pays, not even the insurer.) When all was said and done we presented cashier’s checks for \$38,000 and everyone was happy and felt good that they were giving a little girl the gift of hearing. Keep in mind that the doctors, the hospital, the procedure, and the quality of care did not change at all, only the amount of the bill changed. As emphasized before, our sincere appreciation in writing and small gifts let these people know we were truly thankful. To this day I try to take Gabriella back to visit every professional that has helped her along the way to let them know that their hard work has made a huge difference in this little girl’s life. When the next family comes along and needs to pay cash they can think, do I need that new Lexus, or do I need to reduce my fees and give this child the gift of hearing? This is a pretty easy decision for most people. Keep in mind that a good doctor is worth every penny they earn, even if it is \$150 for a visit or \$5,000 - \$10,000 per operation. There are circumstances when that doctor is the difference between speech and hearing or sign language. I would hope more professionals would donate their time or fees in these special circumstances.

### **Formal Appeals**

Most insurance companies have a procedure to follow if you would like to appeal a decision. In my case our insurer was local and I met various doctors and administrators in person. In a lot of cases you will need to deal through the mail, Fed Ex, etc. Insurance denials are the area where the Let Them Hear Foundation’s legal team can be a huge resource to you. They may even take on your case and keep fighting all the way to the top until the insurer changes their policy! When making a written argument to the insurer refer back to the plan summary where it supports your case, point out their inconsistent policy, try to find cases they have covered, and most importantly of all address every point individually by number. Give a date they are to respond by, send certified mail with a signature required and CC your lawyer or legal team even if you do not have one! Make it clear that you demand approval of the

procedure, and if they do not approve they must address every point individually and you will not accept a form letter denial. In other words they need to defend their side of the argument with written proof.

## **Private Oral Schools**

Your child's educational facility and the expertise of the teachers and therapists is in my opinion one of the biggest factors of success. The role of the parent is also a huge factor and I would put these two things at the very top of the success hierarchy. The parent is the driver, the facilitator, the advocate, and full-time teacher at home. The school will move the child along in an ever-increasing and challenging curriculum until that child masters spoken language and great articulation. The school will also be the primary teacher to the parent. As I mentioned before, you must have a great relationship with your child's educational facility and they need to have the time to let you observe and teach various aspects of oral education.

There are many schools and programs to choose from. The public school will provide their program, and you will be inundated with programs such as Cued Speech, Total Communication, and others. You will meet people that will tell you they have twenty-plus years of experience in helping deaf children to speak. That all sounds great but unless they have a huge amount of experience with cochlear-implanted children you must move on. Cochlear implants work so well that some of the limitations put on deaf children in the past just do not apply today. We want the teachers to set the bar high and let the child achieve that milestone. We do not want their judgment to be clouded by children they have worked with in the past with 50dB – 60dB hearing levels. We are now talking about 15dB – 20dB hearing with remarkable auditory-only discrimination skills.

The key words and philosophy to adhere to is the Oral Deaf teaching methodology. This methodology is practiced by the numerous Option Schools throughout the US and Canada. My daughter's school was an Option School and the expertise is just remarkable. Option Schools put a strong emphasis on teaching the parent, challenging the child, and improving speech and language to a level that is close to or identical to a hearing child's. Of course every child is different and there are medical conditions that are outside of your control, but these dedicated professionals will do whatever is needed to help that child speak and communicate without the use of sign language. (Contact information is in the resource section for the various Option Schools and Oral Deaf education.)

Some schools will provide the first twelve months of educational training free of charge to the family while they obtain funding from the local school district or regional center through the IFSP process. Obviously the oral school would like to get paid as soon as possible and as a parent it is our obligation to do everything possible to get our child's education funded. This will ensure that money will be left in the pot for the next family who attends one of these fine schools. In our case we had a very educated staff who knew about the IDEA law and the IFSP process, and worked with us to obtain funding. As mentioned before do not place your child into one of these schools unilaterally on a permanent basis, you could be denied funding based on the IDEA law. The language needs to reflect that you are exploring your options in different programs and you have not made a decision on where to place your child. This is true. It does take time to explore different options. (I am not in a position to give legal advice. The IDEA law and other laws change periodically so please consult with a special education lawyer if needed.)

## **The IFSP Meeting, and Backing up Your Case**

We have covered many areas of funding such as private insurance, self pay, the local school district or regional center, and even using the resources of a private oral school. I am sure there are many programs available to help parents with low to moderate incomes. I am not an expert in this area and would refer you to do your own research if you fall into this category. The primary funding vehicle for all services will be the IFSP / IEP document backed up by what is written in the IDEA law. With this said I would like to cover a few very important things that should be addressed when preparing for an IFSP / IEP meeting.

When getting ready for a meeting you should have all of your research done and know exactly what outcome you want from the meeting. This would include knowing what program and service provider you feel is the most appropriate for your child's situation. It also includes an idea of what speech, language, and auditory goals you would like your child to achieve over the next six months. To learn this you must talk with experts and read a tremendous amount very quickly. Your very first IFSP meeting will be difficult because the education level will be limited. Let me say this: if you want your child to be educated in an oral capacity then you must talk with experts in this field and just tell them, "I am having an IFSP meeting in two weeks and my child is eleven-months-old, her hearing levels are 100 dB unaided and 50 dB aided, and her cochlear implant surgery will take place in two months. What type of program would you recommend in her situation?" Ask this of two, three, four experts until you get a feeling of knowing exactly what your child needs. In our case the oral school that Gabriella went to knew exactly what our daughter needed and I went with their recommendations. I always reinforced any and all recommendations by talking to other experts and reading.

Many public schools offer a Total Communication program, but more and more are offering an oral program. The first thing you need to find out is what types of programs does the public school have available. This is different than what type of program they would like to place your child in. After getting a full understanding of this, visit the program, speak with the teacher, and understand the expertise within, then ask yourself if this is the program that you feel is appropriate for your child.

If the school provides TC and you want TC for your child you may have a very hard time to get funding for a private TC program. The same would be true for oral-only. If they provide an oral-only program and this is what you want then there will be real problems in convincing them to send your child to a private program. The only way to address this situation is to look at the program itself and try to break it apart and compare each aspect of it with a private program. You may win, you may lose, but it is guaranteed that it will be a lot of hard work!

In our case and with many parents I have talked with, the situation usually revolves around the fact that an oral-only program is the most appropriate option for their child and the school district does not provide this type of program. In either circumstance let's address backing up your point, and the actual IFSP meeting.

The IFSP document is a six-month agreement between the parents of a deaf / hard-of-hearing child and the local school district. This document is re-written and re-agreed upon every six months until the child

is three-years-old, and then they will be covered by the IEP process. So you have done your research and you know the exact program and service provider you would like for your child's situation. The section on language goals is a bit fuzzier and most of these goals will come out in the meeting itself. Still you should know what you would like your child to accomplish in six months from a layperson's point of view. The language and auditory goals themselves are written very specifically and with terminology that most people outside of the SLP world do not understand. This is done so the goal can be measurable and tracked throughout the course of the IFSP /IEP process.

Take out a piece of paper and write down point by point the program you want for your child, the number of therapy sessions, the amount of class time, the amount of therapy time, extended school year (summer school), etc. Also write down your speech, language, and audition goals, which really do not need to be backed up—they just need to be reasonable and age-appropriate. Look at your paper, compare it to the school district's program, and then ask yourself how are you going to back up every point with written proof?

In most situations letters from various doctors, speech language pathologists, formal case studies, and even letters from other parents can be very helpful. Hearing tests and all medical reports are vitally important to bring to the meeting. The medical case studies will be your strongest resource to prove your point. (My daughter is a medical case that I feel will help many people understand what is possible with oral education in the right circumstance.) Bring three copies of everything to the meeting so you can give one copy to the school district for their records, one copy to the oral school for their records and one copy for yourself. Certain documents you will need to request to be part of the IFSP document and not just put in your child's general file. You will receive a copy of the IFSP. Make sure it includes all crucial documents that support your case. This becomes a little less important if they agree fully with you and then you can retain your own file at home. Have written proof, invite experts to the meeting, and be prepared to back up and defend your position. We always had more than what was needed at the meetings and much of our backup documentation was never presented. This is because our district was excellent to work with and could see the benefits of oral education.

Going into the meeting you should already have a very good relationship with everyone on your team. If personalities conflicted previously, it is vital to send a letter and apologize so everyone will attend the meeting with an open mind. Never talk negatively about any professional's expertise or program. Please do not ever sound like a lawyer because you are not! Listen to every person's point of view intently, even if you do not agree with it. Do not cut people off, and make sure that all parties have a chance to express their opinions.

The background information will be written into the IFSP, the language, speech, and audition goals will be written in, then the all-important question of the exact program and service provider will be addressed. The program is usually discussed and bounced around the room for a while. It is very important to have a professional on your side of the table to designate the exact program frequency, times, and structure. This will carry a lot more weight than if you try to design a program yourself based on what you just learned a few weeks ago. Do not use words such as "best," "better than," "I like," etc. The entire conversation revolves around what is most "appropriate" for the child. Use case studies, stories of previous students' success, etc.

Of course a lot of the information being presented is factual and relates directly to the ability of your deaf child. In reality everyone in the room is a caring human being who probably has their own children. I made a point to bring a photograph of my daughter so everyone knew whom we were speaking of and in the sincerest of voices I addressed the entire room with the following statement:

“I just want to thank everyone for being here today to discuss my daughter’s future educational needs. My wife and I love our daughter more than anything in this entire world, we will do whatever is necessary to give her the ability to communicate with the hearing world around her. You will not find more dedicated parents than we are, we will work hand in hand with the school district to achieve every goal on Gabriella’s IFSP document. We look forward to her attending a mainstream kindergarten when she is old enough. I am asking for your support to please give the oral process a chance and give Gabriella the opportunity to speak. Thank you.”

This was absolutely sincere. If you are not going to pull through and be the most dedicated parents working side by side with every professional, please do not make such a statement. Many districts and professionals have experience dealing with parents who put very little effort into their child’s future. To find a truly dedicated, loving, caring family who has the support system and time to do whatever is needed to benefit their deaf child is a rarity. The district can see this and in a lot of cases will work with the family and provide the needed education with very little resistance.

Many things in life are a trade-off. Trade this job for that job, this house for that house, this money for my child’s voice. You will never appreciate what you have, including your family support structure, until a situation like this is thrown in your lap. You can always get another job, buy a different house, and even take more vacations in the future, but this is not the time. In reality how much do we Americans really suffer? I personally think not enough. There are stories of tremendous struggle of individuals and we look at these stories and are in awe that the person persevered and succeeded. These stories raise us up and make us feel that anything is possible. Now look inside yourself and know that this story is being written about you. You will be the person who will not let anything stand in their way; you will go through the time and effort needed to reach that all important goal: perfect speech and language. Good luck.

## Chapter 8

### A Medical History

Two in one thousand children in America are diagnosed with hearing loss. One-third of all children with hearing loss have additional medical problems. There is an absolute shortage of good oral schools and qualified professionals. These are the facts and to put it all into perspective I have laid out my daughter's medical condition and medical history from birth to age five. With many things in life the earlier the better, especially when it comes to intervention, implantation, and testing for hearing loss. We took what was presented to us and with no formal medical training or knowledge tried to make the best of it.

My wife and I tried to conceive for a total of five years. We were just having one problem after another, never bringing a baby to full term. Then came the day we looked very seriously at adoption. All of a sudden our sixth pregnancy occurred and we hoped that this pregnancy would go full term not knowing what the future would hold for us. On the date of September 23, 2002, Gabriella Marie Hall was born, seven pounds, two ounces, fully healthy and crying up a storm.

**Birth** - September 23, 2002, a full-term healthy baby who passed the newborn hearing screening test.

**Ten Months** - Diagnosed with a moderate hearing loss in the 30 dB – 50 dB range. Hearing aids were fitted and an ABR test was scheduled.

**Eleven Months** - Enrolled in the JWPOSD school for oral deaf education with therapy twice per week. Gabriella attended this school for a total of four years and graduated when she was 57-months-old. Genetic testing was done and found to be normal.

**Twelve Months** - ABR test is performed with a diagnosis of being profoundly deaf with a hearing loss in the 90 dB – 110 dB range. Strong Widex Senso P-38 digital hearing aids were fitted and Gabriella would now have an aided sound booth test in the 40dB – 60 dB range. This is not a significant amount of hearing to gain great speech. It is also such a lack of hearing that many environmental sounds would go unnoticed.

I need to interject my personal feedback on what many doctors, professionals, and educators told us about hearing aids. (This did not happen specifically in my daughter's case but the language still existed and I heard it time and time again. Every professional that worked with our family was great and encouraged us as parents to make the best decision for our child.)

Many professionals used, and I hope it is not the case today, language such as, "Let's try the hearing aids and see how she does, if she does not get sufficient benefit from the aids we can look into an implant." This is a waste of time! The numbers tell the story. Will she get more benefit from hearing at 50dB or 20dB? You as a parent do not have time to jeopardize your child's future. If you feel that you want your child to have the absolute best quality of sound and hear everything this world has to offer go directly to an implant do not waste time. Be forceful but polite and demand a cochlear implant. There is too much science and research that proves hearing at an optimum level and with clear quality sound leads to great articulation and speech. As a layperson it is sometimes disheartening to have to bring this

up to professionals but if this advice is still prevalent than you need to put an end to it because we are talking about YOUR child.

**Thirteen Months** - A decision to have a cochlear implant was made and the first CT scan was taken. The diagnoses of Mondini Dysplasia and enlarged vestibular aqueducts were found. The implant surgeon stated that these conditions form in the fetus in the first trimester of pregnancy and lead to progressive hearing loss due to the fluid in the aqueducts damaging the hair cells in the cochlea. Balancing issues and gross motor issues are also a result of enlarged vestibular aqueducts. Through minor occupational therapy training and some work at home Gabriella overcame these gross motor problems, but to this day still is not as agile and confident as her peers in many gross motor situations.

Mondini Dysplasia meant that Gabriella's cochlea wrapped around the hearing nerve 1 ½ times and not the normal 2 ½ times. This meant that the surgery would be more difficult and a straight electrode array was chosen because of the malformation. (In reality the straight array did not go into the cochlea properly and the Nucleus Contour array was used in both ears, which turned out to work excellent.)

**Fourteen Months** - First cochlear implantation with the Cochlear Corporation's Sprint Nucleus 24 processor unit. The surgery was performed by an experienced doctor who specializes just in ears and head and skull base surgeries. Various shots were given as a preventive measure for meningitis and other infections which have a very small possibility of occurrence during surgery. Keep in mind that your standard ENT probably is not the right doctor for this type of surgery. You need an experienced specialist.

The surgery took place at 7:00 a.m. on a Friday and by 12:00 noon Saturday we were home. Our daughter spent one night in the hospital and was released with antibiotics for infection and some pain medication. The surgery went well and after five days of taking it easy she was back to her normal self. Immediately after a short recovery period of a day or two the hearing aid went back on her left non-implanted ear. There were some minor balancing issues due to the enlarged aqueducts which self-corrected in about two weeks. One week later she was checked by the operating surgeon to make sure the wound was healing properly with no infections. Gabriella wore the body-worn processors for a total of three years and then transferred to the Freedom BTE processing unit.

**Fifteen Months** - The all-important mapping date took place to program her new processor. The mapping generally takes place between four and six weeks after surgery. In our situation four appointments were set, the first two appointments being one day apart the next appointment in four days, and the last appointment thirty days later. The amount of stimulation (or volume of sound) is increased at every appointment along with sound booth checks.

Electrode impedance is tested along with the child being tested on every electrode for sound awareness. If they respond to stimulation on all electrodes this is a great start. It is very important not to expect too much in the beginning. The key here is to have the child bond to the device and not dislike it because it is too loud. The level of speech detection and pure tone detection will increase over time and may start in the 40 dB – 45 dB range.



Speech services one time per week were offered by the implant hospital. Most insurance companies will pay for 20 – 30 speech sessions per year. We continued on with this speech language pathologist for about two-and-a-half years, reducing services as time went on.

**Eighteen Months** - Due to reoccurring ear infections, tubes were placed in both ears and remained until they fell out naturally. This procedure requires that the child be put to sleep and can be performed on an outpatient basis.

**Twenty-One Months** - Receptive language is excellent but behind, expressive language consists of one and two-syllable words.

**Twenty-Four Months** - Gabriella continued at the JWPOSD with classroom and therapy three times per week. Keeping in sync with the therapist and using various strategies at home became prevalent. Gabriella was enrolled in various play and music classes to enhance listening and communication with peers. Playing with hearing children became a very big priority. A decision was made for a second implant. To prepare for surgery, another CT scan was performed on the left ear.

**Twenty-Five Months** - The second cochlear implant operation was performed on the left ear. We used the same device, the same surgeon, and the same hospital. The main difference with this operation and the first one was that due to her enlarged vestibular aqueducts her balance was compromised quite a bit. We were assured that she would have her balance back and walk normal in time. This took a few months but she did make a full recovery and never had an episode from that point forward.

**Twenty-Six Months** - Mapping took place with pure tone and voice sound booth testing. The therapist at JWPOSD worked on the new implanted ear alone for 50% of the therapy time. We used only the new device for one hour per day. Going back to the language hierarchy and working forward taking a total of four months for the new ear to “catch up” with the old ear. Keep in mind that if you just put the new implant on and never take the time to test independently or check for discrimination, etc, how will you ever know the performance of the new ear alone? Today Gabriella’s ears are identical in a sound booth, in discrimination, whispers, or any other test that could be performed. Never take anything for granted. As parents we must check and re-check because we know our child’s abilities better than anyone else. With proper testing at home we will know how well they will do in a sound booth test before even getting to the audiologist’s office.

**Thirty Months** - Gabriella’s older device failed the integrity test. Some professionals were using the terminology of “soft failure,” which is a slow, progressive failure of the device. Re-implantation was discussed but after numerous tests and time it was determined that the integrity testing was inaccurate and this was not a “soft failure.” The device seemed to work fine and three years post-diagnosis it still works great. (Please keep in mind that any results from any test must be taken very seriously. We did not, and I suggest that you never become defensive and not listen to what the professionals are telling you. As with everything throughout this process, listen to all parties concerned, research, talk to numerous people, and then make the best decision. Do not make a decision prematurely without the facts.)

**Thirty-Three Months** - Upwards of 175 – 200 expressive words consisting of one- and two-word combinations. Three-word combinations are being worked on and would soon be mastered. Receptive language is excellent with the ability to answer any question auditory-only, with no visual cues. Articulation sounds have been monitored and tracked since the first implant surgery. If particular articulation sounds were not present then these sounds would be addressed independently. Various oral motor exercises were given to enhance the ability for proper articulation.

**Thirty-Five Months** - Gabriella attends three weeks of summer school every year at the JWPOSD auditory oral school. Year three of training consists of four days of classroom and four days of therapy each week with a twenty-minute music class in the morning. Exploring the world and increasing vocabulary and understanding of the world around us became part of our daily lives. Educational and language-based videos / DVDs and toys were enjoyed from a very young age. Limited mainstream experience in a fully hearing preschool is strongly encouraged.

**Thirty-Eight Months** - Stuttering becomes a concern with first consonants and vowels consisting of I, W, K, T, Y, A, D, being the worst. A “partial word repetition dysfluency” was the diagnosis. By having the child slow down, think about what they want to say, and not get too excited about expressing their needs and wants, this self-corrected in a matter of 18 months, and the stuttering went away.

**Forty-Five Months** - Consistent age-appropriate language is observed receptively and expressively. Normal age-appropriate conversation is carried on daily. Length of utterance is expanded to ten-plus words. Auditory-only responses are the norm. Gabriella’s strong cognitive skills are tested and rank in the 97<sup>th</sup> percentile. Only 3% of all children in her age range would have stronger cognitive skills. She now reads any children’s book put in front of her and knows most numbers, letters, phonics, shapes, colors, etc.

**Forty-Eight Months** - The last and final year at JWPOSD included three days of classroom and three days of therapy. Gabriella attends a mainstream preschool two days per week. This is an uneventful year. All parties concerned are working on expanding language and providing a strong foundation for the fast-paced, somewhat noisy mainstream experience she will be entering next year. At this point, attending a fully mainstreamed kindergarten is an absolute. There is no question that she will be graduating from this excellent program in June.

**Fifty-Seven Months** - Graduation Day! Four years of an intensive auditory oral program pays off. For some children three years may work, and for other children it may take five years. This three- to five-year commitment has changed a deaf girl’s life forever and I hope and pray your child has the same success!

**Sixty Months** – Gabriella currently attends a mainstream kindergarten in her local school district with twenty hearing children. The IEP process continues, but she receives no school-supported or private speech services at this point. The teacher uses a sound field system which may be changed to an FM system as she gets older. Cognitively Gabriella is one of the top performing students in her class. Speech, language, and articulation testing will be done privately every nine to twelve months to make sure her language skills and articulation stay on target. Mappings and hearing tests are performed every twelve months.

## **The Cochlear-Implanted Child**

At about age three I realized that even though my daughter was deaf I looked at her as a fully hearing and functioning child. With her processors she hears everything and without her processors she hears nothing. It was made clear to the school district and every professional involved that any testing on her would be compared to a normal developing child. When statements were made that our daughter was doing “great” my response would always be, “compared to a hearing child?” There were expectations at this point for her to perform and function as if she had normal hearing.

The feelings of being lost, overwhelmed, and shortchanged in life subsided around this time and the only thing that mattered was helping Gabriella succeed in her program. At times I wish my daughter had normal hearing, but I feel very thankful to have been part of this incredible journey and provide the very next best thing for her. Today I never feel sad or sorry for her (like I did when she was diagnosed) because with her cochlear implants she can communicate with the world.

Our little girl is treated the same as any hearing child. At five-years-old she realizes she has a hearing problem and knows that she needs her processors to hear the world around her. Since the very beginning we have called the processors her “pals.” These two “pals” help her hear. This in my opinion has helped Gabriella bond to these devices and for a child it is much easier to understand this word than the word “processor.”

The first thing in the morning are cartoons. Within minutes she will yell “Daddy, I need my pals,” fully realizing that she needs these devices to hear. I know there will be a day in the future that she turns to me and asks why do I have these processors? Why can't I hear? When did I have the two surgeries? At that point she will look at other children and know she is different, she may even become self-conscious about it. Being a girl, she has the ability to hide her processors, but I never, ever want her to be ashamed of needing these devices to hear. Whether the devices are fully visible or not, be proud of the fact that your child has taken this disability and made huge strides toward great speech and language.

### **A Final Thought**

Hopefully the information set forth in this book has provided you with a deeper understanding, and guidance to help pave the way on this journey of oral education. I have tried to list everything that my family and my daughter have been through the past four years. The most time-consuming part of this journey is figuring out exactly what to do. There will be times that you will be given wrong advice, not a different opinion but just plain medically wrong advice. As a parent you need to have the knowledge to recognize that the advice is incorrect and a different course of action is needed. If not you will go down a particular path and a year or two later realize that a very big mistake was made. You cannot gamble with your child's future. Time is very valuable and can never be replaced.

Digest this information, keep it as a reference and a checklist as your child's education continues. Every chapter addresses a specific point in your child's education and future. Read the lines, read between the lines, and really understand what is being said. I would suggest pulling out a paper and writing down the top twenty things that you must do right now and move forward on that entire list. When that list is completed write down the next twenty items. We always had a list of to-do items on our refrigerator to

remind us of what needed to be addressed with our team of professionals. Do not get bogged down with information overload. Most of what I read when going through this process was pretty much the same information reworded over and over. The information I read made a huge amount of sense but to get deeper into exactly what to do really was not there. This is why there are a few books in the reference section that you absolutely must have, such as Ausplan, the Nolo Press IEP guide, many publications from the Moog Center, information from the Option Schools, the Let them Hear Foundation, etc. These books and organizations tell you exactly what to do.

Even though this book is written as a parents' guide, I highly recommend that all family members and close relatives read and follow the advice given. In our case, if my wife and I were to pass away there was no person who could carry the ball forward and continue on with my daughter's education seamlessly. (Whoever took over at that point would need to be on a very rapid learning curve full of frustration and unanswered questions; valuable time could be lost. In addition to this, would their motivations and understanding of this process be as strong as mine to see Gabriella through to the end and acquire great speech?)

Give this book to close family members involved in your child's success. Their education in this process will help your child if they need to be called upon to carry the ball forward. As we go through this three-to five-year journey, educated parents such as us know where we are in the process and where we need to go. Our family members should also know. I did take the liberty of writing a three-page document on how Gabriella was to be educated. There was information on how to maintain the implants, the IFSP / IEP process, and the contact information of every professional on her team. I would suggest the same for you and let other family members know where this document is kept. Make copies, pass it around, and change the document as needed.

It is my goal to help parents and children have a clear path and to actually understand what is possible with cochlear implants and oral education. My goal for the future is to hold educational forums and open an oral school in the interior of this great country we live in.

I wish you the greatest of luck, the greatest of doctors, schools, and programs, but most of all I wish to you the greatest motivation of anything you have ever taken on in your entire life.

Good luck.

## **Chapter 9**

### **Resources**

Just like a craftsman working on a fine piece of art, we as parents must have tools available to help us. The following list of resources, books, toys, and organizations are all geared to help in the oral habilitation process. Having the following programs and tools available to your child will make a huge difference in their educational, auditory and language abilities.

### **Books / Toys / DVDs**

#### **AuSplan Book**

This is a must-have book which stands for auditory speech and language. This book follows the language hierarchy of cochlear-implanted children. Purchase from Children's Hospital of Oakland's Audiology Department.

Phone: 510-428-3885

#### **Baby and Me**

Printed by the Moog center, this book goes through many things that parents must do to help their young deaf or hard-of-hearing child listen and speak. Available in Spanish along with other educational books the Moog center produces.

Phone: 314-692-7172

<http://www.oraldeafed.org/schools/moog/>

#### **Baby Einstein**

This company produces books, videos, and DVDs designed to help infants and young toddlers learn words and explore different vocabulary. The full set can be purchased in stores such as Costco, Toys R Us, Target, etc.

[www.babyeinstein.com](http://www.babyeinstein.com)

#### **Disney Videos / DVDs**

In general many cartoons will help with audition, listening skills, and language, but I find the Disney cartoons and movies very well-made, and most children love them. You can bring all of these characters to life by visiting Disneyland and having a "conversation" on what the child likes, doesn't like, who is their favorite character, etc. Even more complex questions can be asked about the story line, such as "Why do you think they did that?" etc.

[www.disneymovieclub.com](http://www.disneymovieclub.com)

### **Handbook on Developing Individualized Family Service Plans**

This is one of many very helpful publications from the California Department of Education.

[www.cde.ca.gov](http://www.cde.ca.gov)

### **Leapfrog Toys and Videos**

This company manufactures excellent language-based toys that will enhance your child's audition, cognitive skills, and language skills. These toys, along with the videos titled "The Word Factory," "Word Capers," and the "Math Circus" are all must-haves for your child's education. The toys can start with infants and work all the way through to young children six years and older. Purchase at many fine retailers and toy stores.

[www.leapfrog.com](http://www.leapfrog.com)

### **Richard Scarry**

Excellent books, videos, and DVDs that help children learn many concepts such as up, down, big, small, different, counting, inside, outside, around, etc.

Run a Google search on the internet or look in stores for these fine videos, DVDs, and books.

### **Teaching Activities for Children who are Deaf and Hard of Hearing**

Printed by the Moog center, this book goes through many teaching activities to help children who are deaf or hard of hearing.

Phone: 314-692-7172

<http://www.oraldeafed.org/schools/moog/>

### **The Complete IEP Guide**

One of many books needed to become fully educated on the IEP process. Nolo Press has numerous books available on special education and other legal subjects that parents should refer to. These books are available in many book stores and on line.

[www.nolo.com](http://www.nolo.com)

## **Organizations**

### **Advanced Bionics Corporation**

25129 Rye Canyon Loop  
Valencia, CA 91355

Phone: 877-829-0026  
[www.advancedbionics.com](http://www.advancedbionics.com)  
[www.bionicear.com](http://www.bionicear.com)

One of two main manufacturers of cochlear implants. Visit their website, educate yourself, and compare this product with other manufacturers such as Cochlear Corp.

### **AG Bell**

3417 Volta Place N.W.  
Washington DC 20007

Phone: 202-337-5220  
[www.agbell.org](http://www.agbell.org)

This organization is one of the leading advocacy and resource groups for children and adults who are deaf or hard of hearing. There are legal resources available to help with the fair hearing process, educational grants, a large online bookstore, and much more. Become a member, receive the *Voices* magazine every sixty days, and make sure to attend their highly educational conferences held throughout the US.

### **American Speech Language Hearing Association (ASHA)**

2200 Research Blvd  
Rockville, MD 20850

Phone: 800-638-8255  
[www.asha.org](http://www.asha.org)

This organization can provide referrals to speech language pathologists and teachers of the deaf in your area. There are also many good language books on their website.

### **Butte Publications**

P.O. Box 1328  
Hillsboro, OR 97123

Phone: 866-312-8883  
www.buttepublications.com

This company has a huge list of teaching books that are directed toward special education and deaf children. Look at their excellent resources online or get on their mailing list.

### **California Department of Education**

1430 N. Street  
Sacramento, CA 95814

Phone: 916-319-0800  
www.cde.ca.gov

Many very educational books and resource guides are available for a small charge to the general public on subjects such as IFSPs and IEPs. Other special education subjects and guidelines for kindergarten are also available. Please look at their website and call if needed.

### **California Ear Institute**

Main Headquarters

1900 University Ave Suite 101  
E. Palo Alto, CA 94303  
Phone: 650-494-1000  
www.calear.com

San Ramon Office

5201 N. Norris Canyon Road, #200  
San Ramon, CA 94583  
Phone: 925-830-9116

Santa Rosa Office

196 Sotoyome St.  
Santa Rosa, CA 95405  
Phone: 707-528-0565

This business is one of the leading cochlear implant centers in the entire United States. They are working on breakthrough technologies and researching new ways to help children and adults hear better. CEI holds yearly seminars which I strongly encourage all parents and professionals to attend. Their sister organization the Let Them Hear Foundation provides audiology, mapping, speech services, legal help, and much more.



### **CCHAT Sacramento**

9350 Kiefer Blvd.  
Sacramento, CA 95814

Phone: 916-361-7290  
<http://www.oraldeafed.org/schools/cchatsac/index.html>

An outstanding auditory oral school serving the Sacramento Area

### **CCHAT San Diego**

221 Pawnee St.  
San Marcus, CA 92078

Phone: 760-471-5187  
<http://www.oraldeafed.org/schools/cchatsd/>

An outstanding auditory oral school serving the San Diego Area

### **Children's Hospital Oakland**

747 52<sup>nd</sup> St.  
Oakland, CA 94609

Phone: 510-428-3885  
<http://www.childrenshospitaloakland.org/>

This excellent hospital provides mapping services, speech services, etc.

### **Children's Hospital of Philadelphia**

34<sup>th</sup> St. and Civic Center Blvd.  
Philadelphia, PA 19104

Phone: 215-590-1000  
<http://www.chop.edu/consumer/index.jsp>

This excellent hospital provides cochlear implants and audiology services. They have presented many times at the CEI / Children's Hospital Oakland conferences held in the Bay Area. This hospital is one of many fine organizations helping pave the way to better hearing and speech in children.

## **Cochlear Corporation**

13059 E. Peakview Ave.  
Centennial, CO 80111

Phone: 303-790-9010  
Insurance Reimbursement: 800-633-4667  
www.cochlear.com

This company is a leading manufacturer of cochlear implants. Visit their website, educate yourself, and compare this product with others. Join the Nucleus Forum online, which will give you the opportunity to speak with cochlear-implanted adults and parents of young children who have implants.

## **Frontrow**

2080 Lakeville Highway  
Petaluma, Ca. 94954

Phone: 800-227-0735  
www.gofrontrow.com

This company provides soundfield systems and other amplification devices.

## **Head Start Preschool Program**

California Head Start Association

1107 9th Street, Suite 301  
Sacramento, CA 95814

Phone: 916- 444-7760,  
<http://www.caheadstart.org/>

There is one area that is severely missing in the habilitation process for deaf and hard-of-hearing children. That area is the mainstream preschool experience funded by the state. When orally educated children get to a certain point a transition into the mainstream is very important to enhance auditory and language skills. There still needs to be a very close eye on our children to see how well they cope in this environment. The way the system is currently set up is that most families need to pay for private preschool and there is absolutely no feedback or specialized training given to the teachers. We really do not know how well our children are doing unless we attend class every day. We used a 50/50 mix of mainstream preschool and specialized auditory oral training in the last year of our daughter's four-year journey.

Head Start is geared toward low income families and is not geared toward special education children in the IFSP / IEP process. If you do qualify, in most circumstances your child can go to preschool five days per week free of charge! Talk to your local school district about this program.

### **HEAR in Dallas, Inc.**

7518 Meadow Oaks Dr.  
Dallas, TX 75230

Linda Daniel  
Phone: 972-889-0010  
[www.hearingimpaired.com](http://www.hearingimpaired.com)

HEAR In Dallas is a specialized private practice providing individual sessions of Auditory-Verbal and Auditory-Oral therapy and parent education and support. HEAR In Dallas is not a school, but they do provide school support services.

### **Hearing Language Speech**

Marsha Haines  
4340 Stevens Creek Blvd. #107  
San Jose, CA 95129

Phone: 408-345-4949

Marsha is a private SLP who has a great deal of experience in oral language acquisition.

### **Jean Weingarten Peninsula Oral School for the Deaf**

3518 Jefferson Ave.  
Redwood City, CA 94062

Phone: 650-365-7500  
[www.deafkidstalk.org](http://www.deafkidstalk.org)

This is an excellent OPTION school specializing in auditory oral training. This school has an infant program that starts as early as six months of age. They provide parent education along with numerous resources and funding information if you are going through the IFSP process. Contacting JWPOSD is a must if you live in Northern California.

### **John Tracy Clinic**

806 W. Adams Blvd.  
Los Angeles, CA 90007

L.A: 213-748-5481  
Long Beach: 562-426-2257

[www.johntracyclinic.org](http://www.johntracyclinic.org)

An OPTION school that provides free-of-charge parent education videos / and DVDs, an excellent resource for information.

### **Let Them Hear Foundation**

1900 University Ave Suite 101  
E. Palo Alto, CA 94303

Phone: 650-462-3143  
Insurance Advocacy: 877-432-7435  
[www.letthemhear.org](http://www.letthemhear.org)

An amazing organization that helps people on a sliding scale basis. They provide mapping, hearing tests, speech services, and an insurance advocacy program to help with approval of insurance claims.

### **LinguiSystems**

3100 4<sup>th</sup> Ave.  
E. Moline, IL 61244

Phone: 800-776-4332  
[www.linguisystems.com](http://www.linguisystems.com)

An excellent resource for games and books to develop speech, language and articulation

### **Lucille Packard Children's Hospital at Stanford**

725 Welch Rd.  
Palo Alto, CA 94304

Phone: 650-497-8000  
[www.lpch.org/](http://www.lpch.org/)

Cochlear Implant Center

Phone: 650-736-4351

This hospital along with the Cochlear Implant Center provides surgery, auditory, and speech services. They also provide numerous services to children of all ages.

## **Music Together**

66 Witherspoon Street,  
Princeton, NJ 08542

Phone: 800-728-2692  
[www.musictogether.com](http://www.musictogether.com)

This national organization is a great resource to help young children acquire excellent auditory skills through music. They will accept children as young as six months of age, and provide CDs and music books with a paid membership. Reinforcing the class music in the car or at home will demonstrate auditory abilities that any parent can be proud of.

## **Nolo Press**

950 Parker St.  
Berkeley, CA 94710

Phone: 800-728-3555  
[www.nolo.com](http://www.nolo.com)

Nolo Press provides many legal books including the IEP Guide, the Learning Disabilities Guide, and other special education texts.

## **Oral Deaf Education**

Phone: 877-672-5332  
[www.oraldeafed.org](http://www.oraldeafed.org)

Pull up this website and be amazed at the excellent free material available to parents and educators. This organization promotes oral education and has very educational and touching videos, DVDs, and books. Please obtain “Dreams Spoken Here” and “Dreams Made Real.” In essence, read and watch everything this organization has to provide.

## **Option Schools**

Phone: 877-ORALDEAF  
[www.oraldeafed.org](http://www.oraldeafed.org)

The “Option schools” are a listing of schools nationally and internationally who provide oral education to young deaf and hard-of-hearing children. This list can be found on the oral deaf website. Each school shares information and research to help the many other schools that make up the Option School network.

### **Protection & Advocacy, Inc.**

1330 Broadway, Ste. 500  
Oakland, CA 94612

Phone: 510-267-1200  
Toll Free: 800-776-5746  
[www.pai-ca.org](http://www.pai-ca.org)

This organization fights for the inclusion of all disabled persons into society. They have excellent publications and legal resources available.

### **The Auditory Oral School of San Francisco**

1234 Divisadero St.  
San Francisco, CA 94115

Phone: 415-921-7658  
<http://www.auditoryoralsf.org/clinical.htm>

This school is part of the OPTION school network and specializes in helping deaf and hard of hearing children listen and speak.

### **The Moog Center**

12300 South Forty Drive  
St. Louis, MO 63141

Phone: 314-692-7172  
<http://www.oraldeafed.org/schools/moog/>

The Moog Center is an Option School who provides numerous educational conferences and they have excellent books and other resources in English and Spanish.

### **University of California, San Francisco Medical Center**

505 Parnassus Ave.  
San Francisco, CA 94143

Main number: 415-476-1000  
Audiology: 415-353-2101  
Cochlear Implant Program: 415-353-2464

[www.ucsfhealth.org](http://www.ucsfhealth.org)

This is a premier children's hospital located in San Francisco. This hospital provides a cochlear implant program, audiology, mapping, and speech services.

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[www.deafchildrencanspeak.com](http://www.deafchildrencanspeak.com)