# A FATHER'S LOVE

# TEACHING A DEAF CHILD TO HEAR AND SPEAK... PERFECTLY

**BY JAMES HALL** 



#### **ABOUT THE AUTHOR**

Mr. Hall spent four years on a journey 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 daughter born in 2002, who was diagnosed as being profoundly deaf at twelve months of age.

By working with professionals, becoming an expert in language development, insurance, the Individual Disability Education Act law and the Individual Education Plan process, he persevered with one goal in mind, perfect speech for his deaf child. By always knowing the next step in the teaching process and building a reference library of core books, Mr. Hall has been called "a highly educated parent" in cochlear implants and language development by licensed therapists and educators.

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

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# **FOREWORD**

**BY CAROLINE CARSWELL** 

## WHY THIS E-BOOK, NOW?

Sound Advice, the catalyst for this e-book, originated from a social venture in Ireland named IDK (Irish Deaf Kids, 2007-14), whose mission was to empower parents to enable their children to reach their full potential.

#### **THE SITUATION BEFORE 2011**

Before 2011, infants and children in Ireland regularly waited up to five years to get hearing aids via the public health service. Speech therapy services were (and in 2014 still are) equally thin on the ground. Families had limited access to hearing and speech services, a situation creating a neurological emergency for the children, whose listening brains were not getting any sound-stimulation from hearing-aids, to learn to hear and speak.

Every level of hearing loss experienced by these children increased their risk of educational struggle due to correlated linguistic challenges — which unfortunately happened among children born in Ireland before 2011.

#### IRFLAND'S LANDSCAPE AFTER 2011

Today's research shows the critical period of 'learning' [to hear] runs from a mother's sixth month of pregnancy to the child's second birthday and therefore early diagnosis and intervention are essential. Children detected today with significant hearing loss who receive digital hearing aids before the age of 6 months, and a cochlear implant between the ages of 7 months to 1 year can develop language skills similar to children with typical hearing, and

start preschool equipped with these critical building blocks for structured, spoken language.

Knowing this, Ireland's move to introduce newborn hearing testing (through the National Audiological Review, 2011) was a first step in the right direction. Secondly, the children need to get digital hearing-devices as early as possible, with sustained spoken-language intervention in the form of regular auditory-verbal therapy (AVT) from a qualified practitioner, whether this person is practising in Ireland or via teletherapy from outside Ireland.

#### **HOW DO HEARING-DEVICES AND AVT HELP?**

Around the world, deaf babies are routinely known as million-dollar babies. Essentially, deaf "children who do not receive early intervention cost schools an additional \$420,000 [to educate] and face overall lifetime costs of \$1,000,000 in special education, lost wages and health complications." (statistics: MASSHAC, 2012)

Here's where hearing-devices and AVT (as outlined in this e-book) help. Children need digital hearing-devices to hear sounds and to acquire speech and language — the basis of communication for most people. Without this access to hearing — and to spoken language, the children risk lifelong social isolation and having their learning abilities limited both in school and in social contexts, even within their own family environments.

The earlier a baby hears sounds from hearing-devices, the sooner their brain's hearing-system can prepare to process speech and language tones. In babies aged six to 12 months, their brain is processing speech sounds in the same part of the brain that manages motor movements for producing their own speech. When a baby has hearing difficulties that go undetected, they

are incorrectly tracking sound, rhythm, grammar, phonemes and language use. Maybe sound is muffled to their ears or they are missing the rhythm and intonation of your particular language. When the hearing issues are addressed, your child may have a slightly incorrect intonation in their speech but a good speech pathologist will work with your family to address this trait.

Most importantly, if this infant language window is missed, the child is always playing catch-up and may never have clear speech. Children need to hear words thousands of times to process those sounds, before they can say these same sounds and put them into words and finally recognise them in written form. Even when a child hears most sounds without hearing aids, they need to hear small sounds like "s" and "t," and other speech pitches and sounds that we take for granted. This is where life-changing hearing-devices, parent coaching in spoken language strategy and language-rich environments are needed as childrens' brains grow and develop.

Caroline Carswell, Founder, SoundAdvice.pro, October 2014.



# Communication Options Reference Chart

Families are advised to talk with other parents and professionals and to visit programs before choosing a communication option to suit their needs. It is the family's right to make this choice.

	Listening and Speaking	Total Communication	Sign Language	Cued Speech
Definition	Children learn to listen with digital-devices and one-on-one teaching to use their residual hearing.  Visual cues or manual communication are not used, but speech-reading and natural gesture are routine.	Using multiple ways to communicate with a child. Access is given to a signing system, finger spelling (manual alphabet), gestures, speech reading, body language, oral speech and hearing-device use.	Manual language distinct from spoken language e-SL - does not use spoken-language grammar or syntax).  Mainly used by the signing deaf community. Written language is taught as a second or additional language.	Visual communication system of eight hand-shapes (cues) to indicate different sounds of speech.  These cues are used while talking to make spoken language clear via vision. This system allows a child to identify sounds that look alike on the lips.
Primary Goals	To develop speech with hearing-devices, and to teach strong communication skills for the hearing world.	The idea is to teach vocabulary and language at multi-sensory level. Presented as a convenient communication method for a child and their family, teachers and schoolmates.	To be the child's primary language and allow communication before learning to speak or even if the child never gets to speak at all.	To develop speech with hearing-devices, and to teach communication skills for a life in the hearing world.
Language Development (Receptive)	Child learns to speak with early and consistent use of hearing aids and /or cochlear implant and/or FM system with some speech-reading.	A child's simultaneous use of speech and sign is encouraged with exposure to spoken and signed language.  Speech-reading and hearing-device use is part of this process.	Language is developed with the use of SL. Written language is taught as a second language once a child is fluent in SL.	Child learns to speak with hearing-devices, speech-reading and use of "cues" to represent different sounds.
Expressive Language	Spoken and written language (both fluent).	Language (spoken, sign or a mix of both plus writing ability) is developed with exposure to oral speech, signs, speech-reading and hearing-device use.	SL is the child's primary expressive language, with written language next.	Spoken language (sometimes with the use of cues) and written language.
Hearing	Early, consistent use of hearing aids, implants and/or a FM system is the basis of this option.	Use of hearing aids, cochlear implant/s, FM system) is advised for child to maximise remaining hearing.	Hearing-devices are not essential for success with SL.	Hearing-devices are encouraged to maximize the use of residual hearing.
Family Responsibility	Family are a child's first teachers. Parents need to build processes into a child's routine and play time for a spoken language—rich home life, with full-time wearing of hearing—devices as a central part of a child's learning.	Family learns chosen sign-system for child to develop language. Parents learning to sign is an ongoing process. As child's expressive sign language deepens, so too should the parents' to give child a learning environment. Family is also responsible for consistent hearing-device use.	Child needs access to deaf and/or hearing adults fluent in SL to develop SL as a primary language.  If family chooses this method, they need fluency in SL to communicate with the child for a lifetime.	Parents are the primary teachers of cued speech to their child. They are expected to cue at all times as they speak.
Parent Training	Parents need teamwork with their child's language teacher (speech, auditory-verbal) to learn strategies for use at home or in daycare.  Training focuses to developing the child's listening, speech-reading and speech skills.	Parents sign as they speak to child (simultaneous communication).  To become fluent, sign must become routine in your communication.	If parents are not deaf, intensive SL education is needed for the family to become proficient in the language.	Cued speech can be learned at classes taught by trained teachers. Much time must be spent using and practicing cues to become proficient in cued speech.  At least one parent and preferably both must learn to cue fluently for the child to develop age-appropriate speech & language.

### **HOW TO USE THIS PARENTS' MANUAL**

This book is written for these purposes:

- 1. To guide parents of newly diagnosed deaf or hard of hearing children who are using oral language.
- 2. To explain how to teach your child, and what services are needed for the absolute best outcome.
- 3. To give parents a roadmap to avoid mistakes that might delay their child's oral language journey.
- 4. To provide parents with a reference guide for the next 3 5 years, for the oral language process.

Firstly, this e-book explains how families can work toward "Perfect Speech, Language and Audition" in a child who is deaf and has a cochlear implant. Guessing games are not needed. Follow the book's format and excellent success will result. [This may not be possible with all deaf children, each child is different]. Second, this book defines intervention standards for best possible outcomes with any 100% verbally-educated child. This guidance is rare and not typically given to parents with a new diagnosis.

Families who pair this e-book with the "AusPlan" book about hearing-devices and acquiring language, will gain the strongest foundation and roadmap possible, to benefit a child with hearing-devices<sup>1</sup>.

The references in this e-book to a "Special Education Department, or local school district" may refer to an "Early Start" program in your country. The key is the entity which funds inclusive education.

<sup>1</sup> All mentions of an "Auditory Oral" program can be interchanged with the term "Auditory Verbal".

These chapter descriptions of "A Father's Love" serve as an index to find information quickly:

**Introduction** — Briefly explains the purpose of this book, its title and what each chapter covers.

**Chapter 1** — The emotions of learning your child is deaf or hard of hearing. What to do next, how to apply laws to access education services and work as a team with professionals to develop your child.

**Chapter 2**— What sacrifices must parents make for their child to become verbal? The commitment for a deaf child to develop spoken language. The mindset required for this process, with an itemised list of services and procedures, the "must have" language toys, videos, and procedures to use at home.

**Chapter 3** — Insights for parents to be able to discuss issues with audiologists working with their child. How cochlear implants work, reading audiograms and understanding hearing thresholds, the speech banana, the CI surgery, mappings, bilateral implants, hearing aids, care and maintenance.

**Chapter 4** — Everything needed for the best outcome for a child with one (or two) cochlear implants. Topics: early detection, early cochlear implantation, types of spoken language programs, the ENT surgeon, pediatric audiologists, a family support network, understanding insurance, the IEP process and interacting with local/regional early intervention team-members.

Chapter 5 — Reading this chapter and pairing this e-book with the AusPlan book (available from the Sound Advice online shop) will place you to team with your speech therapist/s for the next 3 to 5 years of your child's language journey. You will be able to update the Speech and Language Pathologist, Teacher of the Deaf and others working with your child on how your child is doing at home. You will know the terms for planning and getting

speech-development into IEP meetings. You will know exactly where your child is on the AusPlan language hierarchy, and the next step in their hearing, speech, and language development. You will learn the building blocks of natural language acquisition and manage your child's goals.

**Chapter 6** — Enabling a parent to take their child's hearing and birth ages and compare them to the program described, to decide if their child's services are adequate. Every child is different, but the four year program listed is a model for the progress of children who are deaf or hard of hearing. At the start of each year the program outlines class and therapy times, and what is being worked on.

After each year the child's progress in receptive and expressive language are listed in a review. The IEP process is explained with a decision for bilateral implants, training a "new" or "second" ear, using hearing children as language models, Transitional IEP meetings, and using intervention services.

Chapter 7 — Who will fund your child to learn to listen and talk? This chapter explores laws, adapting IEP processes to your ends, financing your child's private SLT or AVT sessions, preparing positive IEP meetings to get your desired outcomes. Sharing insights for professionals to better understand your child. Working with insurers to get things covered. How to appraise early intervention programs. Read this chapter with an IEP book to be able to facilitate your child's oral-education.

**Chapter 8**— Is it possible for every deaf child to have perfect speech, language and articulation? Can every deaf child have excellent receptive language skills which rank in the 97th percentile for open-set words? Is every child able to differentiate 5 to 10 rhyming words with no visual cues? Can every deaf child lead

their hearing peers in cognitive skills? This is what this book is about. When parents and educators put everything into this process, more children will have "Perfect Speech and Language."

Every procedure James Hall's child went through, is in this chapter: the age she had her first hearing test, Auditory Brainstem Response test, Computerised Tomography (scan), cochlear implant surgery, when she started oral training, when she had her second implant, her Enlarged Vestibular Aqueducts and Mondinl Dysplasia diagnosis, and her receptive and expressive language progress. Use this chapter to give yourself a baseline of where your child stands from a strictly interventional standpoint.

Chapter 9 — Where to buy the language tools and toys mentioned, where to get the AusPlan Book, the IFSP / IEP legal books from Nolo Press, contact details for cochlear implant manufacturers, programs like "Music Together," and where to find every "OPTION" School in the US. It also lists various children's hospitals with CI programs, where to get soundfield and FM systems, and where to find an organisation to educate your insurer (free of charge in most cases) for your child to have a CI. A national contact database is also listed for speech language pathologists (ASHA), and a website which lists speech-therapists (AG Bell): http://www.agbellacademy.org/locate-therapist.htm.

### THE MOTIVATED PARENT

Looking at the steps for a deaf child to get to communicate, sometimes we forget the driving force to make it all work. Parents need the mindset for the challenges and to climb the educational mountains, doing multiple tasks while they might still be grieving their child's prognosis. As a father, I have been there. I felt the lowest lows of helplessness, not knowing what to do, praying for a miracle to change my daughter's life and having no idea what outcome oral education would bring. In this teaching process, there will certainly be emotional high points and low points.

Here is some advice on the mental mindset and tasks needed for being a motivated parent.

What is a "motivated parent?" What do motivated parents do that other parents might not? We all want the best for our children and we want our kids to flourish. If you read this text and gauge yourself with what is written, you will know if you are among the few who can use the word "motivated." Everything written here, I have done. This text is not written to judge any individual. If you read this chapter with another chapter in this e-book, "How to Obtain the Absolute Best Medical Outcomes for Children Using Oral Education" and apply all that is written, there is no way your child can fail. He or she will make great achievements and reach that cherished status of excellent communication.

Consider the determination that marks the motivated parent. First, we must all grieve and accept that our young child has a lifelong challenge. One motive for writing this e-book, "A Father's Love," was to give hope and promise to every parent who puts

in the effort and time for their child to get to speak. At the start, I never read about outcomes for oral education. All I heard from professionals was "every child is different, there is no guarantee [she will talk]." What does this mean? I needed a real goal to work toward. This e-book gives parents a view of a possible future when the right steps are taken.

#### ARRANGE FLEXITIME, IF YOU NEED

You might think each day lacks time to do what is written in this e-book. This is why one parent needs a flexible job. This is a must. Just two to four years of flexibility is needed, not your full working career. I was fortunate to be in sales for the last fifteen years, which enabled me to make phone calls, go to therapies, speak with professionals, and deal with insurance in the daytime. The educational reading, letters and teaching your child to speak can be scheduled for the evening and weekend hours.

#### YOUR MINDSET FOR MOTIVATION

Here is the mindset and motivation to give you the knowledge and ability to put the pieces together. My wife and I were told by professionals, "Oh, you are great parents, I wish all parents were like you." I would not say we were "great" parents, just parents who knew we had one chance to shape our daughter's early life into her future, one chance not to make any mistakes, and only one opportunity to give our daughter the precious gift of speech. Our approach had to be right the first and every time. Time was too valuable to make one mistake that could jeopardize our goals for spoken language.

Maintain this mindset: "I will find out everything possible about this process, I will not let anything stand in my way, I will get my child on the right track to learn spoken language, I will do whatever is needed every day at home to help my child hear and speak."

#### TWELVE TIPS FOR LISTENING AND SPOKEN LANGUAGE

**Draw Your Map** - For a parent with a newly detected infant, it may seem strange to have a long-term game plan and procedures to follow. Do not guess at things or get tangled in opinions people will tell you. Have a plan and move to action it. A road map for young verbal children to learn language and audition, "How to Obtain the Absolute Best Medical Outcomes for Children Using Oral Education", is in this e-book. Read and follow the text, knowing this is the path my family followed for our daughter's outcome. If you need to check the validity of this text, ask three different professionals for opinions.

Gather Your References - Build a reference library of books, and read daily. Here is the process: First, learn everything you can about your medical insurance plan. Do not say, "My daughter is deaf. Is XYZ covered?" Request your "Plan Summary" or "Benefits of Cover" statement. This paper is the formal contract between you and the insurance firm. It states exactly what is covered and what is not. Read the pertinent information regarding your son or daughter. I hate to say this; you do not want a track record as a long-term financial risk on an insurance company's computer system.

Once you are comfortable with the medical insurance issues, read everything on early intervention services for your local area. Contact the relevant early education department to research services for your child. Talk to people and read everything about

oral education. Like an arrow to a bull's-eye, know what you and your family want in the oral education process, and go straight for it.

**Build Your Team** - Start to build a mutual relationship with all the professionals on your team. Be courteous, easy to get along with, thankful, appreciative, and keep the professional on your side. You are the contact point for assessments, information, medical reports, hearing tests, IEP and education documents. Ensure each professional has copies of the needed detail to do their job more effectively.

**Play With Your Child** - From infancy, give your child toys to build their hearing skills. Get DVDs and CDs for your child to "hear". Play with your child and love them like a precious thing at this time.

**Team With The SLT** - Go to every therapy session you can. Early on, we had two sessions per week, then three sessions, and finally four sessions weekly. The initial therapy sessions are most important. Watch what the therapist does. Establish what you can do at home to build your child's listening and spoken language after those particular sessions. Get the AusPlan book to see how natural language is acquired and gauge your child's goals six months out, twelve months out, twenty-four months out.

On Good Terms - Learn the terminology of language (chapter 5 in "A Father's Love), and update the therapist on what is happening at home. Once you know how language is gained and where your child is in the speech, language and audition hierarchies, home-learning strategies can be devised.

Name Your Sounds — Once your child has hearing-devices, you can name every sound. 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", "apples are round". Everything, all the

time, narrate what your child is doing and what they are holding. "You are playing with Elmo. Elmo is red." Narrate what you are doing. "Look, Mom is cooking. I take the pan and put it on the stove..." Repeat the words dozens of times. The phone, door, birds, car, hoover. Whatever the sound, point to your ear and say "I hear that, that is the

**Explore Your World** — Every weekend, go to the store, the park, the zoo. Use these trips to build your child's vocabulary and let them see the actual object or item while you name it. Know that children must learn to listen before they can speak. Structured therapy sessions and your home-work enable this goal. Your child needs time for listening (receptive) before they can produce spoken (expressive) language. Do not teach topics too fast or explain things in detail. Work at the level your child is at.

**Simplify Names** - One name for each item. Many items have different names, but choose one name for each item. Stick with it until your child fully understands that name. (A pair of shoes is SHOES, not sandals, boots, slippers, tennis shoes. They are all shoes for the first six months. Same with plates, cups, cutlery). Make a list of 40 - 50 items with one name only, for the family to use. Hand a copy of this list to your therapist. Over time, as your child learns, you can move on to the next synonym.

**Go To The Top** - Do not take "NO" as a final answer, go to the top. As a motivated, informed parent you will and should exhaust every possible avenue to get what your child needs. If a procedure is not covered, have the insurer show you in writing where it is not covered. If services are not granted, then find out specifically why and defend why those services are crucial to your child's long term outcome. A letter with strong points can be effective if written well, and put into the hands of the right person.

**Educate Yourself** — Confirm with three or more professionals about what is right. It is your job to educate yourself on every aspect that will impact your child's outcome. Ask parents and professionals questions, think for a few days and trust yourself that you are informed to do what is right. I have seen too many parents listen to one opinion and move forward with no search for additional answers.

**Know Your Educational Rights** - The international laws for inclusive education and the IEP processes are the basis for every service and educational program that your child will be involved in. As a parent and advocate you need to understand all aspects of these laws and the procedural aspects of the IEP process. Talk to lawyers, read books, go to conferences and understand your rights as a parent.

Define your goals before each IEP meeting. Have professionals on your side and a defense for every point you make. Actively participate in these meetings, with you and your child a primary focus. These meetings are the one and only chance you will have to obtain the services that your child deserves.

Become A Hearing Technician — Know how cochlear implants and hearing aids work. Talk to the manufacturers, your audiologist and read the manuals. With these programmable devices being your child's 'ears', it is vital for you to discuss the functions, challenges and maintenance of these devices with others. Understanding and explaining hearing thresholds and audiograms to others helps, too.

Attend conferences, particularly those backed by the major device-makers, creating the chance to discuss challenges or issues with an employee at the firm who makes your child's hearing devices.

Avoid Making Mistakes - Do not make mistakes that will cost precious time. During my daughter's oral education I kept two thoughts in my head: (1) I had to do everything possible for my child to develop oral language, and (2) I could not make any mistakes. Each and every mistake costs precious time. This is why my wife and I met with professionals, read everything possible and bought one of the best books written on language development. We educated ourselves to be involved as active members of this process and to have the insights to make changes to a specific program or suggestion if needed.

By putting everything into this teaching process for the next three to five years you as the motivated parent will have a sense of accomplishment unmatched by anything else you will achieve in your life. Today I look back on the effort, the highs and lows and the commitment that I and my family put into this process, and there is no bigger achievement or accomplishment, nothing that I could be prouder of than the ability to give my one and only daughter the precious gift of speech and hearing. There is no business or personal success that matches how I feel when I hear my beautiful daughter speak.

To look back and think of myself as "an expert in providing speech and language to deaf children" is amazing. This process of becoming an "expert" fell in my lap from necessity. Yes, the word "expert" is strong and yes, I am just a parent, but with the tools and books in this e-book, you have a plan for a child to develop excellent spoken language. I never imagined that teaching deaf children to speak and oral education would ever be part of my life, until we were told our little one was deaf. At that point I knew it was the most important part of my life. Take this document and the other educational material provided on this website, absorb it, think about it, but most importantly, act upon it.

# HOW TO TEACH LISTENING SKILLS TO PRE-VERBAL DEAF CHILDREN

#### **INITIAL GROUNDWORK**

When we first learn our child is deaf, many thoughts rush through our minds. Uncertainties throng our thinking, relating to 'now', and to the future. What will life be like, for our child, into adult-hood? As time passes, we search for answers and rely on a team of professionals for our children to hear, to learn to listen and finally, to speak. A primary individual in your child's learning-to-listen-and-talk process is the licensed Speech and Language Teacher (or Auditory-Verbal Therapist). In some cases we work with a Teacher of the Deaf [TOD] and other professionals who provide support to our young child.

#### DO NOT MODEL THE SLT'S APPROACH!

When you and your child (aged 12 months to 36 months old) see a speech teacher, all interactions are in a clinical room with very specific goals. Our infant children sit in a chair for tasks like identifying animals in a set of four to five, based on one key word, or a key word within a sentence. A slightly older child may be asked to pick two crayons from a set of 20 and colour three different items. These are very structured tasks with room for error. However, they are needed to build on the hierarchy of receptive and expressive language that each child must acquire in their learning to listen and speak process. But is this the way we should work with our children at home? Should we try to model what the speech

teacher does, in a clinical setting? The answer to this question is a resounding NO.

#### **TEACHING LANGUAGE SKILLS AT HOME**

Young children can manage an hour of speech therapy, or maybe two to three hours of therapy per week. Trying to model the SLT's formal technique at home is too much however and your child will get frustrated and disengaged. Instead, you can teach your child listening skills and practice your shared, expressive language learning process ALL the time. This can happen wherever you are, without their ever knowing you are teaching them.

How do we teach our children critical listening skills while interacting in a fun way? How do we teach vocabulary words daily while we are playing, while we are at the store, while we are driving the car? Let's face it, we are with our kids every day, all day long. Our first goal as educated, caring parents is to turn every waking hour into a learning experience. This process builds our kids' receptive language skills, which in turn will prompt excellent verbal speech. Let's look at this very structured systematic interaction process which will teach our children to hear and speak to the best of their ability.

Firstly, we must understand how language is acquired. Knowing why a speech teacher works as they do, is vital for you to report the progress and pitfalls of your young child's language in a clear way. Families with a child who wears digital hearing-devices, need a professionally-written guide on how children acquire receptive and expressive language as the basis for spoken-language ability.

For everyone's progress, it's critical to know how long a child with hearing-devices should take to reach certain goals in the language hierarchies mentioned. One title is the AuSpLan book (short for Auditory, Speech, Language), from Children's Hospital Oakland (Audiology Department) at 510-428-3885, ext. 2017, (\$35 plus \$10 shipping), which is also available from Amazon and from the Sound Advice online shop, www.sound-advice.ie/shop. An outline for this book is on James Hall's website at: deafchildren-canspeak.com.

#### PLAYING — WHILE TEACHING OUR CHILDREN TO SPEAK

Now that we have considered what the professional/s will be doing, and have reviewed the education background that every parent in this teaching process must have, we can look at the very enjoyable process of "how do we play with our children and teach them auditory skills at the same time"?

Remember, this teaching process is long-term and three to four years is needed to teach our children excellent auditory and expressive language skills that will be equal to their hearing peers.

This e-book focuses (1) first to infant children who got their cochlear implant/s in the last 12 months and will then (2) discuss older children aged about three years old.

From the day a child is implanted, the beginning of their receptive language hierarchy begins. With the AusPlan book, a parent can pinpoint exactly where their child is, in language terms and know precisely what the current and next steps will be, for their child's audition (hearing) and speech.

A parent who follows this e-book when teaching receptive language can manage exactly how much their child learns, and when. Specifically, when a parent uses the techniques mentioned, a verbal child will have an ever-growing vocabulary and language skill-set to use in their early school years.

#### **AFTER ACTIVATION - THE VERY FIRST STEP**

Once your child's hearing-device is activated, sound awareness is your main focus and not words or nouns. From the first day of activation, point out every sound to your child — for example, the phone rings. You say "I hear that, that is the phone" and point to your ear. Whether it is a phone, the door, birds, a car, a vacuum cleaner, whatever the sound is, point to your ear and say "I hear that, that is the\_\_\_\_\_." As time passes, and your child knows their environmental sounds, you can move into the crucial process of learning nouns and expanding on receptive vocabulary.

Keep item names simple, with one name for each item. Sit down with your partner and make a list of about 50 items in your home, with one name only. Many items have multiple names and synonyms. You should use only one name in the very beginning.

- Some examples for your list:
- plate (not saucer),
- phone (not telephone),
- shirt (not blouse),
- jeans (not Levis),
- trousers (not jeans).

The exact words don't really matter. What does matter is that the same word is used all the time. Type a list, post it on your fridge, and let your speech teacher know what words you are using and say these words hundreds of times to your child, while pointing to those exact items. Use the words in sentences and always reinforce with a visual, pointing the finger or showing the object to your child.

#### **BOOKS AND TOYS AS LEARNING TOOLS**

Children's picture books are perfect for this type of word-interaction teaching. When your child reacts appropriately to a word or action in a book, give clear praise and let them know you are proud of them. It is vital that our children be in play groups and other social events with hearing children. Have your child around hearing children as much as possible. This will benefit their speech and language.

All children love to play with toys. When they are new to hearing, educational toys can benefit their sound-identification and listening skills. LeapFrog and other makers have toys that require the child to react appropriately to a sound, a word, a song, or even a phrase. Children will play with these toys for hours, learning to discriminate different sounds and words by listening.

When buying a toy, think how it will help your child's sound-discrimination skills. You want toys that require your child to decipher what is being said and react appropriately. Try a small xylophone with your child so they hear the different tones and frequencies of sound. Just sitting there and banging on a xylophone, teaches them sounds can be soft, loud, high pitched, low pitched, or bass in nature.

#### **AUDIO-DESCRIBE EVERYTHING TO YOUR CHILD!**

Speak to your child all the time. Again, look directly to their face so they can see your mouth. Explain everything to them. Be within 3 to 4 feet when speaking and just talk, talk, talk, in English. 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. Read every night if possible. Play childrens' music CDs in the car, sing songs, and talk, talk, talk.

Make sure their sound-processor(s) are working every day. Check the sound program is accurate, the batteries are charged and the Sensitivity and Volume settings on the remote assistant are correct. Read the app or manuals, or watch product DVDs to know how your child's processor works. At this time, file every assessment report you receive, to use at your child's IEP (individual education plan) meetings as relevant.

With regard to teaching a verbal child a spoken second language, generic advice is to wait until your child is speaking three to four word sequences and has excellent receptive language. At that time, a second language could be introduced. The mix of 75 % to 25% of new words is positive if a second language is used. Please check this viability with your speech teacher and do your own research as addressing a verbal deaf child like a hearing child in this regard may be confusing for everyone.

#### NARRATING, MODELING AND EXPANDING

Here are three 'core' words in your educational arsenal, and how to use them as the basis for almost everything you will do at home. As this e-book moves to older children who have their CI's for 2 or 3 years, these three words will resurface, so please fully understand their meanings. To start with, each word is listed, in the chronological order of how children learn receptive and expressive language.

- 1. Narrating is first: 100% talking and feeding nouns and verbs to your child to recall at a later date.
- 2. Modeling is next: getting the child to say what they should be saying, in an expressive manner.
- 3. Expanding language is last: the child has a handle on expressive speech, and we as parents are trying to expand or make their utterances longer. This could be going from two words to three words per utterance, or alternatively taking two complete sentences and conjoining them into a longer ten to twelve word sentence by adding "and" or some other conjoining word.

#### **NARRATING**

Narrating is the act of explaining things all day long in a very systematic manner.

Try to keep your narrating in blocks or chunks, just enough that the kid can pick it up. Repetition is the key here, the same thing every day or every night — and at a speed that your child understands.

#### Example One — Setting The Table

You are setting the table and you say "Let's grab the fork (grab the fork and show it to her), let's grab the spoon (grab the spoon and show it to her.) "Let's grab the salt", grab the salt and show it to her, set each item on the table and name it as you put it down, looking at her and then looking at the item.

#### Example Two — At The Supermarket

Go to the store and grab three fruits: "look baby, the orange is round, it is yummy, mmm (show the orange, emphasize round.) The banana is yellow (show the banana), the apple is green, I like apples," (show the apple). If your child asks you to describe an item they bring to you — talk away!

Keep things in blocks or chunks, do this for a few weeks then test to see if the child is picking up new words for their receptive language.

#### Example Three — Making Lunch

"Mommy is making lunch, I will grab the bread and make a sandwich". When the sandwich is made, show the child and say, "look baby, mommy made a sandwich for you." "Mmm, sandwiches are good. Let's get some milk for our sandwich." Grab the milk, pour it and say "Mommy is pouring the milk in the glass." Always give praise each time the child tries to speak or understands receptive language.

#### **REPEATING WORDS**

The key to narrating is to repeat words numerous times and then give a little bit of an explanation. Do not put your key word in a long sentence - say the key word one time, and then add it to a very short sentence. If you were to go to the store and just toss all the fruit into a bag and say nothing, or pour the milk and set it in front of the child by saying nothing, what has she learned?

By using this narrating format you are saying the word three to five times and showing the object at the same time. By doing this for a few weeks the child should get a good handle on the words, and at this time testing would be appropriate.

#### **TESTING FOR RECEPTIVE LANGUAGE**

To test the child for receptive language, set three or four items on the floor and then say "Banana, give Mommy the banana" When she reaches for the correct fruit you have made progress. If she does not reach for the correct fruit then grab the banana and say "Banana, this is the banana, the banana is yellow" and hand it to her. Keep building on these words and then add a new set of items to teach for a few more weeks. Try to make a point to "teach" the items that the speech teacher is working with in the therapy sessions. (Keep in mind this structured testing is only done for very short and brief moments, five minutes max. The rest of the day is just playing and narrating, as described. The purpose of the testing is to verify that the child is gaining new words receptively.)

#### **MODELING**

Modeling is saying the correct word or phrase for the child in response to a question.

A person says "How old are you?" The child is silent and the parent says "Two, I am Two." Not too much, just a short word or phrase. Look at the child and then look at the person asking the question.

Do this whenever the child needs to answer a question. Be careful; give the child a chance to speak for themselves, if they say nothing, then use modeling.

The child reaches out and starts to grunt. The parent says "I want milk". Put your finger on the child's mouth and say it again "I want milk". This way, they know what to say, and exactly when.

Someone asks "What is your name?" The child is silent. The parent looks at the child and says "Lisa, my name is Lisa," looking at the child and then at the person asking the question.

#### **EXPANDING LANGUAGE**

Expanding Language is the ability to take what your child is already saying and adding to it.

By following the AusPlan book you will know the very next step in language acquisition. Your speech therapist will be doing this on a consistent basis and you can tie in with their focus.

So if the child is currently saying two words, try to model three or four words. No more, just the next step in the process. The child says "Mommy fruit". You look at her and say "Mommy, I want fruit."

The child says "go park". You turn to her and say "Let's go to the park." In our family we extended by saying, "You could say, let's go to the park." Sometimes saying the expanded sentence twice helps.

#### **OLDER CHILDREN**

As children get older their expansion of language will be an ever-increasing task. When I drove my daughter to school in the morning it took 45 minutes. One of our favorite games in the car was 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 was saying. By doing this for a few months she caught on and was more descriptive about what she was seeing.

As time progressed, 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 would respond "I see a yellow school bus, I see a man riding a bicycle." These are six- and seven-word sentences, fantastic!

Now let's join 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.

Another tip, if your child likes children's songs then play children's songs and sing along. My daughter would know the title of the songs just by the first few bars or words. It was amazing. She would say, "Old MacDonald" and when 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.

The national Music Together program is an excellent resource

for your child to learn to identify tunes. This program has one instructor who gets the children to sing songs in class in a fun setting. The company will make CD's for all the songs the kids are singing for you to play in the car or at home.

Keep in mind, even with these instructions to help with hearing and language, it is essential to speak in a full context like you would with a hearing child. When a hearing or language opportunity arises seize it and emphasize its importance with one of the above mentioned methods.

### A DAY IN THE LIFE OF A VERBAL CHILD

Remember, continuous reading of these tips is vital as the years pass. Do not read anything in this e-book or the AusPlan book just one time. These books are to be used consistently and regularly. Once you have plotted your approach, the spouse who is less involved in the teaching process should read the relevant documents. Following this format means you will both become extremely educated and knowledgeable on the oral-education process and how best to advocate for your child.

#### **MORNING TIME**

Here is a typical day for a young child with cochlear implants and all the ways she can learn auditory skills. It is 8:00 AM and Mommy wakes her precious daughter. Many kids do not want their implant on first thing and that is O.K, just try to get it on within the first 30 minutes. Check the processor works and everything is OK for the best hearing possible. A parent needs to know how well their child hears.

You wake your child, they stumble to the couch in the TV room and you put on some cartoons. The processor goes on and you say "Good morning." As a caring parent, you must decide what cartoons help auditory learning and which ones do not. Cartoons that speak to the child and ask questions are excellent. Dora, Diego, Sesame Street and others are very good. Watch the cartoons yourself to check if the show is teaching anything useful and is it asking my child to respond to questions?

#### BREAKFAST — AND PLANNING THE DAY

As the child watches cartoons, Mommy makes breakfast. Mommy puts the food on the table and calls her child to sit down. When Mommy sits down she says: "How is my beautiful daughter to-day? Look, Mommy made you an egg, some bacon and some nice strawberries, mmm this looks so good. The strawberries are red and the eggs are white, (pointing to each item.) Mommy also gave you some orange juice," (picking up the glass and showing the child.) Mommy and daughter start to eat.

Mommy then says, "What should we do today?" Mommy pauses so her daughter can answer the question. "I think we should both go to the park and play in the sandbox, remember the nice kids you met last time we went to the park?" Mommy makes an inquisitive expression on her face hoping for a reply. The child smiles and shows that she remembers by a nod of her head and a giggle. The baby then points to her glass because the orange juice is finished. Mommy says "What do you say? What do you say?" Nothing comes from the child, modeling is needed. "I want juice. Can you say I want juice?" (The word orange is probably too big a word for now so we just say "I want juice.") The glass is picked up, the juice poured and set down in front of the child and Mommy says "here is your juice."

Breakfast ends and we go to get dressed. All the clothes are laid on the bed. Mommy picks up the jeans and says "Let's put on our jeans, one leg in then the other leg in, these jeans are nice, I like how cute they are, these are your jeans." Then, "Let's put on your shirt, look this shirt has a picture of Elmo on it; Elmo looks happy, raise your arms so Mommy can put on your shirt." Put the socks and the shoes on in the same way, repeating the name of

the clothing item many times. (In the beginning always look at the child when naming the item/s. The same thing EVERY day, explain every piece of clothing and every bit of food the child eats).

Mommy and her daughter go to the bathroom. "OK baby, I am going to turn on the water and wash your face, wash, wash, wash, Oh, you look so nice with a clean face. Open your mouth so Mommy can take the toothbrush and toothpaste and brush your teeth, brush, brush, brush." (Pointing at each item and picking up each item as we describe what it is.)

#### INTERACTING DURING YOUR EXCURSIONS

We put our precious daughter into a stroller and off we go to the park. As we leave the house we see a car, we say "look a red car" as we pass by it. We then say "look, a white car" and we pass by it, then we point across the street and tell our daughter, "I see a blue car next to that house, do you see a blue car?" The child looks at it and smiles. We are pushing the stroller down the road and we spy a bunch of flowers on the side of the road. We tell our precious child, "I see a bunch of red roses. Oh these flowers are so beautiful." We then pick one and hand it to our kid and say "These flowers are so pretty, I love the way they smell (and then smell the flower,) put it under her nose so she can smell it also. Give the flower to her and say "Flower" one last time.

At the park our child is ready to play in the sandbox. We let her play with the three hearing kids for as long as she likes and Mommy sits at a park bench to relax. After a while we walk over to the sand box and ask one of the children "What is your name?" The child says "My name is Robert." We ask "how old are you?" He says, "three years old." Your child is watching this interaction,

learning how people converse with each other. We say "This is my daughter Lisa, she is eighteen months old." "Lisa, can you say HI to Robert?" Your child looks at the other kid and says "Hi." Any chance a child gets to watch people converse is a great learning experience. We pack up our things and head home. We stop by the flowers again, look at and name them. We find a tree and say that it has green leaves and a brown trunk. We pass the same cars and name the colours again, we are now back home.

#### A STORE TRIP — AND PREPARING FOR THE ZOO

It is about 12:30pm, and lunch time. We put our young daughter into a high chair and set a plate of pasta and cheese, strawberries, an orange and some cooked chicken in front of her. We name each item and we ask "What do you want for lunch?" She points to the Pasta and Cheese and the Orange. "What do you say?" "I want Pasta and Cheese." "I want an Orange." Can you say this? Try to get her to at least say one word "Pasta" or "Ore," anything, give great praise and start cooking.

After lunch, Mommy remembers she has to go to the grocery store. We put our daughter in the car seat and say to her: "I am going to play your favorite song, Twinkle Twinkle Little Star." Mommy starts to sing "twinkle twinkle little star, how I wonder what you are..." looking at her daughter and making motions. She starts the car, puts in the CD and on comes that famous song Twinkle Twinkle. Mommy mimes as the song plays, the young child is laughing and giggling and trying to pronounce the words. At the store we seat our daughter in a shopping cart. We explain "We need to buy some vegetables for Daddy's dinner." We roll over to the vegetable section, we grab a head of lettuce, some potatoes

and carrots, naming and describing each item, then setting it into the shopping cart. We change aisle and tell our daughter we need to buy some water, we grab a case of bottled water, show it to her and set it in the shopping cart. At the checkout, we unload and bag all our items by naming each one.

We get back home and there is one hour until her two brothers return from school. In the next hour we are going to gather five or six of her toy animals and describe them to her, we are then going to describe how much fun we will have when we go to the Zoo this Saturday with Daddy. (Since today is Friday, it is OK to talk about the zoo. Children at this young age can only remember things for a very short period of time, I would not mention the zoo if it were two or three days away.)

#### FINDING LANGUAGE IN EVERYDAY ACTIVITIES

We grab the toy animals and say, "this is the horse, this is the cow, this is the duck, this is the elephant. All these animals live at the zoo, do you like the Zoo?" The child says "yes." We grab the horse and make horse noises and tell our child "the horse eats hay, the horse likes to run, and cowboys like to ride horses." We then grab the cow and say "Mooo, the cow gives us milk, the cow lives on a farm." Then we grab the duck and say "the duck lives in the water, the duck likes to swim, the duck is yellow. We grab a book of animals and explain everything we are going to see at the zoo.

After a while Lisa's two brothers knock on the door, they are 10 and 12 years old. Mommy looks at her daughter and says "what is that?" Mommy looks inquisitive, and is waiting for the child to say something or point to the door. The child does neither. Then Mommy puts her hand to her ear, (the boys knock again)

and Mommy says "I hear the door, let's see who is at the door." (See if the child catches on at this point,) Then go to the door and open it and say "Look, your two brothers are at the door." (Any environmental sound should be pointed out, always ask the child what they hear and then point out the sound, naming it multiple times). After answering the door, Mommy realises it is time for her daughter to nap. Lisa sleeps for an hour, she then wakes up and is ready to play some more.

# LEARNING BY THE COLOURS

After some initial holding and talking with our daughter we ask her "do you want to draw a picture?" She says "crayons." Mommy looks at her and expands the sentence by saying "I want my crayons."

Mom and daughter go to the table with a coloring book. Mom turns to a page that has a house, some trees, a car, the sun, the sky, a bird and other things. Mom sets out five crayons. The crayons are red, blue, green, orange and yellow. Mom describes the color of each crayon and says can you color the sun yellow? The child grabs the green crayon and starts to color the page. Mom says, "no, no Lisa, Mommy said Yellow." Hand her the Yellow crayon and say "this is the yellow crayon" and ask her if she know where the sun is. She colors the sun and all is good. Mommy grabs the blue crayon and says "look baby, Mommy is coloring the car blue." Mommy then grabs the green crayon and says "let's make the tree green," as she starts to color the leaves. Then Mommy turns to her daughter and says "Can you color the house red?" This back and forth style of playing teaches by example and gives the child a bit of leeway to color on her own. An hour goes by and Daddy walks in the house.

# **DINNER TIME**

Daddy plays with his daughter, while dinner cooks. Before dinner Daddy says, "Lisa, can you help me set the table?" (This is a long sentence which the child decodes by picking out the key word "table" within it.) Daddy goes to the kitchen and gets the cutlery, plates and cups, naming each item as he sets it on the table. "This is the fork" Daddy says, looking at Lisa and showing the fork. "This is the spoon; can you put one spoon here, and one here?" (Dad is pointing to the two place settings missing the spoons while saying this.) Take this approach every night, and after a few weeks, Dad can be setting the table and he can call out for certain items — with the child being able to bring the right items. Repetition is the key, every night.

At the table while the family eats, the conversation is structured and organized. Multiple people are not talking at the same time. One person talks, one person answers and this continues for the meal. The child is learning how conversation is structured in a back and forth format. Include little Lisa in the conversation when appropriate. Explain to the family what Mommy and Lisa did that day. Get Lisa to laugh and smile at her actions, involve her to get her to remember what took place that afternoon.

After dinner the family watches a Disney movie in the TV room. Try to involve your child in the movie. Ask questions about what is going on, as your child gets older (predicting the outcome of the plot is a good approach). Once the movie ends, it is time for bed. We go to the bathroom to brush our child's teeth, as described earlier. We change our clothes by naming each item, we grab the pajamas, explain why people wear pajamas and tuck our little girl in. We read a short story and say Good Night to our daughter.

Mom pulls off both processors, charges the batteries and sits at the table. Mom and Dad read for 45 minutes to become more educated on the Oral language process. This is a typical day and it all starts again in the morning.

Please review the multiple ways a child can learn vocabulary, and be prepared to speak as described here. Think about the ways you can interchange items, but keep to the same format. Remember to present the information in a concise and ordered way, not too much too fast, just the right amount for our kids to grasp the words and remember them.

# **AUDITORY TRAINING FOR OLDER CHILDREN**

Fast forward 24 months and our child is now 3 years old. Kids at this stage should have a grasp on (1) verbal responses, (2) answering open questions and (3) following two and three part commands. They should also pick out two key words in a sentence, hold a one-to-one conversation with two to five exchanges, discriminate five rhyming words, and they should be starting spontaneous expressive speech with multiple word utterances. Children should be able to sing complete nursery rhymes at this stage. If you do not understand the benchmarks here, please read Chapter five of A Fathers Love (in this e-book) and reference the AusPlan book.

What more can parents do to build hearing and expressive speech skills? Let's tap the routine events in our daily lives and bring in the receptive and expressive skill building for your child to learn to hear and talk. With the AusPlan book, an informed parent can place their child on all three hierarchies and know the next stage in their learning. Your child's IEP goals

should reflect the next stage of language acquisition (as the AusPlan book explains) with input from the speech teacher's work with your child.

Please note the timelines to reach defined levels of hearing and speech comprehension and check to see if your child is keeping on track. Auditory training is a process that occurs every day. It is vital for a speech teacher to review your child's speech sounds to check all sounds are coming in as needed.

- Tasks at this stage include:
- expanding language (as described previously),
- · providing more descriptive explanations,
- · using multiple synonyms,
- · putting objects in groups,
- using verbs, using structured grammar and even conjoining sentences.

Your child's place on the three hierarchy levels of Audition, Speech and Language will show the tasks to prioritise. Here is a typical day: It is Wednesday morning and we must take little Johnny to the auditory-verbal school he has attended for 24 months. We get up and make breakfast. "Johnny what do you want to eat this morning, pancakes or eggs?" He answers. "Do you want milk or juice?". He answers this, too. These questions are asked with no visual cues. To check his hearing in a noisy setting, try moving pots and pans as you ask these questions and see how well he understands. As you sit down to eat, you start talking with your son, "Johnny did you know some eggs are brown, many are white and eggs are used for baking. We can make a cake for Daddy this weekend and I will show you how the recipe uses eggs." Johnny says "mmm. I love cake." "You know eggs come from chickens and milk comes from cows right?" He answers "Of course, Daddy!"

# INTERACTING, MODELING AND EXPANDING LANGUAGE

We finish breakfast and go to the bathroom to brush our teeth and take a bath. Using words only, we tell our son, "Johnny can you brush your teeth, then go to your room and take your clothes off for your bath?" (two key commands; brush teeth, and THEN remove clothes.) If Johnny does both tasks, he is listening and understanding well. Many children will do the first task and ask about the second. These two-part commands can be used through the day, just think about what to say. When the bath is done we look out the window and we explain to our son; "Look the clouds are really grey and it looks like it might rain today. So what should we wear?". In a playful way, say "should we wear these shorts and a T-shirt, or should we wear jeans and a jumper?" He starts to smile and giggle. He says "We need jumper," Mommy expands his sentence and says "We need A jumper AND jeans."

The child gets dressed and we are ready to leave. Go outdoors, stand on the porch and say "It looks like rain, what do we need in the rain?" If the child does not answer say, "What do we need in the rain to cover our heads?" The boy should answer "An Umbrella." Open set questions should be routine at this stage, always praise your child when they give a right answer or try to say new words.

# FIT TEACHING EXCHANGES INTO YOUR DAILY ROUTINE

Now we get the umbrella and we go to the car. Inside the car we ask our son "Do you know where rain comes from?" He says "The sky." "Well actually, Johnny, rain comes from the clouds up in the sky, so next time you're asked you will know all of those clouds up there hold a lot of water." So off we go to the auditory verbal school. We discuss all the fun things that will happen at the school that day, trying to get three to four exchanges going back and forth.

As we drive, we ask our son, "Can you tell mommy what you see out the window?". Johnny says, "I see a bus." Mommy says "I see a YELLOW bus," emphasising the word yellow. What else do you see?". Johnny says "a house, a car". Mommy says "I see a BIG house. I see a BLUE car," always adding descriptive words to Johnny's words. Over time, you can join two short sentences with the word "and." When joining sentences, you will take the short three to five word sentences your son is saying now and make them into longer eight to ten word sentences.

(To read up on adequate program frequencies, please read Chapter 6 of "A Father's Love".)

# COACHING FROM AN AUDITORY-VERBAL THERAPIST

At the oral school, three-year-old Johnny's program has 2.5 hours of classroom time and 50 minutes of therapy, three times weekly The class is run by proven professionals who fully understand auditory verbal language and work with five to seven children. During AVT time, the therapist has 20 crayons and hands Johnny a colouring book with 20 items on it. She stands behind his chair to say "Johnny, can you pick up the red crayon and colour the house? Also pick up the yellow crayon and colour the sun." Johnny does what he is asked, flawlessly.

The therapist drops her voice and gives another two-part request; Johnny accomplishes that task too. Now the therapist will change the word order and the action. So she says, "Johnny, can you grab the purple crayon and colour the car, and can you give me the black crayon?". Johnny gets half of this task correct, but we know practice makes perfect. (The first listening example above has two closed sets of 20 items and uses sentences with two-part commands. The key words in these sentences were the colour of the crayons and what the action was to be.) Johnny is doing very well receptively!

# **LUNCHTIME CHAT**

School finishes and Johnny and his Mom go to lunch. They sit down and the waiter arrives. "What can I get you?" the waiter asks. Mom says "I would like a chicken sandwich with a diet coke. Johnny what do you want?" (Look at him and wait expectantly till he answers. Speaking has big rewards... yummy food). Johnny says "peanut butter and jelly". "Do you want a peanut butter and jelly SANDWICH?", Mom says. "Yes" he says. What do you want to drink? "Milk please." Mom and her son eat lunch and drive home with the children's songs playing. Remember, auditory training in the car is not a time to listen to the news. Children's songs are the key. (It is a 45 minute drive to and from school, an intensive 1.5 hours per day of listening.)

The two get home and sit in front of the TV to watch cartoons for about one and a half hours. After the cartoons, Johnny goes out in front of his house and plays with a group of three, four and five year old children. He is having a great time. All the kids are talking amongst themselves and Johnny is enjoying his free time. (Playing with hearing kids is crucial to gain good listening and speaking skills.)

# **EVENING-TIME FAMILY INTERACTIONS**

Dad comes home and Mom calls Johnny indoors. It is time to set the table. Mom puts cutlery on the counter; she puts glasses next to the cutlery. "Johnny can you grab four glasses and put them on the table?" He does this. "Can you grab four spoons and four forks and put those on the table?" (These tasks are advanced for a three year old, but listening and recognizing key words is the key.) "By the way, we need placemats." Let him figure out how many to get, if he gets less than four placemats, ask him why. The family eats dinner. Mom and Daddy explain what they are eating that evening. Mom summarises what happened that day and she directs questions or cues to her son to keep him tuned into the conversation and happy. Dinner ends and the family goes to the TV room.

For children aged three to four, there are great DVDs to benefit hearing and learning skills. LeapFrog for example, has a DVD for the alphabet, another for phonetic sounds, and a simple math DVD. At age three, an array of toys can educate, benefit audition and expand a child's thinking skills. Richard Scarry has nice DVDs for counting, the alphabet, colours, concepts like inside, outside, over, under, and more. Johnny sits down to watch 30 minutes of his favorite cartoon or DVD. He is learning and doesn't know it. After the DVD ends, the family watches TV a bit longer, and now it is bedtime.

# **QUESTIONS DURING STORY-TIME**

Before Johnny sleeps, we read a story to him and ask a few questions. "What do you think will happen next?". "What would you do?". "Why do you think the girl did that?". Sometimes children find open questions like these difficult. With therapy being structured, Johnny can think there is a "right" answer for everything. Now we are giving him the flexibility to think up his own answer. Often, there is no right or wrong answer and children may need to learn this, to know many answers can be correct.

We finally put our child to bed. The day is near its end and tomorrow, the expansion of language will continue. The speech teacher should be doing standard language tests, based on hearing children. If Johnny is not age-appropriate now, hopefully by age four he will be. Just because you are told your child has age-appropriate language, his receptive and expressive skill building still needs to continue. (You will know when you can sit back and treat your child like a hearing child, and lay off the "drills.")

# HOW MUCH THERAPY SHOULD MY CHILD GET?

Many parents ask how much therapy their child needs, for good auditory and speech skills. This is an easy question to answer. Detailed programs can be built to suit most oral deaf children with residual hearing. Parents choosing therapy totals for a child must base their decision on default Auditory Oral / AVT guidelines. The factors to consider are: The child's age, age at implant, their receptive and expressive language skills. To understand language-teaching, check the AusPlan book for where your child fits on the language hierarchy.

Teaching spoken language to deaf children with digital amplification is a hierarchical process. A very specific start and end point exist, as the AusPlan manual shows. Once a child's language skills are assessed, that child can be plotted on the AusPlan hierarchy with a strong roadmap or game plan drafted. Knowing where a child is in oral language terms helps, but does not specify the amount of therapy for every step in this process.

# INFANTS DETECTED AT BIRTH

For the weekly therapy amounts needed to achieve excellent receptive and expressive language skills I will refer to an infant detected at birth. Therapy times and frequencies are explored in Chapter 6 of A Father's Love. When a child is detected as being deaf or hard of hearing at birth an emotional devastation may result, with a chronic sense of helplessness. However, with full education and a committed desire for your child to progress, an excellent language-rich outcome should result.

Doctor appointments, hearing tests and professional consultations will fill the first three to six months of this baby's life. Ensure to schedule an ABR test. This test confirms the extent of hearing loss and once parents have a firm diagnosis, the best response can be explored. Please review the time-frames below for therapy, and remember two or three months either way, should not be detrimental.

Remember, I am not a doctor, I am not a speech therapist and I am not a licensed educator. I am a parent who experienced the oral process with the best outcome I could possibly imagine and now I am sharing my insights with you. The time frames given, reflect one of the best Oral school programs in the state of California (US).

# TIME-LINES FOR THERAPY FREQUENCY

These guidelines are complete when coupled with the at-home procedures on the deafchildrencanspeak.com website and the 14-page guide titled How to Teach Auditory Skills to Oral Deaf Children. By combining the time frames listed below with the procedures just stated and using the AusPlan book as a guide, any parent can be in full control of their child's language journey.

CHILD'S AGE (months)	AVT / AUDITORY ORAL THERAPY FREQUENCY
1-5	Diagnosis and Parent Education
6-12	One Hour Per Week
12-24	Two Hour Per Week
24-36	Two Hours Per Week / Plus 6 hours per week of a self-contained oral class with approximately 5 students.
36-48	Four Hours Per Week / Plus 12 hours per week of a self-contained oral class with approximately 5 students.
48-60	Five Hours Per Week / Plus 15 hours per week of a self-contained oral class with approximately 5 students.

Mainstream preschool classes can be substituted for oral therapy classes if appropriate, please see below.

Note: A two to three week summer school should be booked each year. I do realise public school programs may not offer these summer school services, but parents can add extra therapy through insurance or support. Having your child mix with hearing children whenever possible is a great step for developing their language.

When your child is aged 48 — 60 months, if all receptive and expressive language goals are on track, parents should decide to keep their child in an Oral program five days per week, or possibly going into a mainstream class for one or two days per week. In our case, we reduced Oral classes to three days per week and started our daughter into a mainstream preschool twice per week. Our child benefited from this real world classroom exposure before her full mainstream Kindergarten teaching began.

# 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

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# FROM THE AUTHOR

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 were 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 critical 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, 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 received in the last four years going through this oral-education process is exactly what this book explains. The target audience is 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 am self-taught on the topics 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 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 doctors, speech pathologists, audiologists, and even the cochlear implant companies' head engineer who designs these miracle devices.

For the past four years Gabriella attended one of the best schools in the US, for 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, some 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 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 the different options of what was available, and the pros and cons of each. I never got this step-by-step guidance, so I had to find out for myself. You will have similar questions. I did the research and travelled this path so I am hoping this book can answer your questions. My goal is that this book becomes a road map for parents to give their children the language and speech that we all desire, 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 strengthens 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.

While I am father to a beautiful little girl, this book is written for fathers and mothers. It is also written for carers, grandparents, aunts, uncles, and any person who is a caregiver for a deaf child learning spoken language. This book is written for anyone 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 or the new house 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 see what these very talented children can do and let's give them the tools to succeed.

A Father's Love 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 a huge bond 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. The professionals cannot educate you, as you need to educate yourself. Don't misunderstand me - our

daughter would not have reached the heights she did, 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 implants. This did not reduce my 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 on this road 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 much do you know in this process? Do you really know the next step and terminology of your child's language journey?

When reviewing 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.

James Hall 2008

# CHAPTER 1 INTRODUCTION

# THE DIAGNOSIS

The audiologist walked into the room and said "please sit down." She 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 specialises 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 world looked different. Everything stopped. Every sound meant more, every word was precious. We looked in our daughter's eyes and after more than 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 typical 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 "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 25th 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 in the United States 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 by 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 education process for deaf children.

There are two main spoken-language modalities, auditory oral and auditory verbal. This book and our journey is with the auditory oral process. The auditory verbal process is excellent but in our case we "fell into" a school who taught auditory oral. Both modalities are backed by case law, the IDEA, and the Federal Government in the US. (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. These are formal agreements between the parents of a deaf child and the local school district on providing an appropriate education to a student. In this case your deaf son or daughter.

In the United States, the IFSP covers ages 0 — 3 years and the IEP process covers ages 3 — 21 years. IFSP meetings are held every six months, while IEP meetings are held every year. You can request extra meetings if needed. Network with professionals to learn about anything that you may be missing or that your child may need. Yes, money is very helpful in the oral-education process but even lower-income families can get what their child needs if they are diligent, informed on the process, treat people with respect, and read this 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 actively helping 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 an entire class of 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 these 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 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 a great relationship exists with your 'team' (as they are called), you will be able to ask pointed questions and fully understand their replies. Again you must inform yourself,and really understand how spoken-language is acquired. Our children acquire language the exact same way that a hearing child does. The only difference is that our children get a lot of help to emphasise everything in this process. A hearing child may learn words just by overhearing those words in natural conversation. Our children must be told that word hundreds of times until they make the connection. Please do not think that by putting one or two

cochlear implants on your child they will pick up everything and learn clear spoken language. You must understand how spoken language is acquired and how to work with your child daily to help them acquire that spoken language.

In the resource section there are websites, books and companies to help you. Learn a little from everyone and I must emphasise that you as a parent will make decisions that contradict what the medical community or experts are telling you. I could fill a chapter about taking opinions from different people and deciding what was best for our daughter. Most people with no formal medical training would be very uneasy doing differently to what an expert is telling them. But you will find out that three experts can have three different opinions. You as the parent must be informed enough to take these opinions, understand 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 to have the information to face the battles and questions ahead).

As mentioned, 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 directly relevant to your child's progress and future goals. The goal of all parties is to get a deaf child into a mainstream classroom as early as possible so that the child can learn in the same way 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 ability of a child with a cochlear implant 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 independently. A sound field or FM system may be needed but not other services or interpreters. The school district is 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, a fair hearing process may be your only option. Remember, 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 without support from anyone. This delivers cost savings for the school district, the parents, and the federal government. Everyone wins.

# CHAPTER 2 THE PARENT'S ROLE

This chapter focuses to the parents' role in this oral-education process. What parents need to do to take their child from hearing nothing, to hearing everything. The following detail outlines how my wife and I worked with our child, with the advice making a perfect roadmap plan for any deaf child.

Let me start with myself. I am a person who hates opinions, I only want facts. My goal in this process was to find the best way to educate my daughter based on people's experience and medical research. To me, if medical studies give clear results, this is factual information. This is what I wanted. Unfortunately our process was not clear-cut; with opinions seeming to dominate fact. (With this said, Gabriella has been part of various medical studies to advance the question of the "best" way to educate deaf children.)

My occupation allowed me a lot of flex time to spend with 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 learning-to-talk 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, 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 a way to teach her to hear and speak. I am asking for your support. Through a four-year process deaf children can learn to hear and speak just like their peers. Without this four-year process, my daughter will never hear or speak fully. Can you help me?

I am asking for flex time for 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 refuses your request, submit your resignation letter the next morning. Write an emotional letter that lets the company know that they are heartless. (Remember, 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. You are bigger and stronger than this, you will succeed and nothing will stop you from providing what your child needs.

I will say again that one parent needs a flexible schedule to go to doctor appointments, meet with the school district and to observe their child's therapy sessions. Our society is not designed to respond to or facilitate long-term habilitation. We live in an all-ornothing 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. It is like a jigsaw puzzle, putting every piece together to give your child the absolute best chance to learn to talk.

# THE JIGSAW PIECES TO MAXIMISE SUCCESS

Here is a macro view of what is needed to have every piece in place for the best chance of success:

1. For severe to profoundly deaf children, early cochlear implantation between the age of eight and fifteen months. Atop-rate cochlear implant surgeon and pediatric audiologist

- should be on your team. Early diagnosis is a factor, too. If you think your child has hearing issues, please get a hearing test soonest.
- 2. A parent driven to give their child everything needed to succeed.
- A parent who actively learns about language development and the oral education process. Attend conferences, read books, observe speech therapy sessions, and talk to parents and professionals.
- 4. A good auditory-oral school or oral-intervention program that represents what a school would provide. Enroll your child early, preferably before twelve months of age. Most schools and Early Start programs want to start parent education and design a program for a child as early as possible.
- 5. A school district that follows the IDEA law (US) and knows deaf children can learn to listen and talk. A district open to funding four years of oral-education, potentially up to \$50,000 (based on 2007 dollars). A district that will work with you and which shares your vision for your child. Seeing other children who had an oral education may change a school district's mind about funding a particular program.
- 6. Never take one professional's opinion. Get different views and use your gut feeling to make decisions. (This author is available to help weigh the pros and cons of the life-changing decisions in this process.)
- 7. Order the Ausplan book or a similar language-development book and tie in with the speech therapist. Continue all progress in the natural home environment. Know where your child is, in acquiring spoken-language and what the

- next step is. Being able to track your child's progress and pinpoint their place on the language hierarchy model is crucially important. (If you do not know this you cannot effectively reinforce at home, the language structures being taught in the speech therapy sessions.
- 8. About three years into this education process provide a mixture of oral training and mainstream classes to give your child language models and fully hearing children to interact with.
- 9. Keep your child around hearing children when possible. Enroll your child in preschool classes for art, music and playgroups to boost their language, auditory and social skills. Young hearing children make great language and speech models. Some auditory-oral programs purposely have a full-time hearing student in the classroom to positively model and facilitate age-appropriate language.
- 10. Appreciate everything every professional does for your child. Buy gifts, send cards, and remind your team that they are changing 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 equally dedicated to this education process for the four years it will take. This means driving your child to school, to therapy, the doctors, and babysitting. Single parents and married couples will be challenged to commit time and effort to this process and need at least one additional, dedicated family member.

12. Prepare for every IFSP / IEP meeting. Know the IDEA law and why the local school district should fund three to four years of oral education for your child. Make the learning-to-talk process cost-effective for the school district. Meet professionals with experience of such meetings and who understand the IDEA law. Terminology and well-constructed arguments that are backed up by the IDEA are essential to this process.

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. But at the start you will be like a baby, needing information fed to you. Over time, you must become a lion who knows what they want and goes after it. You are guiding a a team of professionals toward the best outcome for your child. It is your responsibility to ensure every professional has what they need and that these people talk to each other during seamless work for your child.

# THINGS THE PARENTS NEED TO DO AT HOME

Here is what is needed in the oral process for your child to speak. You will learn what to do at home to give your child the best possible outcome. Like you, I wanted my daughter to order her own food, ask for directions, talk on the phone, and have a typical social life. I did not want her 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 first thing you need is a 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 fund if they lack

a relevant program. If you are in the US, you can find most of the oral schools at www.oraldeafed.org. Call this organization to order some of their DVDs, which show children with cochlear implants who speak near-perfectly. If you are not close to an oral school, find a good auditory-oral or auditory-verbal therapist in your local area.

After your child's cochlear device is activated, the first few months are for learning to listen with the implant. These kids need to identify what they hear and it is our job to point everything out. Hearing children listen for 12 months before speaking their first words and our children are no different. A first step is sound awareness with step two being sound discrimination, which will happen after the first few months. Give your child time to learn to listen before you expect any speech. This is the difference between a therapist who understands cochlear implanted children and one who does not. Much time needs to be spent on listening, with the therapist fully understanding the hierarchy of oral language for implanted children.

# HOME STRATEGIES TO ENCOURAGE SPEECH

While your child is attending an auditory oral school and therapy sessions, you need to practice at home every day with your child to encourage speech.

1. Point out every sound, namely, 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," and show her "the apple is round". Everything, all the time, say what your child is doing and what they are playing with. "You are playing with Elmo, Elmo is red." Say 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 through the day. The phone, door, birds, car, vacuum cleaner. Whatever the sound is, point to your ear and say "I hear that, that is the\_\_\_\_\_."

Remember, children need to learn to listen before they can speak. Much time needs to be spent listening before they can progress to spoken language.

- 2. Cut out ALL background noise at home, as possible. I love music and used to listen every day. While my daughter was learning to talk, I reduced my stereo-listening time, with the competing noise. You need to divide the day into parts: the time you work on talking with your child, and the time you watch TV, listen to music and vacuum. If your family has a TV going 24 / 7 in the background you need to plan quality "quiet" time for your child to learn to listen. Run the washing machine and dishwasher when you are away from home or while you watch TV. Make everything a quality listening experience.
- 3. Have the hearing children in your family play and talk with your deaf child. These children are an age-appropriate language model for your child to learn from. Let them play and talk about games, fight, yell, and do all the things young children do. Don't sit there with them all glued to the TV or computer. Your child's language development will really benefit from quality talking time and interaction with relatives. Television is good for playing age-appropriate language-rich DVDs to benefit speech and language.
- 4. Speak to your child all the time. Look at their face so they can see your mouth. Explain everything to them. Be within 3 4 feet when speaking and just 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, children will use this as a crutch. The thinking in oral education is to teach them to use their voice and that their voice has meaning. Always respond when they use their voice, and let them know that you understand their words.

The approach is to give oral speech a chance before any signing is introduced. Use signing as an absolute last resort. Some people 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 old and put them into a Total Communication (TC) or signing program (ASL) in my opinion is medically wrong.

You will have professionals steer you in this direction at 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 being negatively impacted. I would rather master one modality than be mediocre at two languages. The key here is that perfect spoken language is what we are aiming toward.

6. Keep to one name for each item. Many items have multiple names but choose one name for each item. Stick with it until they understand that name. (A pair of shoes is SHOES, not sandals, boots, slippers, tennis shoes or flip-flops. They are all SHOES for the first six months. Same with plates, cups, cutlery.) Make a list of 40 - 50 items with one name for each item and direct the entire family to use this one name. As your child learns more words, you can start using word-variations. Speak only one language to your child for the first three years post-implant. Do not confuse these children with a second language. For our family living in the US, English is our first language, and Spanish is our second language. Children with implants 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, spoken language.

We introduced Spanish at three years post-implant, with the same hierarchy of language that was learned with English. One word and one name at a time. Overhearing conversation and having opportunity to give input in a second language is also good. The three-year rule worked for us and and for others we met.

- 7. Play quality, language-rich DVDs. Let your child play with educational auditory toys that require good listening skills. These toys will ask a question and then your child will need to make an appropriate response. Read every night if possible. Play children's music in the car, sing songs, and talk, talk.
- 8. Turn on the implant or hearing aids within 30 minutes after your child wakes up. Keep them on all day. Check the implant / hearing aids daily for full working order. Know how these devices work, and how to solve any issues that may arise. Cochlear implants typically have a 10-year warranty on the surgically implanted device and three years on the external parts. Listen to the microphone, check it is on

the correct program, the batteries are charged, and the device is working fully every day. Check wires for any crimps or shorts. Once a week use a Dry and Store dehumidifier unless you live in a humid area, which may require more regular use. Check with the manufacturer for proper care and maintenance.

9. Ensure your child has an appropriate program to learn oral speech and that the teaching environment has qualified professionals. Check that the acoustics will facilitate learning with a noise-free classroom.

The first five years of a child's life are crucial for spoken-language development. This is a one-shot time. I can set four to five years of my life aside and focus to my daughter because I have lived my life, I am an adult. What's four or five years to me? Nothing. For my daughter it is the most critical time in her entire life. What is done now will shape her language forever. One day in the next two to three years, you can sit back and relax because your child's spoken language will match — or be better than - other children of similar age. This sacrifice is only for a few years and I am willing to help with any advice or questions you have.

It really upset me at the start when I asked three people their opinion of what to do and they all had different answers. 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 oral education 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?"

Trust 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, for any child to develop language.

- 1. Baby Einstein Video or DVDs. (Good language learning videos that children can watch.)
- Video-recordings of your child's oral training sessions.
   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. 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 from Children's Hospital Oakland (California). This book covers 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 give their child the best opportunity for success. You are in the driver's seat, and at times, you may need to disagree with the professional advice that is given. You will feel confident that your view has merit because it has been researched and you have data to back up your point of view. Remember 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 parents should have similar knowledge in this oral-education process so they can discuss progress 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 revolutionised the way deaf children hear. These pages discuss hearing loss, how cochlear implants work, and the differences between implants and hearing aids. Cochlear implants are approved for use in adults since 1988 and in children since 1990. Most people do not understand how cochlear implants work and the great hearing these devices can give deaf children.

### **HEARING LOSS**

You may have heard the term sensori-neural hearing loss at the doctor's office but not known how it affects your child. This type of hearing loss is where the tiny hair cells in the cochlea are damaged or absent and do not naturally allow electrical impulses from sound to reach the hearing nerve. While the physical parts of the ear work such as the bones, eardrum, and membranes, the hair cells are damaged in the cochlea. The hearing nerve itself may be working well, but everything stops at the cochlea due to 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 this type of loss can generally be addressed with surgery.

Cochlear implants have been around for over twenty years. Only in the digital age did these devices reach a point that children who are profoundly deaf can hear whispers and respond to open-set commands at levels as low as 15 - 20 dB. These devices, with a good oral education program and dedicated parents,

are an absolute miracle. To begin, we should understand audiograms and the "speech banana" that audiologists refer to. As an informed parent, when a professional asks you "how well does your child hear?", you do not say "Oh, they were diagnosed as having a severe hearing loss". The answer should be: "Johnny can hear 70dB to 80dB in the low frequencies and 85dB to 100 dB in the high frequencies unaided. With hearing aids he is between 40dB—60dB on all frequencies. I will get the audiologists' report to you."

The audiogram is marked in decibels (dB) and Hertz (Hz). This graph plots 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 a lt of speech and will have a hard time following conversations in an auditory-only manner.

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

### **COCHLEAR IMPLANTS**

Cochlear implants are designed to address sensori-neural hearing loss at levels which plot at severe to profound on the audiogram. If your child's level is less than severe or a combination of moderate

to severe, a hybrid cochlear implant may help. Cochlear implant devices have two main parts which consist of the internal device and the sound processing unit.

During surgery, the internal device is implanted under the skin behind the child's ear/s 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 encased in titanium for durability. Theoretically the internal device is intended to last a lifetime without needing 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 on the speech processor "picks up" audible sound and transfers it to the processor's chip, where it is turned into electrical information. Next, the sound-detail transfers to the internal device via a headset and magnet. From here, this detail moves to the device's 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.

Your audiologist has mapping options for the external device. Most implants have four sound-programs and every electrode can be set to stimulate as much or as little as needed. The device is always checked by taking the child into the sound booth and testing all frequencies and sound levels. Speech recognition and discrimination is possible at 15dB — 20 dB with these amazing 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. Remember, you cannot just

put these devices on and think your child is cured. It takes years of speech therapy and a formal education in the Auditory Oral or Auditory Verbal\ method to achieve this with a deaf child.

### **HEARING AIDS**

Hearing aids are generally used where people have mild to severe hearing loss. While a cochlear implant bypasses the damaged part(s) of the deaf person's ear to stimulate the nervedirectly, a hearing aid makes the volume much louder and feeds that volume through the damaged ear. Hearing aids are a solution in certain circumstances. The key with either device is to have the child hear the entire speech banana with clarity. I cannot emphasise 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 get a cochlear implant within the next few months.

Today's top-range digital hearing aids can be fine-tuned with excellent sound for wearers. Hearing aids need ear molds and can "feed back" with buzzing. 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 to a charity. 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. For us, the aids were a temporary patch until the cochlear implant surgery date. Remember, 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 bit about how the brain hears and stores information. The auditory memory as it is described by professionals is a brain function that stores auditory sound. The child must hear sounds, words, phrases, songs, the more the better. Just keep feeding the detail in, words and sound in a structured way, following the child's progression of speech. This is why 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 can even speak their first word. The speech therapist and program you work with, need to spend much time on listening and following auditory commands before anyone even expects one word from your child.

After the sounds, words and phrases are fed in for months, when a child hears a sound like a door and says "door" you know you are on the path to a speaking child. The brain stores all this detail in the "auditory memory," clear sounds and words in, clear sounds and words out. This is why cochlear implants are crucial in giving your child phenomenal sound clarity. Doctors will tell you "If your child is getting good benefit from the hearing aid(s), keep using them." What does good benefit mean? It may mean your child hears at 30 — 40dB. Is this enough? To me the answer is no. I want my child to hear at 15dB with the best clarity viable.

### **BILATERAL COCHLEAR IMPLANTS**

Bilateral cochlear implants are more routine today than in 2004 when our daughter had her second implant. Personally I hated that my daughter had one good ear and another ear that heard only 45 - 50 dB across most frequencies with a hearing aid. I had no idea if this was affecting the clarity of sound to her brain. I was born with two full ears, I love music, and enjoy sound in 360 degrees. I wanted the same for my child.

In our case we were denied a second implant by our insurer. I did not understand. Doesn't it make medical sense to have two good working ears? In the appeals process with the insurer, ten people were sitting in a room. Not one was an audiologist, ENT advisor or surgeon, they were all MDs 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 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 situation. We were not fortunate enough to have their expertise available in our case.) and ended up paying for the second implant. Today things are different, with many insurers covering both implants and case law that now backs up bilateral implants.

So there we were all insurance appeals exhausted and I would look at my daughter, read 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 digital hearing aid. So the question became, Keep the hearing aid on or take it off? Is it helping or hindering her hearing? After speaking to people, all I wanted were two ears that could hear equally well. So on November 5, 2004, Gabriella received her second cochlear implant.

This second implant had very little to do with her ability to gain speech. Children can and do gain excellent speech with just one implant. Our reasons went much deeper. Studies have shown that bilateral implants are better in noisy environments; they help with localising sounds and word recognition. My reasoning was 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 the first. By altering her auditory oral sessions and taking a methodical approach to teaching her new ear to listen, both ears could hear identically well within four months. The process of working with a newly implanted ear must be addressed by an experienced therapist. Do not rely on trial and error, or trust a person without experience in this area. Factors to consider include length of time between implants, how well the new ear hears, and how much auditory access that newly implanted ear has had in the past.

In our case, Gabriella had a hearing aid on her second ear from when she was diagnosed to the day she had her second cochlear implant surgery. During 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 processor on her ear for one hour every evening. Otherwise, she wore both implants. When you read about the hierarchy of receptive and expressive language and the steps every child takes to acquire speech, you will see the newly implanted ear needs to "catch up" with the old ear for both to hear the same.

Many children today get both implants in their initial surgery, which makes sense. It is more cost-effective, there is no alteration in the education process, and they get great sound in both ears at a very young age. I would strongly advise having both implants during one surgery if your medical team feels it is appropriate.

These days children as young as seven months of age receive both-ear cochlear implants. This is not typical but our surgical team has operated on very young babies. Again, this is a very medically oriented question to answer, when your child should be implanted. The sooner the better if your doctor believes 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 hinders childrens' listening in the un-implanted ear is one that is still unanswered. It is true that the auditory nerve needs stimulation to keep it healthy and vibrant, but what of the hearing? I did not want to lose more thought to it so two implants was the decision our family made.

### **CARE AND MAINTENANCE**

Since Gabriella had her first implant we protected her from falls and electromagnet static that could damage the internal cochlear device. Like all very young children, she did fall. Running in the house, "bang" against the door jamb on the implanted side, our hearts would drop. Walking along outside, she would trip over her feet and fall to the ground. Once she even fell off the bed. She must have fallen or hit her implanted ear at least six or seven times. Every time we tested her at home to ensure her hearing was still OK.

The external devices need care and maintenance too. Just like a car, if you never change the oil or the spark plugs, it will stop running or sound very strange. Check daily that all the cords are working, and that the batteries are fully charged. Weekly, make sure the microphone is working. Use a dehumidifier for your area. 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 like 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 extra help for her school years and life, just her two implants. Currently she is using a sound field system at kindergarten and I would recommend this in the first few years of school or even an FM system. There will be an age when the child can tell you what they need.

Remember every child is different, and do not get too concerned about talk of assisted listening devices, interpreters, and supports. Again, this is based on age of implants and an excellent oral program. In our case Gabriella wore hearing aids from 10 months of age, 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

The two main companies that make cochlear implants, are Cochlear Corporation and Advanced Bionics. There are a few smaller vendors but these are the two leaders with the largest market share. Our daughter uses the Cochlear Corporation devices and all of my experience is with this implant system. I am very familiar with the Advanced Bionics product and have seen many children do very well with them.

Before your child's surgery, do your research, attend seminars, talk to parents and review the makers' websites. Honestly, I was so busy with insurance companies, hearing aids, doctors and appointments that I didn't put much thought into which device to use. I felt whatever device the surgeon advised should be fine. In reality both devices are excellent. Do your research and then talk to the doctor doing the surgery and ask what device they prefer and exactly why. Be the informed parent at this stage.

### THE SURGERY AND MAPPING

The implant surgery takes about two hours. Most surgeons will tell you it is a minor procedure smaller than a tonsillectomy. Your child is anaesthetised and some young children spend a night in hospital. Depending on the country and hospital, older children and young adults go home after the surgery. After a few weeks for healing, you will go to your audiologist for the initial mapping session, known as "switch-on" or activation.

Most families are very emotional before this session as it is the moment of truth and tells you how many electrodes in the device are working. The audiologist hooks your child to a computer whose screen shows each electrode. The audiologist can tweak the sound level on each electrode until your child hears comfortably. Initially the detection of sound is all anyone is looking for. The audiologist will stare at her computer and talk to the assistant, while you sit and pray. Electrode #1 a little more, a bit more, then... your child's head turns and the audiologist says good. Yes, your child

has sensed sound in that electrode. This process repeats until every electrode is mapped. Your child can hear and the tears of joy start to flow. Usually there are three mapping sessions over two-to three weeks, with the volume increasing each time.

# CHAPTER 4 WHAT TO DO

Helping parents navigate this informed-decisions process has always been my desire. When parents make the right decisions, the children benefit with top quality hearing, schooling and speech. Here are some of the essential details of how to teach a deaf child who wants to speak and communicate just like their hearing peers. As you will hear a hundred times from people, "every child is different and there is no guarantee they will speak." All you can do is try your best, and provide exactly what your child needs.

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

My experience is with the auditory oral process and the 100% oral approach. Gabriella was diagnosed with a moderate hearing loss at ten months of age, and was profoundly deaf by twelve months of age. She had her first cochlear implant at 14 months old, and her second implant at 25 months old. We worked with the local school district's education department right after diagnosis. They offered only a Total Communication program but after research we found The Jean Weingarten Peninsula Oral School. Gabriella started at this school at eleven months old and graduated in June 2007, a total of four school years or 36 school months.

### LOOKING, LISTENING, SPEAKING

After the joy of delivering a full-term, perfectly normal baby, we knew nothing could go wrong. 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 having problems getting one ear to pass the newborn hearing test, he finally said she passed. We were overwhelmed with joy! Even today, I do not know if this young gentleman misdiagnosed our daughter or not, but I am thankful that many states now require this test for all newborn children.

Coming home from the hospital was a precious experience. There we were with this beautiful little girl. All she wanted to do was cry and drink milk. A few months passed and then the hands and legs started moving, and I wondered, is this normal? Out came the infant guide book and this was a typical reaction of the muscles in the baby's body. I didn't know because I was a new father!

With every little incident, we had to talk to another parent, the nurse, or read about it. As parents, we were travelling this road totally blind because this was our first child. Most of our friends had children aged five to fifteen. They were good to talk to but for the day-to-day specifics, we sought advice from our local nurse.

After about seven months I noticed Gabriella's eyes tracked almost everything but she seemed somewhat tuned out when it came to sound. She did react to sound, but not consistently. Having nothing to compare to, we read the infant book again and asked her pediatrician. "How do you check for the senses, sight, smell, hearing, etc." The pediatrician replied "Oh your baby is fine, 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 says?" The doctor replied, "Different children speak at different times and your daughter looks fine, now go home and have a good day." We heard this from two doctors who said "don't worry everything is fine." Another two months passed and we had a vacation planned. In my mind I said OK, let's go away, and if my mind does not change about our daughter's hearing after our trip, I will march into the doctor's office, and demand a hearing test.

Vacation was wonderful and we had a great time. About a week after return, we were scheduled to see the pediatrician. This time I had my list of concerns and after the initial examination I said to the doctor, "I feel Gabriella needs a hearing test because..." The doctor agreed and off we went to the Audiology department. Ten-month -old children cannot tell you "Oh I hear that, but I did not hear that." They are more difficult to get a good audiogram from because they cannot tell you what they hear. The tests must be done by a qualified pediatric audiologist, with years of experience diagnosing infants. If necessary, demand to be referred to a childrens' hospital. One wrong diagnosis at this point could be devastating to your infant's long-term results.

Behavioral response testing is used with young children to assess their hearing. Sounds are presented to the child through headphones and the audiologist looks to see if the child reacts. Whatever your diagnosis, please verify it with another test and audiologist. There you are, with the results. Now, the next step is to get sound to your child with the absolute best hearing aids possible. Emotionally the world is falling around you, your precious little child has hearing difficulties and you know this leads to challenges in life. Why you? Why your 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 focused, query doctors' opinions when they do not match your gut feeling, work with professionals, and demand, don't ask, for the best care for your child.

Early detection is the key to great speech. Some people reading this, got their child's diagnosis at 24 or 36 months of age for whatever reason. Do not worry. What you can do is to put everything into the next three to four years, for your child to learn to talk. Some adults are profoundly deaf with great speech from wearing hearing aids their entire life. That's from hard work, and little or no use of sign language. This book outlines the best case scenario and what to do, from my family's experience. We had factors that really helped our child: a school district who supported our goal 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.

Living in a large metropolitan area raises your chance of accessing these facilities. There are still places in the US with very few facilities for deaf children to acquire great speech. The advice in this book and hard choices on your part will make the difference in your child's life. Don't forget what I said, your sacrifices for the next three to five years will change a child's life forever. This methodology of great speech is a sacrifice for us parents. Children with the right teaching can achieve anything. Just ask me because I see it every day with my daughter. It amazes me today 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 needed for your child to obtain great speech. When I was starting out with my daughter I never had a checklist or roadmap. I used my gut feeling and thankfully the choices were correct. Speaking with professionals, going to conferences, and talking with parents really shaped the decisions for our daughter. Back then, I had no idea how well our daughter would hear, how clearly she would speak, no idea how well she would articulate words. I wanted her to be able to communicate with the world around her. Four years later I can tell you that perfect hearing and speech are possible. As parents, we educate "professionals" we meet, that hearing and speech is the goal for everyone to work toward. Self-reliance so that a deaf child does not need to rely on anyone to communicate is what the hard work and money is for.

- 1. Early detection and implantation are the keys. Implantation at, or around twelve months of age is ideal. (If your surgeon suggests an earlier age, definitely consider this advice.) If your child has been implanted later in life, just move forward and 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 and/or with other parents you meet either in person, or in online groups.
- 2. To start your child's listening journey, find a good oral language program to acquire speech, the younger the better. Children as young as six months of age can enroll in an auditory oral / verbal program. 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, health insurer, the program director(s), and many other people to find the right program.
- 3. A great relationship with your school district's special education / early intervention team is a must. Many children are served by their local school districts and if other medical issues present, by a regional centre. We have experience with our school district and really did not have any experience with our regional centre. Both entities fall within the Early Start program for 0—3 year-olds in the US, meaning your services can start from day one. Confirm the time lines that they must follow to progress quickly, and know your rights. Again, I must emphasise, 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 provided things are moving forward and you are getting services in place.
- 4. Your child needs to access a top auditory oral program that builds listening-only responses, either in-person or via Skype (as is happening now). Children can attend such programs from six months old, to listen and respond via facial cues and then over time, 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 vital: listening precedes speaking as a natural progression with all hearing children. Remember, our children follow the exact same speech development path as a hearing child. The only difference is that our children are given more emphasis at every step until they are articulating full paragraphs and using language appropriately.

- 5. You want an experienced cochlear implant surgeon. Do not be afraid to ask, how many of these surgeries have you done? What is the result you have from other children with similar hearing levels? Do not be rude or sound as if you know more than they do. You need always to be nice and polite. You will be dealing with the doctors and professionals for years, so do not start on the wrong foot. Just be clear with what you want for your child. "I want my child to hear and speak well. I have met parents whose children speak and hear, and I want the same for my child. I will do whatever it takes for this happen. We are committed as a family." When your doctor hears this, they know you are on board. And you are one of the very few parents that genuinely is committed to work with these fine people. They will bend over backwards for you, provided they know you are on board and you always show your sincere appreciation for what they do.
- 6. You also need an experienced pediatric audiologist who has detected and mapped children with implants. Do not be afraid to demand a different person if necessary. Ask other families for referrals. Many surgery centres contract the audiologist or sometimes a surgeon is recommended by an audiologist. Talk to other families for their views on a particular doctor or audiologist. Remember, you need a pediatric audiologist who has a great deal of experience with cochlear implanted children, not a general practitioner.
- 7. A family support system that works when you cannot be home or you cannot take your child to school. Remember, children with hearing devices can start school as young as six months of age. One partner needs 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 run this process with both parents working 9 — 5 and 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.

- 8. Time to find out everything about cochlear implants and language learning. The desire to order every book and read it fully. You also need insights to ask professionals hard questions and understand the answers. Start a bookcase and maintain a reference library that you will be building for the next three to five years.
- 9. Be part of the cochlear community. Attend conferences and educational events. You will meet parents, professionals, and children experienced with cochlear implants. Know what programs these families attend and compare them with yours. Volunteer your time, donate to your school, and give support because your child is going to this school or program and hundreds of children will be diagnosed in the next few years. You want their excellent program to continue because giving a child the gift of speech is a great outcome.
- 10. A full understanding of health insurance, with understanding of coverage, "negotiated contract pricing," co-pays and your policy documents. When the insurer says, "We do not cover that," tell them to show you in writing where it is not covered. The legal resources and track record of the Let Them Hear Foundation are priceless in such cases and they have won or overturned many denials from insurance companies!

Now comes a question that may represent a small number of people reading this text. What happens if you do not have insurance? A few options are 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.

Hearing-devices are in a completely different area to the mother's policy. When your child fails a newborn hearing test, they are labeled with a pre-existing condition and a huge red flag for health insurance. Group plans with employers typically cover people with pre-existing conditions. People designated as low income can qualify for different programs. The state of California has a program, HIPPA, that provides insurance if you present in writing three denials from insurers. This policy is less good than others because it sets limits on yearly payouts that may not cover what your child needs. I hope that other states have such a program.

This education process is ongoing. To fully understand and learn everything about hearing can take years, just like it took me. Learn the critical steps first that correlate with your child's listening and talking process. Do not worry about assisted listening devices or mainstreaming if your child is only two- or three-years old.

A real understanding of your insurance policy is a priority in your knowledge base, with a full understanding of the IFSP / IEP process, your legal rights and a good relationship with your school's special education team. Sit down and talk with your partner, run it through your mind a hundred times if needed, reach the absolute decision 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 professionals mention they know families where the parents will not get an implant for their child. They will not enroll their child into an auditory program or attend their child's IEP meeting. These parents sadly are in complete denial. As parents we have the legal right to do everything for our deaf children to help them speak. We also have the legal right to do nothing. 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 moving the ball around, and like every great football team you need a group of 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 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 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, abstract ideas, communication, spontaneous expressive speech, age-appropriate language, age-appropriate articulation and the hierarchy of language.

We will now review the different aspects of language, speech, and auditory skills. With these essential topics, various issues associated with language and your child's development will be discussed.

This is a father's explanation of what was learned over four years about speech, language and articulation. Many books on these topics have terminology that most of us do not understand. This will happen with your child's IEP, 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 full 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 facilitate this goal for your child? If the speech teacher 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 vital to know where your child is, in language terms and where they need to go. Observing speech therapy sessions in the early days is crucial. At the start, I had no idea how children gained speech and language, but with hours of reading, and attending speech therapy sessions I soon learned how children acquired language. My job was to provide feedback on what we were seeing at home. It was not a matter of saying, "Oh Gabriella is speaking a lot." I went to 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 guide the professionals since they need to know exactly what language processes are going on at home.

Open up your mind and get ready to learn the terminology that every parent needs to understand for their deaf children to speak. I hope this book is a real help to you.

### **RECEPTIVE LANGUAGE**

Receptive language means, how well does your child take in information and listen? Alternatively, how well do they follow instructions? This is very different from how well your child hears. Hearing is documented in the sound booth and on your child's audiogram. An expert speech therapist will focus to receptive language for months before expecting any words or vocalization. Children will hear sounds, words and phrases for up to twelve months before they speak their first word. This applies to hearing children, but our children must "catch up" very fast. We soak our children in words, phrases, and songs for months to build their receptive language before expecting any words or vocalization.

This is why early hearing aids for a child are so vital. The more the child hears at the start, the easier it is for them to catch up on their receptive language skills.

### **AUDITORY DISCRIMINATION**

At an IEP meeting when I was told one goal for my child was to react to a two-part question in an auditory-only manner, I did not know what that meant. The person working with us gave us an example to try at home, for the IEP. With Gabriella in another room, we were to say: "Gabriella, grab Elmo 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 with what the therapist was saying because if she had confidence that my daughter could do this then I should, too.

Auditory discrimination is listening to a word or a phrase and picking out the key word(s) and responding to that statement or question. The key words in the above sentence are: Gabriella, Elmo, and Couch. I could say, "Mommy, grab Elmo and put him on the couch." Or I could say "Gabriella, grab your book and bring it to the table." There are key words in every phrase and as humans we tune into those key words. Hearing children do this naturally but our children need more input and repetition. As we play with our children we must say words hundreds of times, such as Elmo, couch, book, etc.. We must ensure 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 words simple, and to avoid synonyms until your child can react to the first word used. Shoes for example are shoes, not tennis shoes, sandals, boots or slippers. They are shoes. Once your child knows the word shoe and can pick that item out of four or five items, they can learn the different types of shoes. Everything in this book needs to correlate to your child's hearing and speech ability. This is the 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 may confuse your child with topics that are too hard and they will take much longer to learn with disruption to 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, toys can benefit discrimination and listening. LeapFrog and others make toys that require a child to react to a sound, a song, a word, or a phrase. 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. Better still, I got a small xylophone for our daughter so she could hear the tones and frequencies of sound. We would sit and bang on the xylophone as she learned that sounds can be soft, loud, high pitched and low pitched.

For your child to learn to discriminate words, sit down with your partner and make a list of 50 items in the home that have one name and one name only. Many items have numerous names. You should use only one name to start with. Use plate, not saucer, phone, not telephone, shirt, not blouse, pants, not Levis. The exact words don't matter. What does matter is to use the same word all the time. Type a list, advise your speech therapist what words you are using and say these words repeatedly 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 teaching — praise your child when they reacts appropriately.

Very soon, you will have five items on the floor and when you say "phone" they will point to the phone, when you say "jeans" your deaf child will point to the jeans. The therapist for our daughter began with sounds of animals and would ask Gabriella to discriminate the sounds of three to five animals. Then when our daughter had the sounds mastered she went on to the words, before putting the words into a question, such as where is the cow? Or, show me the cow. Each day she started the session with the seven Ling sounds and had Gabriella respond to these to confirm she heard all the frequencies that make up speech.

As an informed parent you will understand the hierarchy of receptive language and know if the therapist is using the correct order. Ideally you get a great therapist from day one, because time is so precious in this process you must know if your child's therapist is equipped to teach YOUR deaf child to hear and speak.

Single words are used at the outset and over time, these words are put into sentences that can be simple or complex, one-part or two-part. As your child gets older, the therapist will use sentences like "Johnny, can you pick up the green crayon and color the tree?". Johnny has 12 crayons and several items on his coloring

book. (This is a two-part question since 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.

Some listening exercises follow an open format and others follow a closed set format. Early on, as your child learns to discriminate, a closed set format will be used. 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 no visual cues to choose from. A question in an open set format may be: "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, and the child could answer or interpret this question in different 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.

This is why home life is an educational bonanza – learning, hearing words, sounds and phrases all the time.

We've discussed words, but what about sounds? Being told that Gabriella would 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 label every one. Sounds like the microwave buzzer, the birds, the dog barking, the coffee grinder, music, the rain, the door knock, 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 identifying the basic sounds and work from there. Repetition is the key to great listening.

### **EXPRESSIVE LANGUAGE**

When we learn that our child is deaf or hard of hearing, the very first thing in our mind is "I want my child to speak." We forget about hearing, discriminating, and everything else; we want our children to speak and to 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 request for milk, a vocalization, or it could be expressing one's thoughts in a full paragraph or two of information. Expressive language has many parts, just like receptive language.

Deaf children learn speech and language the exact same way as hearing children do. Our children need repetition and guidance for every part of the language hierarchy. They follow the same learning path as hearing peers, and as parents we must know where they are at all times. For expressive language, this is why the term "age-appropriate" is so vital. As a father to one child, I had no idea what was age-appropriate for my daughter's receptive and expressive language. My recourse was books on language development, talking to the therapist and understanding their tools, such as standardized language testing models.

This learning gave me a good understanding for Gabriella's next steps in natural language development. Too many professionals compare our children to past deaf children who did not access cochlear implants very young, or 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 hearing children through every step of this teaching 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 who is given every tool to acquire speech and language can and should have a big vocabulary, great articulation, and good use of words in the correct order and context. This child should understand abstract ideas, and give a great explanation of the world around them. They should have completely typical speech and language in three to five years after this teaching starts. This is our goal, our hope, and my daughter's reality. I pray that your child reaches the highest stars and never lets anyone stand in their way.

### SPONTANEOUS EXPRESSIVE SPEECH

In these years you as a parent, with the therapist, will be feeding appropriate language to your child. You are their model so they 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 someone asks, "How old are you?" and your child just sits there motionless with no words, you will say "two." (You will work on just one or two words at that point in time, if that is where they are at in their expressive language skills.)

Older children will say 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. Typical hearing children pick all this up naturally but our children need more input at the start to gain excellent speech and language. So what is spontaneous, expressive speech? This is speech that a child uses to get what they want, or to ask questions with no input from any other person.

The child starts a conversation with no cues from anyone. Two or three children are playing together and one says" "Can I have the doll?". This is spontaneous. No one asked her if she wanted the doll. She 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 how they were feeling; they simply said it. As time passes, 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 aim for a back-and-forth conversation with you and your child using a few exchanges.

### BIRTH AGE AND HEARING AGE

In formal meetings such as the IEP, your child's birth age, and their hearing age will be discussed. The birth age is how old they are, while the hearing age is how long they have heard with amplification. A child who is born fully deaf and does not get hearing devices until ten months of age has a chronological age of 12 months and a hearing age of 2 months on their first birthday. In most reports the evaluators and assessors will use the hearing age, chronological age, and whether your child is speaking and 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. Over time, 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 it sounds extraordinary to be deaf and have better communication skills than most hearing children, but it happens regularly.

### **COGNITIVE SKILLS**

Most students going to college take the SAT (in the US) to see how "smart" they are. Measuring cognitive skills is similar in young children and shows how smart they are, at that point in time. Cognitive skills alter, so if your child is behind, work with them to catch up. Very simple tests are used with young children: can they stack blocks, can they detect shapes, letters, colours, or stay within a line when using a crayon. As the child grows, vocabulary and use of language move into cognitive skills tests. Close work with your child's teacher is crucial to know what they are learning at school for you to re-emphasize and reinforce at home.

### **ARTICULATION**

Have you wondered why children do not have clear speech from the very first day they put words together? As humans, our mouth and brain work together to form sounds. Our tongue, lips, cheeks and teeth must harmonise to make clear sounds. It takes time and practice to form all the sounds in the English language, so children form the easiest ones first with the more complex sounds at upwards of age seven or eight.

Vowel sounds are easiest to form and arrive first, followed by vowel-consonant or consonant-vowel. Then consonant-vowel-consonant will form to end this part of articulation. Remember, specific vowels and specific consonants arrive before others. The previous description is of a single-syllable word. In time, two-syllable and three-syllable words will follow. We would not work to have a baby say the word "unsuitable," a four syllable word. We also would not ask a ten year old to say "dog" or "cat." The therapist

must know the natural order and age-skills for articulation. Their reports and interactions with you should track the child's full repertoire of sounds, and which ones need work. Clear articulation is so crucial for clear speech.

Oral motor exercises build the muscles in your child's mouth, tongue, and cheek. Things like using a straw, blowing a feather and other exercises will give your child strong oral motor muscles for good articulation. We as parents will never be the "experts", but how can we interact equally with our child's therapist or think of what goals should be on their IEP documents without knowing these things, and knowing them well?

It hurts to talk with a parent who is two or three years into this process with no idea what these terms mean. Are they in the driver's seat? No, the school district, speech therapist, and other people around their child are in the driver's seat. Remember, these professionals have other children to look after, too. We and only we as parents know our children best. We must be ready, willing, and able to work with them as needed.

### **AUDITORY PROCESSING**

A child can have great hearing, articulation, and speech, yet their brain may not be making sense of the words. This is called auditory processing. Some children have minor processing issues and others have no issues at all. When processing, the child listens to a question or a statement and decodes it, then answers with a relevant response. Sample questions are: "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) with other (open) questions requiring an explanation. Both types of questions take some processing to answer correctly.

Auditory processing is crucial when we discuss complex language. Language gets more abstract with ideas presented, and the child has to think how the pieces fit together, making auditory processing and language comprehension essential areas to understand. The simple summary here, is that language comprehension and auditory processing is how well the brain makes sense of what is being said out loud.

### **COMPLEX LANGUAGE**

Our children can, and should be enabled to develop age-appropriate complex language skills for adulthood. When Gabriella was first diagnosed as hard of hearing at 10 months of age and then completely deaf at 12 months, many thoughts went through my mind. Because I am a very expressive person and love talking about theoretical and complex subjects I thought how terrible it must be to have all these thoughts and ideas in your mind and not be able to express them. 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 deepest feelings and thoughts with. I wanted my daughter to express herself the same way.

Spoken language is complex. We do not just say "I want food." We say "I would like a steak medium-well done, 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 you are not paying attention. (Little do they know you are deaf!)

Using language accurately with proper sequencing, forming 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 gain complex language. With the right implants at an early age, committed parents and a great oral program, the sky genuinely is the limit!

### THE HIERARCHY OF RECEPTIVE AND EXPRESSIVE LANGUAGE

Here is a basic understanding of how children progress through receptive and expressive language skills. Remember, our children learn language the exact same way as hearing children. The difference is that we emphasize every part of the learning process and guide them every step of the way until that beautiful day when we know they have mastered language and can walk on their own.

Listening always precedes speaking and time needs spending on the auditory (hearing) skills that all deaf children must gain 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 don't hear well? Listening comes before speaking.

This is a primary difference 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 to develop strong auditory skills which are crucial to function in a hearing world. Without good auditory skills the language they receive 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 read these hierarchies to explore this overview of processes all children follow to listen and speak.

## HIERARCHY OF LEARNING ORAL LANGUAGE Receptive Language - "LISTENING"

STAGE IN HIERARCHY	EXAMPLE
Awareness of Environmental Sounds	The door, the phone, music, a bell, a dog barking
Discrimination of Sounds	Discriminate oink, oink vs. quack, quack, vs. ruff
Discrimination of Words	Discriminate pig vs. duck vs. cat
Discrimination of Single Words in a Sentence	Where is the pig?
Completing One-Part Requests	Pick up the pig. Color the dog, etc.
Completing Two-Part Requests	Pick up the pig and put him in the box.
Discrimination of Two Key Words	Where is the black car?
Fully Understand Over 100 - 150 Nouns	Phone, car, plate, shoe, cup, rug, couch, table, etc.
Fully Understand 50 - 75 Verbs and Adjectives	Run, walk, brush, climbing, small, big, long, short, etc.
Answering Questions	What color is the car? What shape is this?

### HIERARCHY OF LEARNING ORAL LANGUAGE

## Expressive Language - "SPEAKING"

STAGE IN HIERARCHY	EXAMPLE
Vocalizing Sounds	Vowels will be mastered first, then consonants
Vocalizing a Full Range of Sounds	Making sounds of different length and shape
Speaking Single Words and Variations	I, Me, My, Ma Ma, Pa Pa, Eyes, Baby, Bye Bye, Milk, Bread.
Repeating and Copying Spoken Words	Dog, Cat, House, Car, Paper, Pen, Monkey, Sleep, Wash.
Attaching Meaning to Words	They know what the word means when they say it.
Speaking Two-Word Phrases	Come home, Let's eat, Want milk, Play outside, etc.
Speaking Three-Word Phrases	Help me please, I want that, HI little doggie, etc.
Speaking Four-Word phrases	I want to play, Let's go to park, I want take bath, etc.
Speaking Full Sentences	Daddy, help me with my shoes. Mommy, I want to eat lunch.
Carrying on Back-and-Forth Dialogue	Back-and-forth dialogue with multiple exchanges

# CHAPTER 6 THE PLAN

At this stage, I hope you are confident that you can teach your child to speak and listen. Having insights and doing the right things at the right time makes a big difference. There is no time for mistakes. If you have made mistakes, dust yourself off, and do not feel like a bad parent. Sadly, the systems do not give clear, concise answers. You must trust your gut feeling, what seems logical and the best decision for your child.

This learning to speak process is a sacrifice for us parents. It is a huge 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 give 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 advice 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.

We have discussed the essential aspects of what to do at home, the parents' role, and so forth. We will now discuss the type of school Gabriella attended, the type of surgeon and surgeries she had, the therapy sessions, the hearing tests and the IEP meetings. 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 across the US in the resource section of this book.

#### WHY US?

Walking into the sound booth with my wife holding our little girl, my life flashed before my eyes. How many times had my parents taken me for any type of medical test? Yes, as a child I had injuries but a few stitches and a short recovery and I was fine. The little I knew about hearing loss told me that whatever the hearing test 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 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 said our ten-month-old daughter had a moderate hearing loss and would need hearing aids. She explained the different types, analog and digital, told us to make a decision and give her a call. While "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 digital hearing aids and put them on her little ears.

A genetic test was suggested, and we agreed. The audiologist at our local hospital was experienced with children, and, looking back, was a miracle worker. We spoke with the ENT doctor and after a few visits it emerged that Gabriella did not have a conductive loss, but a sensorineural loss, affecting the tiny hair cells inside her cochlea. These hair cells give electrical impulses to the hearing nerve, and without enough hair cells the hearing nerve is not stimulated, in short, a permanent hearing issue without a simple response.

We put the hearing aids on and had more sound tests to program these very advanced devices. At this time the audiologist and ENT doctor suggested an ABR (auditory brainstem response) test for our child. These tests tend to have thirty- to sixty-day wait times so we were scheduled at our local children's hospital. This one decision by the audiologist and doctor to run this test was crucial. Without this test, how long would we have continued this oral-education research, not knowing the actual severity of our daughters hearing loss?

The audiologist explained that the ABR test required that our child be anaesthetised. Electrodes and wires would be attached to her head for a very, very accurate hearing test on our little angel to see exactly how deep her hearing loss was. Keep in mind that hearing tests in the sound booth are very subjective due to the child's age and the audiologist's experience. This one ABR test is the tell-all and is very accurate.

Meantime Gabriella's hearing-aids were a pain to keep on her tiny ears. They always fell off and I had no idea how well she heard with these devices. Immediately the special education team was contacted for Gabriella's local school district. We met a very caring person who arranged services three times per month. The Hearing specialist would visit our home to explain how to work with our child. Simultaneously I called every audiologist and speech pathologist I could find. I must have spoken to twenty different people to get a speech evaluation, knowing that my daughter was behind in her hearing and speech development.

In hindsight, I should have been seeking the options for acquiring speech, instead of a speech evaluation. I wanted a person experienced with children and who dealt with deaf and hard of

hearing children only. I got the name of different people and either the waiting time was months, or the person did not specialise 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.

Two days later I arrived at the Jean Weingarten Peninsula Oral School and met a very caring woman. I walked in the door and sat down on a couch and explained to the woman that my daughter had a moderate hearing loss and I wanted her to speak, no matter that it took. I explained that I loved her dearly and wanted her to communicate with the numerous people around her, as a child and as an adult. Tears flowed and the feeling that this school with their expertise was our one and only chance for speech hit me.

After the meeting the woman said she would 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, 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. 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. 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 they will pay us, but we feel it is important you learn 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 explained about the IDEA law and that every deaf child deserves an "appropriate" education but some school districts may not offer an oral program for deaf children, aged 0-3 years old. It seemed 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 old It was late August and the start 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 school for over twenty years with 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 and 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 she knew 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 said Gabriella was over nine months behind on her listening skills and we needed to address this first. All children develop receptive language skills (listening) before expressive language (speaking), and Gabriella's

listening skills needed to be on track. In short, 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 for our daughter's ABR test at our local children's hospital. I woke and said prayers, knowing this test would conclusively tell us 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.

About two hours later, the test was complete. We 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.

Little did I know, bigger and better things ahead of me. This process has brought me closer to my daughter, given me the chance to volunteer my time, meet some incredible people, raise money for her school, and the opportunity to show varied professionals and parents the miracle that happened over four years.

Gabriella's story inspires people as to what works in oral education. Little did I know that I would write this book for parents to teach their children to listen and speak. Four years later every prayer is answered, Gabriella can hear the birds, the leaves under her feet, our voices, and she talks just like a hearing child.

The next day I advised the Jean Weingarten school of Gabriella's profound deafness. They mentioned a cochlear implant to help our daughter, but otherwise we would not change her educational process at all. We then made an appointment with a cochlear implant surgeon at the California Ear Institute in Palo Alto. Before this appointment we had a CT scan on both of Gabriella's ears and hoped for good news.

As the doctor reviewed the CT scan, 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 1½ times instead of the normal 2½ times. This means the cochlear implant surgery 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 hearing. Then this very experienced surgeon said: "Mr. and Mrs. Hall, I have implanted hundreds of children, many who have 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."

Our insurance covered this doctor's counterpart in San Ramon, CA—who said the same thing 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 Nucleus 24 implant device in her right ear. She would still use the very powerful hearing aid in her left ear.

Our local children's hospital where the surgery took place arranged speech services once 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

School continued and Gabriella progressed through the receptive and expressive language hierarchies. We were attending the Jean Weingarten school on a "trial basis" only Rather, we were working with the school district while exploring options to acquire speech. (This is a critical legal concept because if a parent makes a decision to enroll a child in one setting, it may jeopardize their access to funding based on the IDEA law.)

About a month after Gabriella's hearing loss was confirmed, the school district offered speech and language options, plus a summer school. Gabriella would be in a Total Communication setting and would immediately receive services three times per month. However, I refused to sign the document until all the options were explored. Not signing this document is OK but remember, services may be refused until consensus results.

In January 2004, four months after Gabriella started at the Jean Weingarten School we set up a full IFSP meeting to review educational services. I attended this meeting with the school's director. We explained to the district officials that an oral education is the "appropriate" education in Gabriella's case. She had a cochlear implant and could hear very well. Total communication or sign language, we said, is not an option. We explained the cost benefit to the school district to fund an oral program for my daughter and to aim for mainstream kindergarten with very few supports, which would save the district significant money over time.

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., with three weeks of summer school. Being at the

JW school, we worked very closely with the speech therapist to reinforce the therapy sessions topics at home, in a natural way.

A public school setting would not offer the family time for this learning-to-talk process to work. If your school district does not provide the information, you need to attend and observe every therapy session. This is "appropriate" and needed for the successful outcome of speech and language. You cannot be in the dark.

Home was a quiet environment for good listening. When we did need to make noise it was all 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.

With one daughter, one-on-one time was easy to plan. Families with more children may think it's more tricky to find quality time to spend with the relevant child. Be creative and think! Ask dad to play with the older children while mom works on vocabulary. Get all the children to play in a structured way so the little one can pick up natural language as you go. Go exploring on weekends to name the flowers, the birds, everything in the environment. Explain to the other children when you name an item it must be clear, loud, and articulate.

#### TIME IS OF THE ESSENCE

You may be asking, who has time to do all this when you leave the house by 8:00 a.m. and return at 6:00 p.m? Who will drive my child to school, work with her at home, bring her to appointments? Having a specific type of job gave me a flexible schedule to work on the phone, on my laptop, as needed. After a few months, I went to my employer and explained that my daughter was attending a specialist school forty-five minutes from home and that there were meetings and therapy sessions I needed to attend with her.

My message was that learning to speak is crucial now, my child cannot wait, I cannot delay this learning to talk process. The company said "Jim, we see your situation, why don't you take time off if you need to, tweak your schedule, maybe you can work on Saturday. Whatever you do we understand, we feel you will do fine. Keep track of your time off and we will review this in three months." Amazingly my sales numbers did not drop at all in the first year and the company never questioned my schedule. I was fair to them about the hours I was working and they were fair to me, regarding 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, and the birds. She loved music and we would sing songs with her and she followed along. Her expressive language consisted of simple words like me, mine, I, ma, ma, eyes, up. Two-word statements followed the one-word statements, with more two-syllable words as time progressed.

That summer was spent exploring the world around us and giving a name to everything we saw. Because she was working on one- and two-word statements, our description of objects were one

and two words long. We would talk to her in full sentences and treat her like any other child but were very aware 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". Next, we would say things like "show me the car, show me the dog, cat, bird." Receptively she knew many words, she was a great listener. We were extending her vocabulary while reinforcing words, concepts and phrases from her therapy sessions. Remember, we are with our children twenty-four hours a day.

#### THE SECOND YEAR

From late August, we began a second year at the oral school across the bay every Monday, Wednesday, and Friday. Therapy and classroom time with five other children were in a day class of three hours, with therapy being forty-five minutes of these three hours. We started class at 9:00 a.m. and finished by noon. Every morning there was a twenty-minute music session before class. Four children in Gabriella's class had hearing-issues and one child could hear, to serve as a spoken-language model for the other children.

In September, we had another IFSP review to discuss funding and Gabriella's progress. The school district visited the therapy and class settings and did not know how to assess the progress. Things were slow but we convinced them to be patient. We secured funding for six more months with substantial evidence that orally educated children need fewer services and lead their peers in essential language and cognitive skills.

#### THE PROGRAM

In class, the teacher worked on the child 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 relevant answer would be fed to the student by the teacher or her aide. The teacher would ask, "What are you doing?" Silence, the teacher would look directly at Gabriella and say, "I am playing with my blocks. What are you doing?" Gabriella responds, "playing blocks."

Praise was given for trying or giving the right answer. Loud sounds and whispers were explored, sound experiments, words, and vocabulary were all taught. Freeze dancing was an essential part of class. As music played, all the children danced. Suddenly the music stopped and the children froze, in a process to teach close listening to environmental sounds without visual cues. Experience books were very important for holidays and vacations, with pictures of the child and a one-sentence subtitle that explained the picture.

These books were brought to class once a month and the teacher would discuss all the books, with the children asking questions and awaiting 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. 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 differed, with full sentences used to ask questions or give directions. Single key words

were put into sentences, progressing to two key word sentences awaiting a correct reply. With fifteen crayons in front of her the therapist might ask, "Gabriella can you pick up the green crayon?" Or she would change tack and say, "hand me the green crayon, please." Soon, two words were used, like "Pick up the blue crayon and color the house." Or the therapist might say, "Can you get the yellow crayon and color the sun?" to derive variables from fifteen crayons and ten different things to color in the book.

For speech practice, the therapist asked a question and Gabriella would give a response. Sometimes just one word, sometimes two words and occasionally three words. The therapist always motivated 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. Production of speech was a main focus with listening practice. Getting the student to feel comfortable talking as much as possible was a very important aspect of this time period.

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, to get back and forth conversation going. While Gabriella answered in short two- to three-word statements most of the time, a dialogue could be established. Vocabulary and articulation were also addressed in these conversational exchanges.

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 work with their child at home. Memory was worked on along, with other tasks. Most importantly, find a good school, a good therapist and work with them in your own time, for your child to reach for their next speech and

language milestone.

Gabriella still saw the other speech therapist once per week at the local children's hospital. These sessions focused to articulation and knowing exactly when every speech sound should develop. We played games to encourage speech production, checking for vocabulary, articulation and age-appropriate syntax.

#### PLAYING WITH HEARING CHILDREN

With our daughter being an only child, she needed to be around hearing children to develop good language and social skills. She attended local playgroups for toddlers and Gymboree, or The Little Gym, or a music class from Music Together. 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 in a preschool twice per week for three hours per day for six months and was the only time she was in a preschool which we needed to pay for.

Rushing between appointments with such analysis of my daughter's words really made me think. Her entire childhood was 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 school and language exercises? This was a real concern to me but great progress was being made. All we could do as parents was to 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 routine. 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 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

With great results from one cochlear implant, we were seriously considering a second implant. We talked with Gabriella's surgeon, speech therapists, other parents and went to conferences to make that decision. The overwhelming answer was a resounding yes! For a long time there was no clear answer if the hearing aid in her other ear benefited her sound quality. We knew that with an implant she would have clear sound in both ears with the benefit of sound localization and better ability to hear with background noise present.

Gabriella wore Cochlear Corporation's body-worn unit at this time. How would she do, wearing two boxes on her waist? After some thought from us, Gabriella's grandmother designed a pouch of quality fabric to cross over her shoulders with two pockets to hold the units. The pockets did not intrude when she sat down. With tops that flared at the waist, this holster under her shirt and the wires behind her no one could tell that Gabriella was wearing an implant under long curly hair that concealed the microphone and headset.

We wanted our daughter to live without stares or looks from children saying things like, "Look, Mommy, that girl has wires on her head." To be honest I did not care what anyone said or thought. I knew the cochlear implants Gabriella was wearing gave her the ability to speak and hear. My goal is to show the world that a deaf child can communicate just like everyone else, I thought. If a parent said something like "Does your child wear hearing aids, or does your child have a hearing problem?" I would educate this parent.

When they heard the clarity of Gabriella's speech and saw we did not use signs, that our child followed directions and questions

with no visual cues, the parent then said things such as, "Is she still deaf? She hears and speaks so well." This was my chance to tell that parent about the great oral school she attended, while knowing the interaction would raise awareness of these verbal children, financially and emotionally.

Bilateral cochlear implants were rare, with one implant deemed sufficient for excellent speech. This is true. A child can develop great speech with one implant. But the question put to the ten-person insurer appeals board, was "Would you like to go around your entire life, hearing only with one ear?". Like politicians, they replied, "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." In late 2004 we did not have 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.

Time is of the essence and we paid over \$37,000 for Gabriella's second implant. Not every family has these resources, but thankfully today more insurance carriers are covering bilateral implants for children.

It was vital to us that the surgeon who ran Gabriella's first operation worked on her this time. In November 2004, Gabriella had her second cochlear implant. Everything went well except for some minor balance issues after surgery due to her enlarged vestibular aqueducts. After about a month she was her old self and we needed to wait a little longer for the all-important mapping session once the wound healed fully.

We were very grateful that the doctors and hospitals charged exactly what they would get from the insurers. Everything was paid for, the day of surgery with cashier checks to the relevant parties. The hospital was paid in full the same day, not ninety days later with

money from an insurer. Certain fees were waived and prices reduced because we had a great working relationship with the hospitals and doctors. We were so thankful that some months later we engraved a beautiful brick that sits by the main entrance to the hospital.

#### TRAINING THE NEW EAR

At twenty-five months old, our daughter had two implants. By twenty-six months, all mapping was complete. The big query was, how do you teach a child with a second implant to use it, when she is receptively using her first ear? Phone calls were made. Mainly the person spoken to, did not work with bilateral children or if they did, the child received their implant years after the first. People said no formal studies existed. I did not have time for studies, I needed answers. We had a top therapist at Gabriella's school, but I wanted to speak with people working with early-implanted children who had both implants within twelve months apart.

#### **GUIDANCE FOR BILATERAL HEARING**

One speech therapist in Colorado said they worked with a few children just like our daughter. My response was to ask what the therapy program was, and how to work with two ears that are at two different stages receptively? She said, "During the therapy session, half the time goes to the new ear only. You need to take a step back and work on receptive goals that she can master with her new ear. Remember you may need to go back to what you were doing in therapy six to twelve months ago. Move up the receptive hierarchy scale and within six months both ears should

hear identically. "

In the evening at home, the advice was to use only the new implant for one hour every night. "This will get your daughter to rely on this new implant just like she relies on the old one." I was floored, a precise direct answer 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 Gabriella's ears could hear the same due to a relatively short period of time between the two operations.

A team approach is needed by parents, doctors, therapists and schools. With foresight, my communication with all professionals involved was very open. I told Gabriella's main therapist what the woman in Colorado said, and asked her opinion of it. Some people may feel 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.

Parent 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 saw our daughter's progress with her first implant. She was doing so well. We wanted her to have similar success with her second implant and for her speech and language to continue to mature. The hard decision came that one of us would quit our job for up to twelve months to provide the learning and teaching experiences for her to speak. In March 2005 I explained to my employer that I needed to quit my job for my daughter's language to develop. 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.

There I was, Mr. Mom, with a thirty-month-old daughter. We spent the next ten months exploring the world about us and talking a lot to each other. Gabriella and I went to the zoo, to the ocean, we saw planes take off at our local airport, we looked at all 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 short answers were not enough. She was very inquisitive and wanted a good explanation of things. Many words, phrases, and explanations were used to build her vocabulary, speech and language skills. Driving to school in the morning took forty-five minutes. We had a stack of children's songs 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," just hearing the first few notes! Then we would sing along together.

A favorite game in the car was to talk about the weather and name as many different objects that we could. 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 said. After a few months she 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 sets of DVDs for home are the Baby Einstein DVDs for children to learn vocabulary and words, from three to four years of age. We fell in love with LeapFrog products, including the DVD with the alphabet, words, and one that explains math. Richard Scarry DVDs also explain opposites, large, small, shapes, counting. And while learning the child gets into listening to full sentences and responding with answers.

#### THE TRANSITIONAL IEP

As a child nears three-years-old, they move to the IEP process. Everything changes at age three. The IDEA law operates in two areas that cover children from 0 - 3 years old and 3 — 21 years old. With the transitional IEP there are meetings to introduce the new team members and make formal evaluations of our daughter's progress. Everyone said how well Gabriella was doing. She was doing great, but this was the wrong thing to say. When the school district responded in this manner we had concerns about funding for the next year.

We were trying to increase Gabriella's school and therapy time

to four days per week starting in September. She did great in tests but we knew her weak points were expressive speech, spontaneous speech, peer-to-peer communication, and some articulation issues that remained. 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 get funding through September 2005.

During that summer, I spent time researching the IDEA law. (In October 2007, this law was revised by Congress. Make sure you are looking at the current version.) I talked with lawyers at AG Bell and people who have dealt with a school district that pulled funding prematurely. We had a great working relationship with everyone. We respected everyone's hard work and truly appreciated their efforts at this time.

#### **A BIG BLOW**

For about three months our daughter would pull off her right side implant and refuse to wear it. She would wear the left side but had a real problem with the right side. When children are this young, their hearing is a guessing game. Her audiologist suggested an integrity test. So we met the Cochlear person at the hospital for the test. First she tested the left ear and all was fine. Then the right ear was tested. After a good five minutes staring at the screen and going "hmmm," the rep said, "There is a problem with this implant."

My wife started to cry and we both said, "What is the problem?" The rep said, "the test results are not consistent with company standards." She mentioned an intermittent issue and that the internal

device was not working fully. I turned to her and said, "Everything works fine and Gabriella hears great with this device." From knowing our daughter, we knew she could hear well with both implants. I could not accept that one device had problems. She hears great with the "bad" implant and can discriminate any word(s) with it.

Over several weeks, we ran tests 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 a new implant will work as well as the old one. A child could have the same hearing after re-implantation or the hearing may be worse. We did not want to take this risk.) After speaking to Gabriella's surgeon, we took a "wait and see" attitude and decided to re-implant only if the device no longer worked.

All that month, Gabriella was tested in the sound booth for discrimination and every possible test to check the right side implant worked. Each speech pathologist 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 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."

Solid answers were needed. My instinct was that her implant worked great and the medical community was wrong. To be sure, I contacted the senior engineer at Cochlear Corporation and told him that my daughter heard great with her "bad" implant despite the test results. He mentioned teen clients whose integrity tests were "way off" like Gabriella's, and they never reported a loss of

hearing and they never got re-implanted.

This engineer said the tests could be wrong due to the "physiological makeup" of our daughter's ear or the chemical composition of the fluid in her ear. Gabriella's surgeon said she would call the engineer to get the details. A decision was made not to re-implant and to monitor the right side. Today the right implant works great and she hears fully with it. In August 2007, three electrodes outside typical limits were turned off and our daughter hears great. The other electrodes take the full spectrum of sound with no loss of frequencies.

#### **PROGRESS REPORT**

By end-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 working on spontaneous five-word sentences, verbs, more expressive speech, ongoing dialogue with exchanges plus "what," "when" and "where" questions. Gabriella sings full songs on her own like "Row, Row Your Boat," "Old MacDonald," "The Wheels on the Bus" and the ABC song. She knows all her colors, shapes, letters, and numbers.

Being around typical hearing peers as much as possible was a big reason for taking time off 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 to the child, in an open or closed set format.

We saw the speech therapist at the local children's hospital, just once per month. After testing and an hour of therapy the therapist said "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 and teachers.

#### THE THIRD YEAR

The summer passed and Daddy worked on potty training and everything else a three-year-old child needs. We attended three weeks of summer school at JWPOSD, visited 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 months of research I felt prepared for any objections the school district might throw at us. Every IFSP / IEP meeting was attended by the principal, director, therapist, and/or teacher from the Jean Weingarten School.

In this meeting, my wife and I had three school personnel with us. The school district had their director, their SLP, a psychologist, and teacher of the "Communication Handicap" class they wanted Gabriella to attend, nine people altogether in this meeting! We reviewed past goals, discussed test results and our daughter's progress, where Gabriella was lacking in speech and language, and her future goals. Would the school district want to pull funding and rely on their in-house program? After this meeting we would know.

A five-day schedule compromise resulted since we felt Gabriella needed four days at JWPOSD and the school district thought three days was enough. In reality our daughter was doing great and three days at the private oral school, I am sure, would have been fine. I did not want to look back and think Gabriella did not get what she needed. After careful review and speaking with my insurer I agreed to three days at JWPOSD, funded by the school district, one day privately paid, and one day at the school district's "language" class.

#### 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 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 music class with about twenty-five children who wore cochlear implants. On Fridays she attended 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 hearing children who were behind in their language skills.

Some IEP goals were for Gabriella to socialize more with children and use spontaneous language. She was happy around adults but with other children she was very apprehensive. Her ability to retell or paraphrase a story with more than short three- to five-word statements was being addressed. It seemed like you had to "pull" the next statement out of her; she was not very expressive. Her abilities were fantastic. We noticed at home she was very expressive and talkative, and loved to speak but at school she was much more "quiet."

Class consisted of talking about the weather, what the children did at the weekend, exploring bugs, flowers, books, pictures, very

open-ended descriptive explanations of the world around them. An assistant fed in language when the children became stuck. This class comprised four children with cochlear implants and a hearing child, all the same age, with the hearing child in the class to model language for the other children.

This learning process raises the bar for the child to move to the next level in natural language acquisition. If they are working on five-word statements then we modeled two five-word statements conjoined with "and," "or," "but". If they know the name of various items, we will expand their vocabulary by explaining synonyms. Item grouping is discussed, such as what items are in the food group, the clothes group and the toy group. More tricky exercises were done such as "what item does not belong" and why? All of this was taught in the classroom in a natural setting. It is also vital 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, and so on.

#### THERAPY TIME

Four times per week for forty-five minutes Gabriella attended therapy. Fortunately, this school provided excellent therapists with the right certifications and education. Most therapists with this focus are qualified teachers of the deaf, or speech language pathologists. During 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.

Here are some of the questions that were 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 the questions in these examples are open-set and the child has to recall from past 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 2005 we noticed a bit of stuttering in Gabriella's speech. It progressively became worse over the next two months. I mentioned this to her therapists, who had an opportunity to look at Gabriella while she was having a hard time with speech. It seemed 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 sentences Gabriella was challenged by 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 "partial word repetition dysfluency" and the professionals believed it temporary with her mind working faster than her mouth. In the next eighteen months she self-corrected and the stuttering went away.

With a new year on us I sought a job, believing our daughter

was on her way to great speech and language. The time I spent with Gabriella over those ten months was amazing. We did excursions to the zoo, the park, feeding the ducks, looking at the hills and the trees, and having picnics. Every day I tried to get her around hearing children to play with. Gabriella and I attended music classes where I was the only man. I took her to play groups with ten mothers, and me. Never did I feel out of place because I had my daughter with me.

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 replicate 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.

#### **VOLUNTEER WORK**

Looking at the great speech my daughter was gaining and the hard work that the school put into it, I wanted to know this school would be around for every parent and child after us, for at least another forty years! That is why I volunteered for the school's annual November benefit auction. I could see the miracle with our child and I wanted every family to have the same opportunity for their child. Opening up the world's eyes to the wonders of cochlear implantation and early intervention was essential to me. Many people today do not understand what deaf children and deaf adults can achieve, but my daughter was living proof.

The key is to give to the people who give your child a voice. I have seen parents with two jobs, or they may be busy. The

problem is, some parents do not write that check for \$100 or \$200, equivalent to a dinner and a night out. What is a priorit These parents could take one day of vacation and volunteer for eight hours. What is one day? Look into a child's eyes as they acquire speech and you will know your time and money might be the difference between that child and possibly even your child receiving the services they need.

#### **HOME SWEET HOME**

My experience is of very close teamwork with my daughter's school, therapists, audiologist and doctors. This book is written from what I learned in 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 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, essential services the child is entitled to under IDEA law.

As Americans we pay heavy taxes, and I did not feel "guilty" about having the federal and local government finally step up to the plate and help my family. As a parent you are your child's best advocate and KNOW what that child needs. Do not just work from 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 detailed many things that need to happen at home. Please follow these guidelines and in time, you can talk with your deaf child just like any other child. Do not see 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 early detection and hearing-devices learn speech and language just like hearing children. The same hierarchy of language and learning as a hearing child. The difference is our children, the professionals and parents working with them take every part of the receptive and expressive hierarchy, break it down, and emphasize each part for months, until the child is proficient. Then we begin the next step in language acquisition, always reaching for the next level with proficient speech from our children.

A hearing child acquires language by listening to other people. Our children must be told the same words and phrases hundred of times until they master them. Visual cues are needed in the beginning and over time, auditory-only with some background noise should be no problem for these kids. Repetition and an understanding of language acquisition are key, here As a parent, if you are not informed, how can you plan your child's IEP meetings, services, and know what to be doing at home? Do not leave this to other people.

You are a team member like everyone else—in my opinion the most important team member. The parent's role is to facilitate this full process. It means work but 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 what she

did achieve.

As facilitator of this process, you must advise all team members of medical reports, hearing tests and IEP meetings. You are the vital information purveyor, keeping detail moving for the team. The time will come when your knowledge hits a level that these professionals respect your opinion and what you want for your child. For example, I believed in year four that my daughter needed less oral services and more mainstream exposure. This was different to the school's plan 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 daily we knew her implant worked properly. We strongly felt re-implantation was not the answer at that time. You need to assess all issues that come your way and advise people what is behind your strong motive for one decision. Please do not get overconfident; we are parents with no formal education in these matters.

We are working with one child and they have experience with hundreds of children. They will guide you in the right direction and do what needs to be done over the process for your child. You will get different views from different people and as the parent you need to sift this information and reach 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 nine-teen months post-implant on her left ear. In my mind she was

age-appropriate in language, speech, and articulation. While the professionals told us this months ago, I now agreed with them. It is hard to know what is age-appropriate when you have one beautiful child. We talked with Gabriella just like any child her age, working on imaginary play, abstract language, conjoining sentences and ongoing dialogue.

With the 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 understands how things work, such as the weather. She can spell 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.

#### THE FOURTH YEAR

That summer, after 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 she could have adapted well. One more year at JWPOSD was agreed at the IEP meeting with three days at JWPOSD and two days in the preschool program at our local school district. We all knew a fully mainstream kindergarten was the next step after this school year.

#### THE PROGRAM

Our daughter's program has three days of oral class from 9:00 a.m. to 2:00 p.m. Tuesday, Wednesday, and Thursday. On Mondays and Fridays she attends her local school district in the Head Start preschool program. This program has twenty students from three to five years and our daughter fits right in. This is a fully functioning mainstream preschool with no services provided to Gabriella because she is deaf.

Until now, we had no assisted listening devices because with two implants our daughter heard very well. We did get a teacher from JWPOSD to check the acoustics, teaching style, and language understanding. For whatever reason, Gabriella still kept to herself. She did not socialize much, and she initiated very little expressive language within her mainstream class. With adults it was different. She was a little chatterbox. At home when she had friends over that she knew well she would be very expressive with good dialogue.

At JWPOSD class and therapy focused to social interaction, making requests, understanding feelings, comprehending stories, abstract language, asking for clarification, and so on. Two classes were regularly joined together for a total of ten students. This helped the parents and children realise that class sizes in mainstream settings are typically twenty kids and the comfort of a small class would soon be gone.

The teachers would read a detailed story and ask the children open-ended questions to check their listening and reasoning skills. With these kids' learning focused so much to an absolute right and wrong answer, they needed to learn to think and to express if they were uncertain of their answer. Through this teaching, they learn that sometimes any answer can be correct. It is OK to take a guess, and sometimes three kids can all have the right answer. Listening to the question, sorting the facts, and taking a stab at what the child feels is correct is OK. Reassurance and praise is always given for trying, and for presenting accurate reasoning.

A stand-out point of the JWPOSD is that a few weeks were spent, deep-diving into a particular subject. For instance, every summer school had a theme, every holiday was observed, and at Thanksgiving the kids would discuss food. The world was explored in depth: the oceans, forests, bugs and animals. Learning was fun and not just a chore. The therapists built their sessions around the current theme being taught and each week, parents got an email with this theme and ideas of home-work to reinforce the language structures.

Stepping back and feeding in less language in class was important. The children now needed to talk among themselves without a teacher's support. If the children were playing and did not react to a student's request, the teacher might give a thought provoking question to remind the children to observe peers while playing.

#### THERAPY TIME

Inferencing, abstract language, problem solving skills, sequencing, and retelling a story were worked on in therapy. The teacher would show a picture book without text and say, "let's make up a story. I will talk about the first page then you talk about the next page." The student would listen and use the teachers' words to extend a story that could go in any direction. Expressive language

and storytelling was emphasised, as was information recall with questions like "what did you do over the weekend,". Then the critical "Really? Tell me more about what you did" — an open ended response with no ideas or suggestions from the therapist.

The child can talk about anything, provided it relates to the question. If this is not the case, the therapist sensitively said, "Is that what I asked you?". Explanations and staying on topic were always emphasized.

By now, Gabriella was much more conversational. Class time focused to expanding and correcting language, having fun, and learning the rules of conversation. Open-ended choices for the child to choose for themselves were also worked on. Cause and effect were covered. Language is very dynamic, and when a child can speak well, questions must be asked — can they think for themselves, problem solve, do they 'get' abstract concepts, are the rules of conversation followed, is their speech grammatically correct?

One of the most importing things to always ask, is whether their articulation mirroring that of a typical 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 attended the local preschool in a class of twenty children, from 9:30 a.m. to 12:30 p.m. This was our chance to see how Gabriella would do in a mainstream setting. Transition time was vital: taking her from a cosy five-child class with one-on-one contact and throwing her into a class of twenty with background noise would not work. We did not ask for a sound-field system to optimum signal-to-noise ratio but looking back, this

would have benefited every student while being simpler than FM. A FOUR-YEAR DEGREE

June 2007 was approaching. The excitement of Gabriella leaving the JWPOSD program was incredible. We were so proud of her achievements. She was still so young and yet she had completed four years of school!

The empty feeling of finishing the Jean Weingarten program was difficult. I knew this school was on my list of charitable beneficiaries and I would always help any parent in need. The four years of intense training was a challenge, not knowing the actual end result, and whether Gabriella would 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 sustainable speech and language. She could hear great and understand any question posed to her.

On the last day of school, Gabriella read out loud a thank-you letter to all her teachers and therapists. She was graduating, and the entire world was in front of her to concur. I could not have felt prouder had she been at Stanford, Harvard, M.I.T., or Cal Berkeley with a 4.0 GPA. This was her success and it was as good as any college education. I 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 into this school for answers and explaining that our ten-month-old child had hearing difficulties was full of uncertainties. However, I knew we were in the right place. Only then and for about two more years, we had to DREAM that our daughter would speak typically, never knowing if this was even possible.

Progress was slow at the start. But over time we saw the amazing progress our child made. About twelve months post-implant her language explosion happened and she was learning new words all the time. She would put two words together, then three words, then four words. The PROGRESS was always clear and we knew she would continue to move forward.

Every setback we had with a hearing test, a medical report, or an IEP meeting, 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 profoundly deaf. We were invited to watch some implanted four-year-olds in their classroom. These children were talking, asking and responding to questions, and following conversation with great articulation. We had HOPE our child would one day speak just like these beautiful children.

Knowing the most caring people who really want your child to succeed fosters huge respect and LOVE. I can say that we LOVE the many people who helped Gabriella, for putting everything into their work and into her success. We have friends for life and are forever thankful that we met such dedicated professionals.

Speech is PRECIOUS. Living independently without interpreters, choosing any career you want, ordering your own food, and

hearing that fast car, is truly PRECIOUS. Speech and language enables you 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 conveys your words to the listener.

These people gave our daughter the gift of speech and we will be thankful forever. Crucially, this school and others like it must stay open. If the public knew what cochlear-implanted deaf children can achieve, the funds would pour in, giving every child a chance to gain great speech and language. But the public doesn't know what is possible, and many schools struggle financially. Together, I am hoping we can make these programs, the education standard for deaf children who want to acquire great speech. Oral deaf education is close to my heart and one day I hope to open a school like JWPOSD in a scenic corner of America.

Our local school district was an instrumental part of this learning 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 as they helped Gabriella. We all learned a lot in this process, without truly knowing what the end result would be. For their unwavering support and dedication, we provided this 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,
Gabriella Hall and Family
June 2007

Every capitalized word on this plaque has a deep meaning to my family. We cannot explain our gratitude to these educators for listening and for understanding the vision we had for our daughter. It was amazing to watch this vision materialize in just four years. No one knew the end result, but the pieces were in place, the program was in place and we now know what is possible for a child with the right learning tools to succeed.

#### **PROGRESS REPORT**

By June 2007, Gabriella 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, Gabriella has normal speech and language. She hears well in background noise, can follow any question auditory-only, responds 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 converses with others just like, or even better than most five-year-olds.

Her tests in the sound booth shows she hears 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 identify many rhyming words with rare mistakes. We have told her story in various medical studies for the researchers find the "best" way to educate deaf children using early intervention and oral deaf education. On to mainstream kindergarten, we have an IEP meeting in September, after a relaxing summer.

#### MAINSTREAM KINDERGARTEN

Another summer of the Little Gym, parks, games, and playing with hearing children. We wanted her to have swimming classes over the summer but how would she understand the instructor without her processors? She reads lips well but could only follow conversations if people were looking right at her. Defining some made-up signs or gestures with the swimming instructor in this circumstance would be one solution.

Before the IEP meeting, the school district ran speech, language, and cognitive tests on our child. We met in September. Gabriella's therapist from JWPOSD attended, with our local school district's principal, SLP, psychologist, classroom teacher, and caseworker. We wanted a sound field system, a specialist to monitor the new class, weekly speech therapy, and progress reports. What Gabriella qualified for was different.

Her tests results showed she was in the 84th-97th 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 speech services through the school district's special education program. (We had some

language skills that we wanted to work on in therapy, but we would address these at home.)

Approval for a soundfield system and regular visits with the school district's hearing specialist were granted. This ensured Gabriella could hear everything in class, understood the language, the background noise was not too loud, and that she socialized and conversed with her peers. The progress reports were like standard reports any child would receive. This was not exactly what we felt was needed in Gabriella's case, but who could complain? We were fortunate to have our daughter in a mainstream class with no personal assistant.

My wife enrolled to help the teacher one day per week so we could see how our daughter was getting on. 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 to her education and ensuring she did not get behind over the years was essential. I did value the special education IEP process for giving us the ability to work closely with the school district and to monitor the progress of our daughter's education.

#### **LOOKING BACK**

If anyone had said to me in 2003, "Your daughter will have perfect speech and language although she is deaf", I would have thought they were crazy. Until then, I had never seen a deaf person with perfect speech and language, and every deaf person I had ever seen used ASL. Sure, I thought, speech is possible, but perfect speech, I don't know. I just wanted my child to communicate. We were blessed with a miracle and now I hope I can say to you,

perfect speech is possible with the right program and the right technology.

Regardless of what the end result is, put your entire life and heart into it and whatever the result, be happy. Look on the positive side. There are children on TV and in the hospital fighting for their lives with leukemia, brain tumors, heart conditions. Our deaf children are healthy and happy. The only thing is, their ears do not work properly. Please be thankful for what you have. When you see a family or child that is fighting for their life with a life-limiting 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 their language option. Many deaf people do not want to have cochlear implants and that is OK. Many deaf people may not have 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 since their beginnings.

# CHAPTER 7 WHO WILL PAY FOR THIS?

Investment for intensive early-years verbal training for children who are deaf or hard of hearing pays off massively in a child's later life when they can independently advocate for themselves.

The figures can add up quickly, in the United States:

\$55,000 for auditory oral training,

\$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 for your child's verbal education in the US? What is needed and what is available don't always coincide. This e-book explains what is needed and how to get it.

For the UK, rates to access auditory-verbal therapy run at GBP 4,500 per year, with the average child and family receiving three years of AVT to close the child's initial language-gap before preschool stage begins<sup>2</sup>.

All children have a right to free, primary education (UDHR, 1948) with most international laws applying the concept of a "least restrictive environment" for a placement. These laws and their points will be the driving force for the services your child receives. Because we are focusing to young children under the age of three, we will mainly discuss the early-years learning process. Please take time to find online guides and books to inform you about your country's policies.

<sup>2</sup> Source: http://www.avuk.org

In the EU, one reference is the European-Agency.org, as is the Salamanca Statement (1994) for inclusive education<sup>3</sup>. Each country in the EU will have their own national policy for education services if you check online.

A free and appropriate education means that your child should have the opportunity to learn general curriculum material in the least restrictive environment. The regional education centre is required by international laws to do everything relevant for a child to enter the general curriculum mainstream setting. For a growing number of children with hearing devices, parents will seek oral education facilitation in a mainstream placement, with no use of sign language.

Many regional centres do not offer an early-years verbal-only program for children with hearing issues, so the funding authority may need to fund an external program. Alternatively, the family may seek a mainstream placement, plus private sessions with a speech or auditory-verbal therapist (possibly working with the family remotely via telepresence). Remember, we are not talking about what is "best" for the child and family, but what is 'appropriate' in education terms.

All your correspondence on these topics should reflect language within the parameters of your rights under national laws. (Please do not sound like a lawyer in your communications. A friendly working relationship is what we are aiming for). My daughter's example involves private insurance (in US), our school district, and the state's Early Start services. I never dealt with our regional center, which is geared to children with multiple disabilities up to age three. Let's examine each area that affects your child, and your own ability to pay for their education.

<sup>3</sup> http://unesdoc.unesco.org/images/0011/001107/110753eo.pdf.

#### **GETTING AN EARLY START**

Research shows that the earlier a baby's hearing issues are detected and intervention services delivered, the better their eventual speech, language and cognitive skills will be. Once a child is detected, their parents should contact the special education team at their school district. This team will assign a home-based teacher or a classroom setting for your child, and teach initial parent education. The child's age-appropriate language skills may be assessed at this stage.

First off, we received home-based services three times per month. From eighteen months of age this usually changes to a classroom setting. Keep copies of all your child's medical reports and hearing tests to inform your therapist and support workers on your child's updates.

Visits from a knowledgeable professional every week or two is a good start as a foundation for the real work ahead. An assessment will be booked to design a program for your child, again free of charge. When our first meeting was scheduled I did not feel informed enough to make a decision on my child's future. I refused to sign the document and postponed it to a later date. I needed to research and compare programs in the private sector and public sector programs.

Time-lines can be agreed between the parents and the school district for families to complete early-intervention teaching. Parents can sign the agreement for what is being offered, or give their own case for why a different program would be the "appropriate" option for their child. Knowing we wanted Gabriella to speak fluently and to communicate with the world around her in the easiest possible way, we knew the verbal-only approach would be her best option.

After a few months' reading, I knew which programs would benefit Gabriella. We reviewed our early-start program in a formal meeting with school district personnel and the director from our oral school of choice. We brought case studies, years of experience, and a strong desire to teach our little girl to speak, based on our review of educational laws. The meeting's focus was high language and cognitive skills, cost savings, and full mainstreaming into kindergarten.

(Many studies today show oral children fare better in school, with fewer supports than children taught via Total Communication (TC) or via ASL — American Sign Language. With our intuition being to choose a verbal-only program for an 'appropriate' education, we focused to 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 oral-only school to the next IEP meeting. (Keep in mind, funding is usually designated for six to twelve months and can be pulled at any time).

As parents, we listed tuition at an oral-only program and a service provider with expertise in teaching deaf children to speak, as priority items in the early-start program. Some school districts offer to reimburse transport but being fair and listing only what is necessary will build a long-term relationship with the school district. Medical procedures are not covered by school districts and the federal government will treat medical mileage and costs as a tax deduction. We would advise only receiving transport reimbursement, if you are in a financial hardship.

This assessment and IEP covers areas like the child's medical history, current language skills, home environment, parents' desire to educate, number of services, and the service provider. Defining goals for the next six months is crucial: if the child is doing very well but has no goals to strive for, why would they need services? You may get the intervention program you want but not the service provider, or you may get the service provider but not the program. The IEP goals may be too high or too low to show sufficient progress, and you may need to negotiate.

This is why, as parents we must know where our child is, and the next step in their education. Being new to hearing and oral-education, we had to speak with many professionals to get their view on an appropriate program for our child. If a program or service provider is offered that you feel is not appropriate for your child, then mediation or a fair hearing process may be your only route. Please try to avoid this lengthy and expensive process. The legal resources at AG Bell and other entities may offer advice or representation if this becomes your only option.

#### **INSURANCE COMPANIES**

While agreeing the IEP document and financing, you will need to source the best amplification system for your child. From the day a child is diagnosed it is vital that hearing aids go on and an accurate sound booth or ABR test is booked. Emotions can run high at this time but please know there is hope. My daughter is living proof that early spoken-language teaching works.

Many insurance firms do not cover hearing aids and this may 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 get their cochlear implant you can donate the hearing aid for another deaf child to hear. (Please review organizations that give loaner hearing aids if you cannot afford your own pair.) Some insurance plans will cover speech therapy and may pay the oral school directly. Mostly, this is a very limited number of visits as a Band-Aid to the full oral-education process. In our case the IEP covered three days per week and our insurance covered one day per week. We were limited to twenty-five sessions per year, and we used every session for two years in total.

If your medical insurance plan has a high deductible, think about switching to one with higher premiums to cover more things. Keep in mind that your child at this point is diagnosed with a pre-existing condition and switching providers is unlikely, unless you are on an employer-sponsored medical group plan that does not require the recipient to undergo a medical review.

Medical billing is messy and you must track all your receipts, payments and statements. These documents ease tax time, but more importantly, when your plan states you did not pay a bill, you owe money, or you are not covered, you can prove otherwise. I had about \$10,000 of medical billing mistakes reversed purely because I was right and the insurer was wrong. To prove my case I needed documentation. Get the plan summary which defines every procedure covered and not covered in a thirty- to fifty-page document. This is the formal contract between you and the insurer. Never, ever accept anything verbally that you do not agree with.

When the insurer staff say, "Oh Mr. Jones we do not cover that," or "Gee, Mr. Jones we only cover that at 50%", ask them, "What page in my plan summary can I find that on?". The person on the phone will have no idea so you need to go to their boss to get the page number. If they do not have it, then go to that person's supervisor. Again, we are dealing with a formal contract between you and your insurer. Your obligation to the contract is to pay your

premiums on time. The insurer's obligation to the contract is to provide the services as stated in that contract.

If staff object, have no opinions, or they say "we generally don't cover that", or "we feel that..." ask the staff 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 not written in the formal plan summary. From my understanding, the plan summary typically changes yearly with your premium increase and cannot be changed unilaterally within the year.

Our insurer had eight words in their plan summary that referred to cochlear implants, and they were: "No amount will be payable for cochlear implants." I read this as meaning no amount will be payable for the CI hardware. The insurance firm said, "We will not pay for the hardware, the operation, any doctors' appointments, 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 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 up to date.

After three weeks of talking to ever-higher people on the insurer'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 the insurance racket. Every insurer negotiates a contracted rate for services with each hospital and doctor. Outside the negotiated rate is the retail or cash rate. So when a consumer like us goes to a hospital for a procedure and we tell the doctor we do not have insurance cover and will be paying cash they say "O.K. Mr. Jones that will be \$3,000 for that procedure." Remember, 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, say "Do you want my business, or should I go to a different hospital?"

For my daughter's operation the anesthesiologist typically charged the insurer \$1,200 and the insurer would pay the negotiated rate of \$400. Which rate are you entitled to? It depends how knowledgeable and diligent you are. Believe it or not the anesthesiologist (a private contractor) had the nerve to send me a bill for the remaining \$800 I did not pay! Because I tracked records and the people I talked with, I presented the cashed \$400 check with their company's letter explaining \$400 would be payment in full, and the \$800 was wiped off the slate in days.

Just like dealing with the school district, be pleasant and friendly and show your appreciation when someone genuinely helps you financially or with great service. The people working at the hospitals, doctors' offices, and insurance companies are regular folks, too. Sometimes they can reduce bills or wipe out money due. You do not know until you ask. Thank you letters, candy boxes and a personal visit can sometimes make a huge difference in your negotiations.

Good relationships with the doctors and hospitals, can get rates reduced by about \$10,000! My daughter's operation was \$70,000 (the dummy rate that no-one pays, not even insurers). We presented checks for \$38,000 and everyone felt good that they were giving a little girl the gift of hearing. Remember, the doctors, the hospital, the procedure, and the quality of care did not change, only the amount of the bill. To this day I take Gabriella back to visit every professional who helped her, to let them know their hard work made a huge difference in this little girl's life.

A good doctor is worth every penny, even at \$150 per visit or \$5,000 to \$10,000 per operation. There are situations when that doctor is the difference between speech and hearing or sign language. I would hope more professionals donate their time or fees in these circumstances.

#### **FORMAL APPEALS**

Most insurers have a process if you wish to appeal a decision. Our insurer was local and I met various doctors and administrators in person. Insurance denials are where the Let Them Hear Foundation's legal team can be a huge asset. When making a written argument to an insurer, cite the plan where it supports your case, point out their inconsistent policy, try to find cases they covered, and itemise every point individually. Give a date they are to respond by, send by signature-required mail and CC your lawyer or legal team! Be clear that you demand approval of the procedure, and 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 teachers' expertise is one of the biggest factors for success. Parents have a big role and these two factors are at the top of the success hierarchy. The parent is the driver, facilitator, advocate, and full-time teacher at home. The school will mentor the child in a broad curriculum until that child masters spoken language with great articulation. The school will be the primary teacher to the parent. You must have great relations with your child's school, with home-time for you to teach various aspects of oral education.

Many schools and programs exist to choose from. The public school will have a program, and you have options like Cued Speech, Total Communication and others. Unless the people you meet have years of experience teaching cochlear-implanted children to speak,

you must move on. Cochlear implants work so well that some limits previously put on deaf children do not apply today. We want teachers to aim high, for the child to reach that milestone. We do not want their judgment defined by children they previously worked with at  $50 \, \mathrm{dB} - 60 \, \mathrm{dB}$  hearing levels. We are talking about  $15 \, \mathrm{dB} - 20 \, \mathrm{dB}$  hearing with excellent auditory-only perception skills.

The Oral deaf teaching methodology in this e-book is taught by Option Schools across the US and Canada. My daughter attended an Option School with notable expertise. Option Schools prioritise parent-teaching, challenging the child, and bringing speech and language to a level near to, or identical to a hearing child's. Every child is different, maybe with conditions beyond your control, but the school works for that child speak and communicate without using signs.

Some schools donate the first year of education to families negotiating with the school district. Clearly, the oral school needs to be paid and as a parent we need to get our child's education funded. This will ensure money remains for the next family attending one of these fine schools. We had a very informed team who worked with us to obtain funding. Do not place your child into one of these schools unilaterally on a permanent basis, or you could be denied funding based on the IDEA law. The language in an American IEP 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.

#### THE IEP MEETING AND STATING YOUR CASE

We have covered funding areas like private insurance, self pay, the school district or regional center, and a private oral school. Many programs are open to parents with low to moderate incomes who do their own research. When preparing for an IEP meeting you should know the outcome you want from the meeting, including the intervention program and service provider you feel is the most appropriate for your child's situation. The plan also indicates 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.

Let me say: if you want your child to have an oral education, you must meet experts in this field and tell them, "I am having an IEP 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 is in two months. What type of program would you recommend?" Ask two to four experts until you get a feeling of knowing exactly what your child needs. The oral school that Gabriella went to knew exactly what our daughter needed and I followed their recommendations.

Many public schools offer a Total Communication (TC) program, but a growing number offer an oral program. The first thing you need to confirm, is the types of programs the public school offers. This is different to what type of program they would like to enroll your child in. After informing yourself, visit the program, speak with the teachers, and understand the expertise on-site, then ask yourself if this is the program that you feel is most appropriate for your child.

If the public school offers TC and you want TC for your child, you may find it very hard to get funding for a private TC program. The same applies for an oral-only school. If the public school has an oral-only program and this is what you want, enrolling your child for a private program will be difficult. The best response is to review the public and private programs, by breaking both down

and comparing each element. You may win, you may lose, but it will be hard work!

#### **NEGOTIATING FOR AN ORAL EDUCATION**

Many parents I meet, say the situation is that an oral-only program is the appropriate option for their child and the school district does not provide this type of program. Let's address your case and the actual IEP meeting. Many IEPs are a timed agreement between the parents of a child who is deaf or hard-of-hearing, and the local school district. This document is reviewed periodically until the child is three-years-old, and transitions into a mainstream kindergarten.

You have researched and identified the program and service provider you would like for your child. Most of your child's language goals will be clarified in the IEP meeting. Still, you should know what you would like your child to accomplish in six months, from a layperson's view. The exact language and auditory goals are very specific, with words unfamiliar to people who are not speech-teachers. This means the goal is measurable and tracked throughout the IEP's life.

Before the meeting, write down: (1) the program you want for your child, (2) the number of therapy sessions, (3) the amount of class time, (4) the amount of therapy time, (4) details for an extended school year (summer school). Write down your speech, language and hearing goals, which just need to be reasonable and age-appropriate. Review your paper with the school district's program, and ask yourself how will you confirm every point, with written proof?

Letters from doctors and other parents, speech therapists and formal case studies are very helpful. Bring hearing tests, medical reports and case studies to the meeting to prove your points. (My daughter is a case who will help laypeople see the potential with oral education, in the right circumstance). Have three copies of papers at the meeting: one copy for the school district, one copy for the oral school and one copy for yourself. Certain documents you will need to specify as being part of the IEP itself, and not just put in your child's general file.

You will receive a copy of the IEP. Ensure it includes all crucial documents to back your case. Have written proof for your points, invite experts to the meeting, and be prepared to back up and defend your position. Much of our backup documentation was never presented because our district was excellent to work with and could see the benefits of oral education.

#### **GET THE DECISION-MAKERS ON-SIDE**

Before the meeting you should have a very good relationship with everyone on your team. If personalities conflicted earlier, it is vital to send a letter to apologize so everyone attends the meeting with an open mind. Never talk negatively about a professional's expertise or program. Listen to every person's viewpoint intently, even if you do not agree with it. Do not cut people off mid-sentence, and make sure that all parties have a chance to express their opinions.

The IEP will record the background detail, language, speech, and audition goals, before the critical question of the exact program and service provider. The program topic can be bounced around the room for a time. It is vital to have a professional on your side of the table to clarify the exact program frequency, times, and structure. Do not use words such as "best," "better than," "I like," as the conversation focuses to what is most appropriate for the child.

Use case studies, stories of previous students' achievements and statistics for reference.

I brought a photograph of my daughter and in the sincerest of voices I said: "I want to thank everyone for being here today to discuss my daughter's educational needs. My wife and I love our daughter more than anything, 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 IEP 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."

If you are not going to be dedicated parents working alongside every professional, please do not state as such. Many districts and professionals know of parents who put very little effort into their child's future. To find a truly dedicated, caring family with the support system and time to do what is needed to benefit their deaf child is a rarity. The district can see this and in many cases will work with the family to provide the needed education with very little resistance.

Many things in life are a trade-off. Trade this job for that job, this money for my child's voice. You never appreciate what you have, including your family support structure, until a situation like this emerges. You can get another job, buy a new house, and take vacations in the future. In reality how much do we Americans really suffer? There are stories of great struggle by individuals that make us feel in awe that the person persevered and succeeded. These stories make us feel that anything is possible. Now look inside yourself and know that this story is about you. You will be

the person who will not let anything stand in their way; you will find the time, strength and effort needed to reach that all important goal: perfect speech and language.

## **CHAPTER 8**

# A MEDICAL HISTORY

Two children per thousand in America, are diagnosed with hearing difficulties. One-third of these children have additional medical issues. There is a shortage of excellent oral schools and professionals like audiologists and speech-therapists. Like many things in life, the earlier the better, with intervention, implantation, and testing for hearing difficulties. We took what was given 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 five years in total. We were just having one problem after another, never bringing a baby to full term. There was a day we seriously considered 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 her newborn hearing 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 Jean Weingarten school for oral deaf education with therapy twice per week. Gabriella attended this school for four years until she was 57-months-old. Genetic testing was done and found to be normal.

**Twelve Months** — The ABR test gave a diagnosis of profound deafness with a hearing loss in the 90 dB — 110 dB range. Strong Widex Senso P-38 digital hearing aids were fitted and

Gabriella now had an aided sound booth test in the 40dB — 60 dB range. This is not an optimal amount of hearing to gain great speech, with many environmental sounds going unnoticed.

I need to add my personal feedback about 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 language like, "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 want your child to have the best quality of sound and to hear everything this world offers, go directly to an implant and do not waste time. Be forceful but polite and demand a cochlear implant. Research proves that hearing at optimal level, with clear quality sound leads to great articulation and speech.

As a layperson it can be disheartening to have to say this to professionals but if this advice still prevails, you need to put an end to it because we are talking about YOUR child and the future.

Thirteen Months — A decision for a cochlear implant was made, with the first CT scan taken. The diagnoses of MondinI Dysplasia and enlarged vestibular aqueducts were found. The ear surgeon said these conditions form in the fetus in its first trimester and result in progressive hearing loss with the fluid in the aqueducts damaging the hair cells in the cochlea. Balance and gross motor issues can result from enlarged vestibular aqueducts. With minor occupational therapy training and some extra work

at home Gabriella overcame these gross motor issues, but to this day still is not as agile and confident as her peers in many gross motor situations.

Mondinl Dysplasia meant Gabriella's cochlea wrapped around the hearing nerve 1½ times and not the typical 2½ times. This made surgery more difficult and a straight electrode array was chosen due to 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 in fact work excellently).

**Fourteen Months** — First cochlear implantation with Cochlear Corporation's Sprint Nucleus 24 processor unit. Surgery was performed by a skilled doctor specialising just in ears and head and skull base surgeries. Various shots were given as a preventive measure for meningitis and other infections which are a very small possibility during surgery. Remember, your standard ENT probably is not the right doctor for this surgery. You need an experienced specialist.

The surgery was at 7:00 a.m. on a Friday and by 12:00pm Saturday we were home. Our daughter spent one night in hospital and was released with antibiotics for infection and some pain medication. The surgery went well and after five days rest, she was back to her usual self. After a day or two, the hearing aid went back on her left untreated ear. Some minor balancing issues from the enlarged aqueducts self-corrected in about two weeks. A week later she was checked by the operating surgeon to ensure the wound was healing properly. Gabriella wore body-worn processors for three years and then moved to the Freedom BTE processing unit.

**Fifteen Months** — The first mapping to program her new cochlear implant processor. This map is typically between four to six weeks after surgery. In our situation four sessions were set, the first two sessions one day apart, the next in four days, and the last sessions thirty days later. The stimulation (or volume of sound) is raised at every appointment with sound booth checks.

Electrode impedance is tested, with the child tested on every electrode for sound awareness. If they respond to stimulation on all electrodes this is a great start. Do not expect too much in the beginning. The key is to have the child bond with the device and not dislike it because it is too loud. Their speech- and pure-tone detection will grow and may start in the 40 — 45 dB range.

Once-weekly speech services were offered by the implant hospital. Most insurers will cover 20 to 30 sessions per year. We saw this SLP for  $2\frac{1}{2}$  years, reducing services as time passed.

**Eighteen Months** — With recurring ear infections, tubes were put in both ears until they fell out naturally. This procedure requires the child be sedated and is available on an outpatient basis.

**Twenty-One Months** — Receptive language is excellent but delayed, with expressive language consisting of one and two-syllable words.

**Twenty-Four Months** — Gabriella continued at the Jean Weingarten school with classroom and therapy three times a week. Synergising with the therapist at home became routine. Gabriella was enrolled in play and music classes to build listening and communication skills 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 surgery was performed on the left ear. We used the same device, the same surgeon, and the same hospital. The main difference with this operation was that with her enlarged vestibular aqueducts her balance was compromised quite a bit. We were assured that

she would regain her balance and walk normally in time. This took a few months but she did recover fully 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 Jean Weingarten worked on the new implanted ear alone for 50% of therapy time. We used only the new device for one hour per day, reviewing the language hierarchy and working forward with 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 run. Never take anything for granted. As parents we must check and recheck because we know our child's abilities better than anyone else. With full testing at home we 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 talked of "soft failure," which is a slow, progressive failure of the device. Re-implantation was discussed but tests and time showed the integrity testing was inaccurate and this was not a "soft failure." Three years post-diagnosis the device still works great. (Please take any results from any test very seriously. We did not, and I suggest that you never become defensive and not listen to what the professionals are telling you. Listen to all parties, research, talk to different people, and then make your best decision. Do not make a decision prematurely without the facts.)

**Thirty-Three Months** — Over 175 to 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 with no visual cues. Articulation sounds were 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 Jean Weingarten 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 growing her vocabulary and understanding of the world around us was 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 was a concern with first consonants and vowels namely I, W, K, T, Y, A, D, being the worst. A "partial word repetition dysfluency" was detected. By having the child slow down, think what they want to say, and not get too excited about expressing their needs and wants, this self-corrected in about 18 months, and the stuttering went away.

**Forty-Five Months** — Consistent age-appropriate language, both receptively and expressively. Typical age-appropriate conversation happens daily. Sentence length grows to ten-plus words. Auditory-only responses are typical. Gabriella's strong cognitive skills are tested and rank in the 97th percentile. Just 3% of all children in her age range will have stronger cognitive skills. She now

reads any children's book and knows most numbers, letters, phonics, shapes, colors.

Forty-Eight Months — The last and final year at Jean Weingarten with three days of classroom and three days of therapy. Gabriella attends a mainstream preschool two days per week. All parties are working to expand language and give a strong foundation for the fast-paced, noisy mainstream setting she will move to next year. At this point, attending a fully mainstreamed kindergarten is an absolute, with no query that she will finish at this excellent program in June.

**Fifty-Seven Months** — Graduation Day! Four years of intensive auditory oral work pays off. For some children three years works, and for others it may take five years. This three- to five-year commitment changed a girl's life forever and we hope and pray your child has the same result!

**Sixty Months** — Gabriella attends a mainstream kindergarten in her school district with twenty hearing children. The IEP continues, with no school-supported or private speech services. The teacher uses a sound field system that may change to an FM as she gets older. Cognitively Gabriella is one of the top students in her class. Speech, language, and articulation testing are done privately every year with mappings and hearing tests run every twelve months.

#### THE COCHLEAR-IMPLANTED CHILD

When Gabriella was about three, I realized that while my daughter was deaf I saw her as a fully hearing and functioning child. With her processors she hears everything and without her processors she hears nothing. The school district and every professional we

met knew that any testing on her would be compared to a typical child. When statements were made that our daughter was doing "great" my response was always, "compared to a hearing child?" From the start, there were expectations for her to function as if she had full hearing.

At times I wish my daughter had full 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 for her (like when she was diagnosed) because with implants, she can communicate with the world.

Our little girl is treated the same as any hearing child. At fiveyears-old she knows she has hearing issues and she needs her processors to hear the world around her. Since the start we called the processors her "pals." These two "pals" help her hear. This name helped Gabriella bond with her devices and for a child this word is much easier than the word "processor."

Within minutes of waking, she will yell "Daddy, I need my pals," knowing these devices are her ears. There will be a day 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 see other children and know she is different, she may even be self-conscious. Being a girl, she can hide her 'pals', but I never, ever want her to be ashamed of these devices to hear. Whether the devices are visible or not, be proud that your child has made huge strides toward great speech and language.

#### A FINAL THOUGHT

Ideally the detail in this e-book has given you a deeper understanding for your journey of oral education. Figuring out what to

do, takes time. Some professionals will give you wrong advice, not a different opinion but just plain medically wrong advice. As a parent you need knowledge to detect that the advice is incorrect and another course of action is needed. If not you will choose a specific 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 vital and can never be replaced.

Digest this detail, keep it as a reference and checklist for your child's education. Each chapter covers a specific point in your child's education and future. Read the lines and fully understand what is being said. I would suggest writing down the top twenty things you must do right now and actioning that entire list. As needed, write down the next twenty items. We always had a list of to-do items to remind us of what needed to be addressed with our team of professionals.

Do not get into information overload. What I read made a huge amount of sense but tips on what exactly to do, were rare. The reference section mentions a few books that you must have, such as Ausplan, an IEP guide, publications from the Moog Center, from the Option Schools and the Let them Hear Foundation. These books and organizations tell you exactly what to do.

While this book is written as a parents' guide, I advise all family members and close relatives to read the content, too. In our case, if my wife and I were to pass away there was no person who could continue my daughter's oral education. (Whoever took over would be on a very steep learning curve full of unanswered questions; valuable time could be lost. And, would their understanding of the process be as strong as mine to see Gabriella through to acquiring great speech?) I did write a three-page document on how Gabriella was to be educated, with detail on maintaining the

implants, the IEP process, and contact details for every professional on her team. I suggest you do the same for family members to have for reference.

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

#### **RESOURCES**

Like a craftsman creating a fine piece of art, we as parents must have tools available. This list of resources, books, toys and organisations are central to the oral education process. Having these programs and tools will benefit your child's educational, auditory and language abilities.

## Books/Toys/DVDs

# AuSplan Book

This must-have book stands for "Auditory Speech and Language". This book has the language hierarchy for cochlear- implanted children. Published by the Children's Hospital of Oakland, Audiology Department and available from the Sound Advice online shop — www.sound-advice. ie/shop

# Baby and Me

From the Moog Center, this book outlines things that parents must do for their young child to listen and speak.

Available in Spanish with other educational books the Moog center produces.

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

## • Baby Einstein

This company produces books, videos, and DVDs designed for infants and young toddlers to learn words and explore different vocabulary. The full set can be purchased in chain stores. www.babyeinstein.com

## Disney Videos / DVDs

Many cartoons benefit audition, listening skills and language, but the Disney cartoons and movies are very well-made and most children love them. You can bring these characters to life by visiting Disneyland and having a "chat" on what the child likes, doesn't like, their favorite character. Questions can be asked about a story line, like "Why do you think they did that?".

www. disney movie club. com

## Handbook for Developing Individualised Family Service Plans

This is one of many very helpful publications from the California Department of Education. www.cde.ca.gov

## • Leapfrog Toys and Videos

This company makes excellent language-based toys to build your child's audition, cognitive skills and language skills. These toys, with the videos "The Word Factory," "Word Capers," and the "Math Circus" are all must-haves for your child's education. From retailers and toy stores. www.leapfrog.com

## Richard Scarry

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

• Teaching Activities for Children who are Deaf and Hard of Hearing

Printed by the Moog center, this book lists teaching activities for children with hearing issues.

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

# • The Complete IEP Guide

One great books to become fully educated on the IEP process. Nolo Press has many books on legal subjects for parents to refer to. These books are available in book stores and on line.

www nolo com

#### **ORGANIZATIONS**

 Advanced Bionics Corporation www.advancedbionics.com www.bionicear.com

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

#### AG Bell

www.agbell.org

This organization is a leading resource for children and adults with hearing issues. There are legal resources for the fair hearing process, educational grants, a large online bookstore, and much more. Become a member, receive Voices magazine every sixty days, and ensure to attend their highly educational conferences throughout the US.

American Speech Language Hearing Association (ASHA)
 www.asha.org
 This organization can provide referrals to speech language pathologists and teachers of the deaf in your area.

guage pathologists and teachers of the deaf in your area.
Many good language books are on their website.

- Butte Publications
   www.buttepublications.com
   This company has a huge list of teaching books geared to
   special education and deaf children. Look at their excellent resources online or subscribe to their mailing list.
- California Department of Education www.cde.ca.gov Educational books and resource guides for a small charge to the general public on subjects such as IFSPs and IEPs. Other subjects and guidelines for kindergarten are also available.

#### • California Ear Institute

www.calear.com

One of the leading cochlear implant centers in the US. Breakthrough solutions and new ways for children and adults to hear better. CEI holds yearly seminars while a sister entity the Let Them Hear Foundation offers audiology, mapping, speech services, legal help and more.

#### CCHAT Sacramento

http://www.oraldeafed.org/schools/cchatsac/index.html An outstanding auditory oral school serving the Sacramento Area.

#### CCHAT San Diego

http://www.oraldeafed.org/schools/cchatsd/ An outstanding auditory oral school serving the San Diego Area

## Children's Hospital Oakland http://www.childrenshospitaloakland.org/ This excellent hospital provides mapping and speech services — plus the AuSpLan book.

# Children's Hospital of Philadelphia http://www.chop.edu/consumer/index.jsp Cochlear implants and audiology services are offered by this hospital. They have presented many times at the CEI / Children's Hospital Oakland conferences held in the Bay Area.

#### Cochlear Corporation www.cochlear.com

A leading manufacturer of cochlear implants. Visit their website, inform 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

www.gofrontrow.com

This company provides soundfield systems and other amplification devices.

#### Head Start Preschool Program

http://www.caheadstart.org/

State-funded mainstream preschool is an area severely lacking for children with hearing issues. When verbal deaf children reach a certain stage, moving into mainstream is essential to enhance their hearing and language skills, with close monitoring of learning. Most families must pay for private preschool with no feedback or specialist training for teachers. We do not know how our children are doing unless we attend class daily. We used a 50/50 mix of mainstream preschool and specialist AVT in the last year of our daughter's four-year journey. Head Start is geared to lower income families and not to special education children in the IFSP / IEP process. If you qualify, your child might go to preschool five days weekly free of charge!

#### • HEAR in Dallas, Inc.

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

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

www.johntracyclinic.org
An OPTION school that provides free parent education videos / DVDs and distance learning.

# Let Them Hear Foundation www.letthemhear.org Helping 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 www.linguisystems.com An excellent resource for games and books to develop speech, language and articulation

 Lucille Packard Children's Hospital at Stanford www.lpch.org/
 This hospital and Cochlear Implant Center provides surgery, auditory, and speech services to children of all ages.

#### Music Together www.musictogether.com

A great resource for young children acquire auditory skills through music. They accept children from six months of age, and provide CDs and music books with paid membership. Reinforcing the class music in the car or at home will give auditory abilities that any parent can be proud of.

#### Nolo Press

www.nolo.com

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

#### • Oral Deaf Education

www.oraldeafed.org

Pull up this website and avail of the excellent free material for 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 particular.

#### Option Schools

www.oraldeafed.org

The national and international "Option schools" provide oral education to young children. Each school shares information and research with other schools in the Option School network.

#### • Protection & Advocacy, Inc.

http://www.disabilityrightsca.org/

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

The Auditory Oral School of San Francisco
 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
   http://www.oraldeafed.org/schools/moog/
   The Moog Center is an Option School that provides numerous educational conferences and excellent books and other resources in English and Spanish.
- University of California, San Francisco Medical Center www.ucsfhealth.org
   This is a premier children's hospital in San Francisco. This hospital provides a cochlear implant program, audiology, mapping, and speech services.
- Author Contact Information www.deafchildrencanspeak.com

### THE AUSPLAN BOOK: OUTLINE AND USAGE GUIDE

Ausplan is a term which stands for Auditory, Speech, and Language. This book (copyright 2003) is written by professional cochlear implant audiologists and speech therapists based at Children's Hospital Oakland. The text has been instrumental in forming a basis of understanding how language is acquired in children. By using this book, parents can be in complete synchronization with their child's speech therapist and necessary timelines for speech acquisition. This vitally important book costs approximately \$35 plus \$10 shipping and handling. It can only be purchased through Children's Hospital Oakland's Audiology department at 510-428-3885, ext. 2017 and from the Sound Advice online shop, www. sound-advice.ie/shop.

Ausplan is a vital resource, in my opinion, for any parent or professional. The Ausplan book is based on 80 children who received cochlear implants. These children were rated as A, B, or C based on various criteria such as age of implantation, medical condition, auditory program, TC or Oral, etc. These children were then tracked for their outcomes over several years. There are three hierarchies, Auditory, Speech / Articulation, and Language, which have timelines of specific goals that each group of children achieved. So in essence a parent or professional can categorize a child, then look at the three hierarchies with timelines and know, for example, six months post-implant the child should be here, twelve months post-implant they should be here, etc.

Exercises are listed on all three tracks, which parents and professionals can follow. This is a true "manual" of how to teach

a deaf child to hear, speak, and converse fluently. Items such as discriminating words in a closed set, picking out two key words in a sentence, and various open-set exercises are listed. This is just in the audition section; the speech section covers pre-speech, formation of articulation sounds, and formation of vowels, consonants, and words. The language section covers grammatical structure, conjoining sentences, and complex sentence production, etc.

Ausplan follows the natural acquisition of language from prespeech to reciting full paragraphs, from hearing environmental sounds to discriminating five plus rhyming words. This is truly a "manual" of how language is acquired. How many parents can place their child on a hierarchy chart, know if they are making good progress, know exactly the next step in language acquisition, be able to work on these things at home, and be in sync with the speech therapist? Since this goes through the natural acquisition of language, IFSP and IEP goals become easier to write and understand for a layperson like a parent. This is a professional book written by and for professionals. Even though it is written for professionals, it is a vital tool for every parent who has a cochlear-implanted child learning oral language. To be able to know where your child is on all three tracks and exactly what the next step is in language acquisition is crucial for the best outcomes.

I will now summarize the format of this book and how to use each section to get the most out of the text.

#### **AUDITION**

Since children listen for many months before their first words and since receptive language comes before expressive language, the audition section should be reviewed and studied first. This section has five levels to be mastered from "Sound Awareness" (level 1) to "Processing and Comprehension" (level five).

Page 33 and page 37 lay out the "Auditory Timelines" for post-implant children. Use these pages and timelines as a guide of sufficient progress for your cochlear-implanted child.

Page 41 establishes an "Auditory Skills Pyramid." Within this pyramid is the progression of auditory language that all hearing and deaf children go through. This is a crucial, crucial skill set for every parent and professional to know intently. Good listening is the key to good speaking.

#### SPEECH / ARTICULATION

The speech / articulation section covers in great detail the speech level sounds and word approximations that every child goes through. It then covers partial-word and full-word production. Since all children produce a repertoire of sounds before word production, a parent and speech therapist can know if the child is mastering all the sounds necessary for his or her age level. This section has six levels to master with pre-speech being level 1 and spontaneous conjoined sentences being level 6.

Page 98 lists the speech level sounds in progression of order. Page 99 lists the hierarchy of speech intelligibility. Page 103 lists the key to pronunciation, and page 107 lists the timelines needed to master all six levels in the speech and articulation section.

#### LANGUAGE DEVELOPMENT

The language section covers six areas including word approximations, grammatical structure of sentences, and conjoining

complex sentences, spontaneous production of words, use of "what" and "how" questions and even inverted questions are also covered. This section explains in detail the benchmarks and exercises needed to help any child reach complex grammatically correct language. Page 162 lays out the six language levels and what they are. Page 163 lists "Brown's 14 Morphemes." The necessary timelines and benchmarks to reach each language level can be found on page 165.

Since this book covers the process of language acquisition, a parent only needs to read each section to the point of where their child is at that point in time. As time progresses, further reading of the next language level can be done. So do not read this book all the way through and set it down. Read only as far as is needed, fully understand the text, and then be able to track your child on all three hierarchies, always knowing the next step in the process.

Most early intervention and special education speech therapists will use standardized language models based on hearing children. These models explain where a deaf child is compared to a hearing child at their particular age level. By understanding these standardized language models and by fully understanding the Ausplan book, a parent can become extremely knowledgeable on speech acquisition and know whether their child is making sufficient progress or not.

This concludes the outline of this very important book. If used properly, this text will be by your side and referenced for the next two to four years as needed to help your child obtain excellent receptive and expressive language. The entire goal of this process is to have our children reach linguistic milestones comparable to their hearing peers. As parents we need to completely and fully

understand the process that we will be managing for the next few years. As parents, I feel we are at an extreme disadvantage without resources such as the Ausplan book.

Good luck on your language journey.

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## HOW TO OBTAIN THE ABSOLUTE BEST MEDICAL OUTCOMES FOR CHILDREN THROUGH ORAL EDUCATION

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

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

The following are excerpts from Chapters 2, 4, 6 and 7 of A Father's Love, which can be downloaded FREE OF CHARGE at the above website.

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

that these guidelines will be beneficial for the next three to five years as you go through this language and audition journey with your young child.

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

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

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

- speech therapy sessions, and talking to many parents and professionals.
- 4. A good auditory oral school or a program that resembles what the school would provide. Enroll your child as early as possible, preferably before twelve months of age. Most schools and Early Start programs will want to start parent education and formulate a program for a child as early as possible.
- 5. A school district / Early Start program which adheres to the IDEA law and can see that deaf children can learn normal speech and language. A district willing to fund four or more years of education. This could be as much as \$50,000 (based on 2006 dollars). A district willing to work with you and understand the vision that you have for your child. In a lot of circumstances all it takes is to let people see the success of other children who have gone down the oral path, and it may change a school district's / Early Start administrators' mind in regard to funding a particular program.
- 6. Never take one professional's opinion. Find out for yourself by asking numerous questions of numerous professionals and decide on your own gut feeling what is correct. (This author is available to help weigh the pros and cons of any of the numerous life-changing decisions in this process.)
- 7. Purchase the Ausplan book or a similar language development book and be in sync with the speech therapist. Reinforce all therapy in a natural setting at home. Know where your child is in acquiring normal language and know what the next step is. This ability to be able to track your child's progress and pinpoint where they are on the language hierarchy model is

- so crucially important. (If you do not know this you cannot spend the numerous hours needed at home to reinforce what is being taught in the speech therapy sessions.)
- 8. About two to three years into this process provide a mixture of oral training and mainstream classes. Provide your child with age appropriate language models 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 / Early Start program should fund three to four years of oral education for your deaf child. It is so vitally important to consult with professionals who have gone through numerous IFSP / IEP meetings and understand the IDEA law. Using the right terminology and constructing your arguments in a manner that is backed up by the IDEA is so very important. Make the process cost-effective for the school district.
- 13. Flextime for one parent. To have a job which gives you the ability to go to the speech therapy sessions, the doctor appointments, the IFSP / IEP meetings and truly be involved in your child's habilitation plan. Trying to go through this process with a boss counting every single minute you need to take off to be with your child just does not work well. You need a boss who wants to help you help your child and give you a flexible schedule. The exact verbiage of how to ask for flextime is listed in Chapter 2 of "A Father's Love."
- 14. You as the parent are in the driver's seat. You must make the right decisions at the right time for the absolute best outcome for your child. This may seem odd, with numerous professionals who have years and years of experience dealing with deaf children. But in the beginning you will be a baby needing to be fed information. As time goes on you must be a lion who knows what they want and goes after it. You are the quarterback with a team of professionals all working toward the best outcome for your child. It is your responsibility to make

sure that every professional is in sync with needed information and that these people talk to each other and the team work seamlessly for your deaf / HOH child.

#### THINGS THE PARENTS NEED TO DO AT HOME

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

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

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

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

- 2. Cut out ALL background noise as much as possible. I love music and used to listen to music every day. Over the past four years I have drastically reduced how much the stereo is on because of the competing background noise. You need to make a few sacrifices in this area and divide the day into two distinctive parts: the time you work with your child, and the time you watch TV, listen to music, vacuum, etc. If the family has the TV on 24 / 7 in the background you must make a sacrifice in this area so you can have quality "quiet" time with your child. Have the washing machine and dishwasher going when you are away from home or the same time you watch TV. Make everything a quality listening experience.
- 3. If there are other children in your family have these children play with your deaf child as much as possible. These hearing children will provide an age-appropriate language model that your child can learn from. Let them play games, talk about games, talk about the weather, fight, yell, and do all the things young children do. Don't sit there and have all your children glued to the TV set. The more quality speaking your child gets from siblings will really benefit their

language development. Television is good if used properly to play age-appropriate language-rich DVDs and videotapes.

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

- 4. Speak to your child all the time. Again, look directly at their face so they can see your mouth. Explain everything to them. Be within 3 4 feet when speaking and just talk, talk, in English. This is what these kids need—a huge input of quality language so they can record everything in their auditory memory. Your therapist will be working on auditory-only exercises and you will soon be able to speak with your young child with no visual cues at all. When the time is right the language will come out and just keep flowing out.
- 5. Iwould be cautious about using any sign language. The problem is kids will use this as a crutch. The philosophy in oral training is to force our children to use their voice. To let them know that their voice has meaning. Let them know when they do use their voice that you understand, and always reward them with a huge amount of praise for using their voice. The process is to give oral speech a chance before any signing is introduced. Some people will call signing a "bridge" to help facilitate oral speech. This may be true with some children but in general, I do not agree with signing. To take a child who has been implanted at or before 12 months of age and put them into a TC (Total Communication) or signing program in my opinion is medically wrong unless that child has other severe medical issues.

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

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

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

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

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

- 7. Play proper language-rich video tapes and DVDs. Let your child play with educational auditory toys that require good listening skills. These toys will ask a question and then your deaf child will need to make an appropriate response. Read every night if possible. Play children's music CDs / tapes in the car, sing songs, and talk, talk, talk.
- 8. Turn on the implant or hearing aids within 30 minutes after your child wakes up. Keep them on all day long. Check the implant / hearing aids daily to make sure they are working properly. Know how these devices function and know how to troubleshoot and fix any problem that may arise. In general when it comes to cochlear implants they have alloyear warranty on the surgically implanted device and three years on the external components. Listen to the microphone, make sure it is on the correct program, make sure the batteries are fully charged, and check for proper function every day. Check all wires for crimps, shorts, etc. Once a week use a Dry and Store dehumidifier unless you live in a humid climate, which may require use more often. Check with the manufacturer for proper care and maintenance.
- 9. Make sure your child has an appropriate program to learn oral speech and that the teaching environment has

- qualified professionals. Make sure the acoustics will accommodate learning with a noise-free classroom.
- 10. On weekends get out and explore the world. Go for a hike, a walk, go to the zoo, the grocery store, even around your neighborhood. Look at every item, explain what it is and give it a name. Make a fun game out of it even if you have other children—explain that we are building the vocabulary of our young deaf / HOH child. Not too much too fast, but just the right pace so your child can absorb every word and phrase.

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

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

These are the steps that a parent must 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 guidance for treatment. You will feel confident that your view has merit because it has been researched and you have data to back it up. Remember that an excellent working relationship with all parties 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.

#### FIND A GREAT SURGEON AND AUDIOLOGIST

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

these fine people. They will bend over backwards for you as long as they know you are on board and you always show your sincere appreciation for what they do.

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

Last but not least is how to pay for all of this fabulous care that your young son or daughter will be receiving. Here are my thoughts and experience in this area:

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

Use the legal resource team at the Let Them Hear Foundation www.letthemhear.org to help fight any insurance denial for an

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

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

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