Dear Parents and Family members,

We are pleased to share with you this guide for parents of children with newly identified hearing loss. Babies bring joy to parents and their whole families. They also bring the challenges of parenting, including fostering their growth and development. Children with hearing loss may bring a unique set of challenges. All parents, at one time or another, face making difficult decisions for their children. We hope the information in this guide will help you as you begin choosing services for your child.

Information is the key to making good decisions. At first, the amount of information in this book may seem overwhelming. Start gradually and just look at the sections that interest you most. You can refer to the other sections later. To help you make decisions about your child’s education and communication methods, we have included lists of books, videos and Web sites that will help you get started. Families of children with hearing loss also share their stories.

As you make decisions for your child, you will probably experience a wide range of feelings. This is normal. Remember to take care of yourself as you go through these difficult stages and talk to other parents of children with hearing loss. They understand.

You know your child best. No one approach is right for every family, and no decision has to be final. What you choose today may be different from what you choose in the future. We encourage you to monitor your child’s progress and change direction as you feel appropriate.

Most of all, enjoy all of the gifts that your child brings to you and your family. Take the time to get to know your child. We wish you and your family the very best as you continue on your journey.

Sincerely,

Bridget Roemmich
Oregon EHDI
1-888-917-HEAR (4327)

Katherine Bradley
Administrator
Office of Family Health
<table>
<thead>
<tr>
<th>Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>4</td>
</tr>
<tr>
<td>Parent to parent</td>
<td>5</td>
</tr>
<tr>
<td>Communication choices</td>
<td>25</td>
</tr>
<tr>
<td>Communication terminology</td>
<td>28</td>
</tr>
<tr>
<td>Early intervention (EI)</td>
<td>31</td>
</tr>
<tr>
<td>Public early intervention (EI) programs</td>
<td>33</td>
</tr>
<tr>
<td>Private early intervention (EI) programs</td>
<td>42</td>
</tr>
<tr>
<td>Hearing and hearing loss</td>
<td>45</td>
</tr>
<tr>
<td>How does the ear work?</td>
<td>47</td>
</tr>
<tr>
<td>Types of hearing loss</td>
<td>48</td>
</tr>
<tr>
<td>Types of audiological (hearing) evaluations</td>
<td>49</td>
</tr>
<tr>
<td>for infants and children</td>
<td>49</td>
</tr>
<tr>
<td>Degrees of hearing loss</td>
<td>51</td>
</tr>
<tr>
<td>Different types of hearing technologies</td>
<td>52</td>
</tr>
<tr>
<td>Topics related to hearing loss</td>
<td>61</td>
</tr>
<tr>
<td>Deafblindness</td>
<td>63</td>
</tr>
<tr>
<td>Usher syndrome</td>
<td>64</td>
</tr>
<tr>
<td>Otitis media</td>
<td>66</td>
</tr>
<tr>
<td>Genetics of hearing loss</td>
<td>68</td>
</tr>
<tr>
<td>Unilateral hearing loss</td>
<td>69</td>
</tr>
<tr>
<td>Funding resources for hearing technologies</td>
<td>73</td>
</tr>
<tr>
<td>Financial assistance information for parents</td>
<td>75</td>
</tr>
<tr>
<td>regarding hearing aids and amplification</td>
<td></td>
</tr>
<tr>
<td>Resources</td>
<td>77</td>
</tr>
<tr>
<td>Books</td>
<td>79</td>
</tr>
<tr>
<td>DVDs</td>
<td>83</td>
</tr>
<tr>
<td>Videotapes and audiotapes</td>
<td>83</td>
</tr>
<tr>
<td>Web sites</td>
<td>85</td>
</tr>
<tr>
<td>National advocacy groups and associations:</td>
<td>86</td>
</tr>
<tr>
<td>Glossary</td>
<td>89</td>
</tr>
<tr>
<td>Abbreviations and acronyms</td>
<td>99</td>
</tr>
</tbody>
</table>
Acknowledgements

This Family Resource Guide was produced by the Oregon Early Hearing Detection and Intervention (EHDI) Program.

A grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, supported the cost of developing and printing this guide.

We would like to acknowledge the following organizations for use of information from their programs’ family resource guides:
- Wyoming Department of Health
- Wyoming Department of Education
- Colorado Families for Hands & Voices
- Colorado Department of Education
- Rhode Island Department of Health
- Stepping Stones Resource Guide, a publication of Raising Special Kids
- The Kentucky Early Years Program
- Infant Hearing Resource, Portland, Oregon
- Texas Connect Family Resource Guide, The University of Texas at Dallas
- Indiana State Department of Health
- Sound Beginnings — A Kansas Resource Guide

The following individuals contributed their time and ideas to this project:
Kristin Anderle  Muriel Goldman  Arla Melum
Judy Brown  Janet Johanson  Nancy Rushmer
Norene Broyles  Jean Josephson  Valerie Schuyler
Christine Christiansen  Laurie King

This directory has been developed to help Oregon families. Inclusion of an organization, group or agency does not constitute an endorsement by the Oregon Department of Human Services and is not meant to be inclusive of all. Any omissions are due to oversight. All information has been verified as of the publication date.

Upon request this publication can be furnished in an alternate format for individuals with disabilities by contacting the EHDI program coordinator at 1-888-917-HEAR (4327). Available formats are: large print, Braille, audiotape recording, electronic format and oral presentation.
We hope this Family Resource Guide will assist you in dealing with the many questions and concerns that may arise upon learning your child has a hearing loss. The families whose letters appear in this section have walked the road before you. Of all the people you will meet along this journey, professionals included, we feel parents of children with hearing loss will be your strongest support.
These are our stories...
Dear Family,

You have just learned that your child has a hearing loss. We are parents whose children were also born with hearing loss. We want to tell you that your child, like our children, can grow up to be a good student, a valued family and community member, and a productive, independent and happy person.

When our children’s hearing losses were identified, we were shocked! We felt confused, sad and angry, even guilty that maybe we had done something to cause or deserve this. You may be having some of these same feelings. You may think the diagnosis is wrong — that there is nothing wrong with your baby’s hearing. You may be asking, “How did this happen?” or “Why my baby?” All of these are normal reactions to an unexpected diagnosis of hearing loss.

We want you to know that help is available to you. There are both local and national organizations (see the lists enclosed in this Family Resource Guide) from which you can get information on hearing loss, how it can affect your child and what you can do to minimize these effects.

Mostly, we want you to know about early intervention programs. The purpose of early intervention is to assist you in acquiring information, devices and skills you can use to help your child achieve the goals of learning to listen, speak and/or communicate in sign language. In Oregon there are both publicly funded and private early intervention programs. A list of these programs is enclosed in this Family Resource Guide. Early intervention programs have different approaches to helping you meet your goals for your child, so we encourage you to talk with specialists in both public and private programs to learn about all your options.
Finally, we want you to know that the earlier you get started in intervention, the better it is for your child. These early months are very important to the development of your baby’s brain. Your baby needs to hear and/or see language to build the parts of the brain that learn to make use of this important information.

Your new baby is a wonderful and unique person. Because of your baby’s hearing loss, the paths you take in raising him or her may be different from what you had planned. We, too, took paths that were not what we had planned. While the new paths were unfamiliar at first, they guided us in achieving the goals we had for our children and we had some great times along the way! In the process of helping our children with hearing loss learn and grow, we acquired new skills to help our other children, as well. Through the early intervention program you choose, you will find other families who are moving along similar paths and you will find the journey easier because you are there together.

We wish you well,

Muriel & Marvin Goldman
Jean & Rich Josephson
Wendy & Curt Keedy
I thought I was prepared for my son Samuel’s diagnosis of hard of hearing at the age of 3 weeks...

After all, it was in the family. My husband, his father, his grandfather, numerous uncles, all were either hard of hearing or deaf. But with all the knowledge I had, I still left the audiologist’s office feeling grieved inside. I just wanted his life to be easier. I even prayed his hearing would be healed.

It had nothing to do with my son. He was wonderful and I absolutely adored him. He did all the things a newborn does — eat, sleep, cry (eat, sleep, cry) — and I was fascinated by everything he did.

I was fortunate, though. The audiologist referred me to the early intervention program at Northwest Regional Education Services District (NWRESD) that day, and by the time Samuel was 7 weeks old, we were receiving services from them. With further testing, Samuel had moderate to severe hearing loss. Samuel was also born with a cleft palate and nearsightedness. He and I had all kinds of help ... a hearing specialist, a speech therapist and a vision therapist. It was so helpful. I can’t say enough about getting in there and finding out about your options. We chose to sign and speak with Samuel and we still do.

My job was to learn everything I could about hearing loss from the therapist. Samuel’s job was to be a baby. He was quite successful at this! Samuel’s first Christmas present was hearing aids at 3 months of age.
As a parent, you want to protect your child from challenges. But as I began to see Samuel learn and grow, I found the grief lessened. I joined a family support group and went to free sign classes from the NWRESD. Samuel signed “Mama” at 8 months and spoke “Mama” at 8-1/2 months.

When Samuel turned 2 I remember how much I enjoyed watching him. He was a very energetic boy, but also very compassionate and caring. He had a great love of life. He wasn’t afraid just to be himself. I suddenly realized I didn’t need him to be a hearing person anymore. I wasn’t grieved anymore. He is perfect just as he is; in fact, those challenges I was so afraid of him facing are what made him who he is. I wouldn’t change any of the challenges he has, whether it is the new pair of glasses or (in the future) the first crush on a girl.

My son is 4 now. He goes to preschool through the NWRESD and he is learning by leaps and bounds.

I encourage every parent to enjoy your baby. Adore them, play with them. They are a great treasure just waiting to be discovered. There are lots of options out there and lots of help. You can do it!

Laurie King,  
Sam I Am’s Mom
Francie was diagnosed with a profound hearing loss when she was 7 months old. I have a profoundly deaf brother, so this was not all new to me. However, we had no idea that his hearing loss was genetic. Like all parents who discover their child has a disability, we were shocked.

My response was first to cry, but I quickly realized that feeling sorry for myself or Francie would not help her at all. So I rolled up my sleeves and got busy researching.

After learning the terrifying fact that most deaf 18 year olds read at a third-grade level, and few go to college, I vowed my daughter would not be part of this sad statistic. I learned that most deaf kids who listen and talk do far better academically than those who sign. I also discovered that an oral deaf school just a few miles from my home was helping kids learn to listen and talk, with amazing results.

The choice was clear. No one we knew signed, and signing would limit our daughter. She would not be able to communicate with most of the family, friends, neighbors, schoolmates, teachers, doctors and employers in her life without a sign interpreter. She would be limited in who her friends and possible marriage partners would be. How could she develop into a literate adult using a language her own parents didn’t know?

After researching we knew that with a cochlear implant, Francie would talk, and, with that skill, she could do anything she wanted in life, in spite of her disability.

What surprised me was how much fun parenting an oral deaf child could be! I started twice-a-week sessions with a parent-infant specialist at Tucker-Maxon Oral School when Francie was 8 months old. It seemed almost too easy. All that was asked of me was that I sit close to my child and talk to her about what she was looking at or playing with? That I teach her to take turns with games like Peek-a-boo? That I read to her? That I nod, smile and imitate her when she attempted to communicate? Wasn’t this what parents naturally do anyway? Granted, I did much, much more of this than I did with my two hearing children, and I did it more conscientiously. But it worked!

She uttered her first word, “hot,” after 3 months with hearing aids., and by the time she got her cochlear implant at 17 months, she had a vocabulary of 25 words. And the parent-infant sessions not only helped me teach Francie to listen and talk, they made me a more responsive parent as
well. Looking back, I’m so glad I wasn’t trying to learn sign language while working with Francie. My lack of fluency with sign would have kept her from learning language as quickly as she did. By the time she was four, I was reading her Beverly Cleary chapter books. I couldn’t have given her this rich language experience with a beginner’s knowledge of sign language.

I had seen many older children with cochlear implants at Tucker Maxon. They talked and listened just like hearing children. It was inspiring. I wanted Francie to be implanted at the earliest possible age while her brain was young and could easily learn language. With a cochlear implant she would hear all the speech sounds and learning to talk would become so much easier for her.

Just three years post-implant, Francie was thriving. To hear her talk, no one would guess she was deaf. She had language well above the average HEARING 4 year old, and no speech delays. She was in a preschool class at Tucker-Maxon with 8 hearing and 5 hearing-impaired children. All of them talked to each other. It was truly amazing and beautiful to watch these children with a disability, supported by their cochlear implants, talking and interacting with hearing children, none of them seeing differences in each other.

Francie was ready for the mainstream by kindergarten. She entered a Spanish-immersion program at the public school where her siblings attended. It was a leap of faith putting a profoundly deaf child in a foreign language school, but I was determined that Francie would have every opportunity her brother and sister had.

Children around the country began getting bilateral cochlear implants. We didn’t hesitate. At 8, Francie received a second cochlear implant. Now she hears with two ears! I was not prepared for what a dramatic difference it would make for her. Her confidence skyrocketed, especially in noise, and what we thought was shyness, vanished. Now ten years old and in fifth grade, Francie is still thriving, and she’s well on her way to fluency in a second language. Her perfect Spanish accent is testimony to what a child with a cochlear implant in a quality oral, early intervention program can achieve.

We are so fortunate in Oregon to have a competent oral school, a world-renowned cochlear implant program, and mandatory hearing checks for newborns. For any deaf baby born today, the sky’s the limit.

by Anne M. Smyth
Letter from a deaf mother of two deaf children

I am the mother of two deaf children. My husband, Martin, and I are both deaf. Together, we have four deaf siblings who attended Oregon School for the Deaf, the school our children also attended.

Reyes was born in 1972 and the birth was normal. There was no hearing screening then, but due to our family history we kept a close eye on Reyes. We did our own testing and started to suspect some hearing loss but we were unsure to what degree. When Reyes was 5 months old we shared our concerns with our doctor who referred us to an audiologist where Reyes’s hearing loss was confirmed. Our reaction was a mixture of surprise and relief knowing the facts at an early stage.

We then were referred to a preschool home counselor for the Portland Regional Facility for the Deaf where we struggled with the home visits, because the lady could not communicate with us that well.

With Rita, we took her to the same audiologist when she was just a few months old and her hearing loss was also confirmed. We were amazed by this news. Fortunately we learned from a friend about a program that worked with babies with hearing loss. We visited Infant Hearing Resource (IHR) and immediately liked the place. We enrolled both children when Reyes was 2 years old and Rita was 1. We felt it was important to provide our children with this training at an early age so that they wouldn’t fall behind in language development. We also wanted to give them an opportunity to develop their speech and signing skills. I was enthusiastic to be involved in the IHR program with my children.
For preschool and early elementary we enrolled Reyes and Rita in the public program for deaf and hard of hearing students in Portland, but we were disappointed by the lack of after-school activities for them. We felt they were deprived of the social activities and challenges that their hearing peers experience after school. We moved them to the Oregon School for the Deaf where they participated in many sports and leadership activities and graduated in 1990 and 1991. Both Reyes and Rita attended Gallaudet University and graduated in 1996. Rita continued her education at San Francisco State University where she will earn a master’s degree in Early Childhood Education. She has also taught the pre-kindergarten class at California School for the Deaf in Fremont. Reyes worked as a cottage counselor at the school where he did some work helping students with self-esteem and identity issues. Reyes recently accepted a job with MCI promoting their services throughout California.

As Deaf parents, it became extremely important to us that our children excel and experience opportunities that were not available to my husband and me. We pushed our kids when we could to ensure that they became independent and confident adults. They certainly are ambitious, and we know their ambition will continue in whatever endeavors they choose. From one parent to another, we believe it is important that you enroll your child in a program as early as possible. Select a program that includes parents and is sensitive to the needs and culture of deaf children. Learning sign language as soon as you can is also an invaluable tool in developing your relationship and communication with your child.

by Charlene Ribera
Letter from a mother of a toddler with a cochlear implant

Jeremiah received a “no pass” on the otoacoustic emission test done at birth. When a later brainstem test confirmed his profound hearing loss, I was overwhelmed. I didn’t stop crying for three days. After that, I cried every time I talked to Jeremiah. It took me about three months to get through the grieving process. What helped me the most was attending the Family Program parent support group. At first that overwhelming feeling returned when I saw people signing. It was just so foreign to me. We continued to attend and were able to meet other deaf and hard of hearing children and their parents. This was the most helpful of all.

The things that helped me get a mental hold on Jeremiah’s deafness was realizing that it was like he was born speaking a different language and the way I could help him most was to learn his language. Hearing aids did not seem to be helping him much, so we needed to look at alternative methods of communication. Once I accepted that Jeremiah had a different language and accepted him, then deciding to sign with him was easy. After a while we could communicate better with Jeremiah than any of our friends could with their hearing babies, and Jeremiah was only 9 months old.

When Jeremiah was about 12 months old, we saw other deaf toddlers getting cochlear implants and began to look into that option for our son. Since our own families live in other states, we knew they would not be able to learn to sign, but we wanted Jeremiah to be able to communicate with them. We saw how successful the implant was becoming and thought this might be a wonderful opportunity for Jeremiah. We want him to be able to do anything he wants to do with his life and to have strong relationships with his grandparents, cousins, aunts and uncles.

After talking to many people and doing lots of research, we decided to go ahead with the implant. Jeremiah was 19 months old. He is now 2 1/2 and we are thrilled with the decision to go through with the surgery, although it was the most emotionally challenging thing I’ve ever experienced. We know that some deaf individuals reject their implants when they get older. If Jeremiah later decides that he does not want to use the implant, we accept that. Right now we are committed to making it work and we are thrilled with his progress so far. As soon as he gets English down, I want him to be able to learn Spanish.
We spend a lot of time on listening and speech development activities and we are also continuing to expand Jeremiah’s sign vocabulary as well as our own. His understanding of language is so good that I can explain to him why things are happening and what will happen later. He understands that first we will do one activity or task and then we can do the other thing that he is eagerly asking to do. His comprehension of language reduces his frustration significantly. We also use language for humor and playful teasing.

I think it is so important to the deaf child that his or her parents accept their child just as he or she is. My concern about cochlear implants now is that some parents of newly identified deaf infants are immediately advised to get the implant as soon as they can. They aren’t given the time to grieve and to eventually accept the child and his hearing loss. I think that kids can sense when they are totally accepted. When the implant is off Jeremiah is still deaf. But, because we’ve chosen to continue signing with him, our communication isn’t hindered, which reduces all of our frustrations.

We don’t put a tremendous amount of pressure on Jeremiah. I think that a 2-year-old can sense that. We accept him as he is, and he has the freedom to develop at his own pace. Early on there wasn’t an expectation that Jeremiah would be able to hear and talk, so now with every new listening and speaking skill he acquires, we are just thrilled. Finally, one of the most important gifts we can give Jeremiah is the sense that he is accepted for just who he is. Because we are willing to “speak” his natural language, we feel that is the missing link for him.

by Loralee Wolter of Oregon City
Summer 2002
It is our pleasure to share with you ... our family's experience in helping our daughter gain the ability to hear. Our names are Tracy and Brian Huget. We are the parents of our only child, Aliyah Huget. She was born in 2002 at St. Vincent’s Hospital in Portland, Oregon.

There were no complications with the birth of Aliyah. Before we were released from the hospital, Aliyah had her hearing tested through the universal newborn hearing screening program. Test results for both ears were referred. We were advised to see an audiologist at St. Vincent’s one week after Aliyah’s birth. It was thought that Aliyah was still filled with amniotic fluid, causing the hearing tests to refer.

The audiologist at St. Vincent’s Hospital tested Aliyah’s hearing using the auditory brainstem response test. Test results showed that Aliyah has profound to severe sensorineural hearing loss. Brian and I were initially devastated with the news. Before we headed home we received several brochures regarding services provided for children with hearing loss. We were given handouts about organizations that provide information about hearing loss, early intervention services for children who are deaf or hard of hearing: American Society for Deaf Children, AGBell assistance, Tucker-Maxon Oral School, the Speech and Hearing Institute and several others.

Little did we think that we would have a child with a hearing loss. In spite of our overjoyment of birthing a beautiful baby, we felt a loss. We shared the news first with Tracy’s father, who dropped by while in town on business. His words of support are never forgotten. One of the things he said was to work hard in helping her hear and speak. He also said to Tracy to look at what she has accomplished and where she is today.

Aliyah’s mother has a severe to profound hearing loss in both ears. She wears a hearing aid in her right ear. She is an oral communicator and relies mainly on lipreading. Relying on the experiences Tracy had with hearing and speech therapy, we knew what we needed to do to help our daughter. We knew that it wasn’t going to be easy, but we knew that Aliyah will succeed with most of the support coming from her parents and people we meet to help Aliyah with her hearing and speech development.

With all the information we were given, it wasn’t easy to know where to turn for assistance with our daughter. We primarily relied on our own instincts, past experiences, and self education to make informed choices for our family.
We met with the staff at the Hearing and Speech Institute to have Aliyah fitted with binaural Phonak BTE hearing aids within two months after Aliyah’s birth. The Hearing and Speech Institute has a financial assistance program that we qualified for to purchase the hearing aids and get started with auditory therapy. We started hearing therapy with a speech pathologist. Our speech pathologist interested us in the cochlear implant for children. She referred us to an audiologist at the Oregon Health & Science University Ear, Nose & Throat Clinic. After meeting with the audiologist and a surgeon and researching cochlear implants, we made the decision to give Aliyah the opportunity to hear more than what hearing aids can allow.

Aliyah had her surgery for the cochlear implant one month before she turned 2. One week before her second birthday, her cochlear implant external devices were turned on. Aliyah is now 4-1/2 years old. Today, her receptive language skills are equivalent to an average child of 4 years old. Her expressive language skills are equivalent to an average child of 3 to 3-1/2 years old. We couldn’t be more pleased with our decision to give Aliyah a cochlear implant.

We sought services from the Northwest Regional Education Service District (ESD) to help us meet Aliyah’s auditory and vocal and speech development goals. We had a speech pathologist from ESD come to our home to help us work with Aliyah on her auditory and speech development once a week until her third year. We enrolled Aliyah in a parent-toddler play group at Groner Elementary School the year she turned 2. Because we were pleased with the program, we enrolled Aliyah in the ESD preschool program at Groner for two years. Aliyah has made progress in big strides in her auditory and speech development with the help of using a combination of sign language and oral communication in the last two years.

We have appreciated the assistance and support from both the Hearing and Speech Institute and ESD preschool program staff in setting and accomplishing various goals for Aliyah’s auditory and speech communication development. Parent support groups offered by ESD and the Hearing and Speech Institute provided support and information to better meet our goals for our daughter. Parental and family support is also crucial in helping Aliyah.

Tracy and Brian Huget
Portland, Oregon
Our daughter Katie was born in April of 2003. As per Oregon law, Katie was given the newborn hearing screening in the hospital. We really never gave it a second thought; neither my husband nor I had any family history of hearing problems.

We were slightly surprised to find that Katie failed the test, but not particularly worried, as there was a possibility that she had amniotic fluid in her ears and she would be retested again the following day. She would definitely pass the test. Katie failed the second test, too. The test had to be wrong ... didn’t it?

Ten days later, we found ourselves sitting in a specialist’s office being told that our daughter had permanent, mild/moderate hearing loss. We were told that this type of loss couldn’t be corrected surgically. We left that office with all kinds of literature and completely devastated hearts.

Our minds raced ... What would her life be like? Would she be teased by other children? Would she talk strange? What kind of job would she ever be able to have? These questions had us sick to our stomachs, and we were desperate to find what we could do to change her life for the better. After many days of grieving, we finally started to look through the literature that had been given to us. We came across the phone number and paperwork for the early intervention program. Katie was evaluated and we began a program that has changed her life significantly.
When we first began with the early intervention program, we had a hard time believing that she had the degree of hearing loss that we had been told. Katie seemed to respond to all sounds in her environment perfectly. We were loaned hearing aids through the Regional Deaf and Hard of Hearing Program. With these aids, we were given the opportunity to change her aid types to best suit her individual needs when her loss was “mapped.” Katie is almost 4 years old and, through hearing tests, we have mapped her and have determined she actually has a mild sloping to severe high frequency hearing loss. We have now also identified that, without hearing aids, Katie is able to identify only about 20 percent of spoken words.

If Oregon didn’t have this newborn screening program, I know that Katie’s loss would not have been identified until she started grade school, maybe even later. If it weren’t for the early intervention program and their specialists, Katie wouldn’t have the tools or services to help her make a difference with her life. The first few years of a child’s life are the most important for speech and language development, and utilizing these programs are what we could do to help change her life for the better.

Charlene Sheasgreen  
Tigard, Oregon
As I write this letter, I am reliving the moments you are going through at this time. The shock and emotions surrounding the knowledge that your baby is deaf or hard of hearing is overwhelming. Give yourself permission to grieve for this loss, but don’t forget to enjoy your new baby!

*Lily* is my daughter, and she is 3 years old. She was diagnosed at 2 weeks of age as being profoundly deaf. I was stunned — there was no known family history nor was there any illness during my pregnancy. After the diagnosis the audiologist talked to us about options and gave us a variety of videos and informational notebooks. They explained the types of hearing loss, the types of aids available, and contact information to several organizations working with deaf and hard of hearing children. However, at that point I wasn’t ready or able to comprehend much of it.

I cried for two days. I felt so lost, confused and angry. But I soon realized I had to be proactive for my child. She was busy being a baby — and she was great at it! I was the one who was reacting to the hearing loss. Lily knew nothing else! So, I began reading through all of the materials we had been given and watching the videos, and I started to feel a sense of hope at the options available. The more I learned, the more empowered I became because there was so much I could do for my child!

We immediately began working with Northwest Regional ESD. By the time Lily was 9 weeks old, we had hearing aids on her (loaned through the ESD), an early intervention plan, and an early intervention specialist visiting every week. The emotional support, encouragement and direction I received from our specialist were invaluable. She was optimistic, a great shoulder to cry on, and very knowledgeable about children with hearing loss. Everything was new to me, so it was great to have such a wonderful resource available.
During Lily’s first year, we used lots of sign language (we learned as we went) and spent lots of time enriching her world visually. As Lily grew and developed it became obvious that the hearing aids were not providing enough input for her to access language. We decided that a cochlear implant was going to be Lily’s best option and began pursuing it wholeheartedly. All along this journey we relied on the ESD for information, audiology tests, and home visits to help us work with Lily and make informed decisions.

Lily received her cochlear implant right after her first birthday (the minimum age requirement), and it was activated a month later. We were hearing results within days and it has been non-stop since then. She absolutely amazed us with her adaptability! Today, she sounds just like any other 3-year-old, and uses her oral language at or above the level of her regular-hearing peers, and sings and loves to listen to music. It is amazing to think about how far she has come in such a short amount of time.

I want you to feel optimistic and hopeful about the future of your child. There are so many options available; you will find one that is right for your family. Take time to process, use the resources available to you, and be proactive. The rewards are immeasurable!

Kris Prince
jkprince@oregoncoast.com
The day our fraternal twin boys, Tylan and Dustin, were born, we had no idea anything was wrong with their hearing. Although neither of them passed the hearing screening test at the hospital, it didn’t cause us much alarm as the nurses assured us that most likely the machine wasn’t working right, or they weren’t lying still enough.

But when they didn’t pass the third test, we were referred to an audiologist in Portland. There, their hearing was tested with otoacoustic emissions and auditory brainstem response (ABR) tests. I was shocked and disappointed to find out that they both have moderate hearing loss. We were suspecting minimal loss; my husband has minimal hearing loss, but I never thought it was genetic. It was hard on me to think that our dear little babies would have to wear hearing aids all their lives in order to hear well, and that they’ll always be “different” from the other children. But I have found out that their having hearing loss hasn’t changed our love for them at all.

They are active, intelligent, normal little boys. We are thankful for what hearing they do have, although at times I still can’t believe this is actually happening to us. They got their hearing aids at 4-1/2 months and it was rewarding to see their faces light up the first time they were fitted! We hardly notice their hearing aids anymore, and our family and friends have accepted it all really well, which has been a big help to us. Right now, the twins are 7 months old, and we are trying to talk clearly and repeatedly to them to lay a good foundation for their speech. They have been copying a few sounds, which is exciting for us! Babies with hearing loss (especially when you have two of them!) seem to take a lot more time, one-on-one, but all the effort will be rewarding!

Julie Trammell
Scio, Oregon
You and your baby are already communicating through touch, eye gaze, facial expression, body posture, and your response to your baby’s cries, frowns and smiles. As with a baby with hearing, your rich interactions with your baby with hearing loss are laying the foundation for the development of his or her growing sense of security, positive self-esteem and beginning language-learning abilities. Responding to your child and encouraging him/her to respond to you is the key to your child’s language development.
Communication choices

There are many ways to communicate and different philosophies about communication with children with hearing loss. You will want to learn about the different communication approaches by reading about them, talking to other parents and to professionals, and maybe by observing programs. (See chapters on communication choices and early intervention.) People may tell you that the communication approach they have chosen to use with a child is best. Keep in mind that no one method has been proven to be best for all children who are deaf or hard of hearing. For some children a combination of communication methods may be beneficial.

Your initial choice of a communication approach does not have to be final. Many families change communication approaches as their child’s needs change. As time goes on, you will learn all you need to know in order to monitor your child’s progress and make decisions based on his/her needs.

Providing your child with services that will meet his/her needs will be both challenging and rewarding. There will be many choices you have to make, such as which communication approach to use and which amplification system to use. Your early intervention (EI) program professionals will be able to support you and provide information that will help you make informed choices.
Communication terminology
What is the difference between a language and a communication method?
Language is a shared “code” that defines the meaning of words and the rules for how words are combined to convey ideas to others. English language, Spanish language and American Sign Language (ASL) are examples of languages.

Communication methods used with deaf and hard of hearing infants are various ways to help a child learn language. The following are descriptions of six communication methods used to facilitate speech and language development with a deaf or hard of hearing child. There are other methods not listed here that you may learn about on your journey. Your early intervention (EI) specialist can help you learn about methods not described here.

Communication methods

American Sign Language (ASL)
American Sign Language is the visual language used by the majority of deaf adults in the United States and Canada. It is a complete language with its own structure, grammar and idiomatic expressions. ASL is a highly complex language, allowing the free and natural expression of any thoughts and concepts that might be produced in a spoken language.

Auditory-oral method
The auditory-oral method of teaching spoken language stresses the use of amplified residual hearing (through hearing aids or a cochlear implant), speech and oral language development. Auditory-oral programs encourage children to use both hearing and speechreading to learn to talk. These programs do not use sign language.

Auditory-verbal method
The auditory-verbal method, much like the auditory-oral method, relies on the principle that children with any degree of hearing loss deserve the opportunity to learn to use the spoken language of their community. Auditory-verbal therapy is conducted jointly by parents and the auditory-verbal therapist. Emphasis is placed on maximizing the use of residual hearing without the use of speechreading or a sign system.

Cued Speech
Cued Speech is designed to clarify speechreading by using simple handshapes and movements (cues) around the face to indicate the exact pronunciation of any spoken word. Since many spoken words look exactly alike on the mouth (e.g., pan, man), cues allow the child to see the difference between them. Unlike signs, the cues have meaning only when combined with speech.
Dual-language approach
The dual-language approach focuses primarily on English and American Sign Language (ASL). English is modeled through sign-supported speech (speech accompanied by ASL signs, through speech alone and through writing). For those children who benefit from their hearing aids or cochlear implants, the signs serve as a “bridge” to speech, which becomes their primary form of communication.

Total communication
In this communication system, the word “total” refers to the use of any form of communication that will enable the child to learn language. Manually Coded English is one part of the system, which also includes speech, listening through amplification, print and speechreading. The term “total communication” may at times be used to describe simultaneous communication.
This section describes early intervention services and provides you with information to assist you in making informed decisions regarding your child. Infants with hearing loss will need an array of intervention services, such as hearing-aid fitting and speech/language stimulation. In the coming weeks and months, you will be asked to make decisions regarding these issues. Making decisions will be easiest when you know what your goals are for your child. Included in this section are descriptions of early intervention programs in Oregon and other information that we hope will help you in making these decisions.

Once you and your infant are enrolled in an early intervention program, your early intervention specialists will provide support and assistance to you. Whatever choices you make for your infant, your time with and commitment to your baby are essential to his/her success.
Public early intervention (EI)

Public early intervention (EI) programs
Oregon has a public system of early intervention and early childhood special education services for young children with disabilities from birth to age 5. This system is called the Oregon Early Intervention/Early Childhood Special Education (EI/ECSE) Program and is operated by the Oregon Department of Education. The Oregon Department of Education contracts with nine Education Service Districts (ESDs) across the state to provide EI/ECSE services in 33 local programs. All of the ESDs either provide services or subcontract with local providers to provide EI/ECSE services. This system provides EI services for infants and toddlers who have a developmental delay, a likelihood of developing a delay or a disability. This includes children diagnosed with a hearing loss who are found eligible for early intervention services. The primary goal of Oregon’s EI/ECSE program is to help infants, toddlers and preschoolers grow and develop and to support their families by providing information, education and encouragement in this process.

There also are various organizations that provide private services to infants and toddlers with hearing impairments. These organizations vary throughout the state; you can learn more about them through your local EI/ECSE program.

Getting connected with an early intervention (EI) program
Your child’s doctor, audiologist, health care provider at the hospital or the Early Hearing Detection and Intervention (EHDI) program may refer you to Oregon’s EI/ECSE program. Once you are in contact with your local EI/ECSE program, the program will assign someone to work with you and your child. This person is a service coordinator. Your service coordinator will give you information about public and private programs that provide services to young children with hearing loss. You and your family will decide on the services you wish to access; your service coordinator will help you contact the program(s) of your choice.

“Service coordinator”
A person, appointed by the local EI/ECSE program, who coordinates all services for your child and family by acting as a single point of contact in helping you get the services and assistance you need.
**Oregon Early Intervention/Early Childhood Special Education (EI/ECSE) program**

This is a public program that provides service coordination and specific services designed to meet the unique developmental needs of each child and their family. Early intervention services may be simple or complex depending on the child’s needs. Services can range from providing periodic audiological evaluations for an infant to developing an infant-family home education program to help the child grow and develop. Specific services are determined based on each child and family’s needs. Services are free to children and families who are found eligible for services.

Early intervention services are made available through a federal law known as the Individuals with Disabilities Education Act (IDEA). Part C of this law requires states to provide certain services to infants and toddlers, birth to age 3, with a disability, a developmental delay or a diagnosed physical or mental condition that has a high probability of resulting in a disability or delay. Infants and toddlers with a diagnosed hearing impairment may qualify for these services.

Early intervention services must include a multidisciplinary evaluation and assessment, a written Individualized Family Service Plan (IFSP), service coordination and specific services designed to meet the unique developmental needs of each child and family. Depending on your child’s needs, early intervention services may include:

- Assisting your family to incorporate your child’s special needs into daily routines;
- Connecting your family to community resources, including parent support groups;
- Coaching your family and caregivers on specific child skills;
- Providing you with specific information about the child’s disability or delay, including information on different communication approaches.

Early intervention services are delivered in a variety of ways and in different places. Usually services are provided in the child’s home with the family receiving information on how to facilitate the child’s development. Services also may be provided in other settings, such as at child care. It is preferable to provide EI/ECSE services to children in settings where they spend the most time (e.g., home and child care). **SERVICES ARE PROVIDED AT NO COST TO FAMILIES.**
Eligibility for Oregon’s EI/ECSE program
If your family decides it wants services from Oregon’s EI/ECSE program, your assigned service coordinator will assist you through an evaluation process to determine your child’s eligibility for the program. You and your service coordinator will work with a small group of people (the evaluation team) to find out what is already known about your child and to determine the need for any additional evaluation or assessment data needed to determine your child’s eligibility for the program.

Deciding what, if any, additional evaluation information is needed
The evaluation team, including you, reviews information about your child. This includes information from your child’s audiologist, doctor or health care provider, existing evaluation data, observations and your concerns.

Next, the team decides what information is still needed about your child to:
- Determine if your child meets the eligibility criteria for early intervention (EI) services;
- Determine how your child functions in five areas of development: cognitive development, physical development, communication, social-emotional development and adaptive development.

The team plans an evaluation that is comprehensive enough to identify all of your child’s developmental and educational needs and to provide information that can assist in addressing those needs. Before conducting the evaluation, the proposed assessments and/or tests are explained to you so you can give your informed consent for the evaluation. Once the team has your written informed consent they may begin the evaluation.

“Informed consent”
Informed consent means that you are fully informed of all information relevant to the evaluation, in your native language or other mode of communication. You must understand and agree in writing to the evaluation. You must understand that your consent is voluntary and that you may withdraw your consent at any time before completion of the evaluation or activity.

1 Adapted from “Finding Help for Young Children with Disabilities (birth to 5),” National Information Center for Children and Youth with Disabilities.
Conducting the evaluation
The evaluation is conducted by qualified personnel trained to use appropriate procedures for evaluating young children with hearing impairments. “Qualified personnel” are people who have met state approval or recognized certification, licensing or registration for the specific type of evaluation.

Determining eligibility
The team, including you, meets to determine if your child is eligible or not eligible for EI services. The team reviews all of the tests and assessments that were part of the evaluation, and documents the information from the reports and the input from the team members. In determining eligibility the team considers:

- If the child has a hearing impairment that meets the hearing impairment eligibility requirements;
- If the child has a hearing impairment (documented by a physician) that is likely to result in a developmental delay; or
- If the child has a developmental delay that meets the eligibility requirements.

The team documents the eligibility determination by completing the appropriate eligibility statement. A copy of the evaluation report and the eligibility statement is given to you.

Copies of reports
If the evaluation report is finished before the eligibility meeting, it should be sent to all team members, including you. This gives everyone a chance to read and consider all of the information before the meeting. If reports are not completed before the meeting you and the other team members should be given time during the meeting to review the information.

Individualized Family Service Plan
If your child is found eligible for EI services, you and a team will meet to develop a written plan for providing EI services to your child and family. This plan is called the Individualized Family Service Plan or IFSP. The IFSP outlines the EI services that your child and family will receive.

One guiding principle of the IFSP is that the family is a child’s greatest resource because a young child’s needs are closely tied to the needs of his or her family. The best way to support children and meet their needs is to support and build upon the strengths of their family. So, the IFSP is a whole family plan with parents as major contributors in its development. Involvement of other team members will depend on what the child needs. This may mean that a teacher of the hearing impaired or deaf, an early intervention specialist and/or a communication specialist will be assigned to work with you and your child.
Your child’s IFSP must include the following:

- Your child’s present physical, cognitive, communication, social/emotional and adaptive development levels and needs;
- Family information (with your agreement), including the resources, priorities and concerns of you and other family members regarding your child’s development;
- The major goals or outcomes expected to be achieved for your child and family;
- The specific services your child and family will receive;
- Where the services will be provided;
- When the services will be provided;
- The number of days or sessions your child will receive each service and for how long each session will last; and
- The name of the service coordinator overseeing the implementation of the IFSP.

The IFSP is reviewed every six months and is updated at least once a year. The IFSP must be fully explained to you and your suggestions must be considered. You must give written informed consent (documented on the IFSP) before services can start. If you do not give your consent in writing, your child will not receive services.
Each county in Oregon has an agency that coordinates referrals and eligibility evaluations for EI/ECSE services. Use this telephone number to contact EI/ECSE services.

<table>
<thead>
<tr>
<th>Area 1 Umatilla-Baker ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Baker County</td>
<td>1-800-927-5847</td>
</tr>
<tr>
<td>Grant County</td>
<td>1-800-927-5847</td>
</tr>
<tr>
<td>Malheur County</td>
<td>541-473-3905</td>
</tr>
<tr>
<td>Morrow County</td>
<td>1-800-927-5847</td>
</tr>
<tr>
<td>Umatilla County</td>
<td>1-800-927-5847</td>
</tr>
<tr>
<td>Union County</td>
<td>1-800-927-5847</td>
</tr>
<tr>
<td>Wallowa County</td>
<td>541-426-4225</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area 2 High Desert ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Crook County</td>
<td>541-312-1195</td>
</tr>
<tr>
<td>Deschutes County</td>
<td>541-312-1195</td>
</tr>
<tr>
<td>Gilliam, Sherman Wheeler counties</td>
<td>541-565-3600</td>
</tr>
<tr>
<td>Harney County</td>
<td>541-573-6461</td>
</tr>
<tr>
<td>Jefferson County</td>
<td>541-475-3770</td>
</tr>
<tr>
<td>Confederated Tribes of Warm Springs</td>
<td>541-553-3241</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area 3 Douglas ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Douglas County</td>
<td>541-440-4794</td>
</tr>
<tr>
<td>Jackson County</td>
<td>541-789-5252</td>
</tr>
<tr>
<td>Josephine County</td>
<td>541-956-2059</td>
</tr>
<tr>
<td>Klamath County</td>
<td>541-883-4748</td>
</tr>
<tr>
<td>Lake County</td>
<td>541-947-3371</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area 4 Linn-Benton-Lincoln ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Benton County</td>
<td>541-753-1202 ext. 101</td>
</tr>
<tr>
<td></td>
<td>1-877-589-9751</td>
</tr>
<tr>
<td>Coos County</td>
<td>541-269-4524</td>
</tr>
<tr>
<td>Curry County</td>
<td>541-269-4524</td>
</tr>
<tr>
<td>Lincoln County</td>
<td>541-574-2240 ext. 137</td>
</tr>
<tr>
<td>Linn County</td>
<td>541-753-1202 ext. 106</td>
</tr>
<tr>
<td></td>
<td>1-877-589-9751</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area 5 Willamette ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Marion County</td>
<td>503-385-4714</td>
</tr>
<tr>
<td></td>
<td>1-888-560-4666</td>
</tr>
<tr>
<td>Polk County</td>
<td>503-435-5940</td>
</tr>
<tr>
<td></td>
<td>1-888-560-4666</td>
</tr>
<tr>
<td>Yamhill County</td>
<td>503-435-5940</td>
</tr>
<tr>
<td></td>
<td>1-888-560-4666</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area 6 Multnomah ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hood River County</td>
<td>541-387-5077</td>
</tr>
<tr>
<td>Multnomah County</td>
<td>503-262-4100</td>
</tr>
<tr>
<td>Wasco County</td>
<td>541-296-1478</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area 7 Lane ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Lane County</td>
<td>1-800-925-8694</td>
</tr>
<tr>
<td></td>
<td>541-346-2578</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area 8 Northwest Regional ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clatsop County</td>
<td>503-325-2862</td>
</tr>
<tr>
<td>Columbia County</td>
<td>503-397-0028</td>
</tr>
<tr>
<td>Tillamook County</td>
<td>503-842-8423</td>
</tr>
<tr>
<td>Washington County</td>
<td>503-614-1446 (English)</td>
</tr>
<tr>
<td></td>
<td>503-614-1263 (Spanish)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Area 9 Clackamas ESD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clackamas County</td>
<td>503-675-4097</td>
</tr>
</tbody>
</table>
Oregon Regional Program services for deaf and hard of hearing

A public program that works with the EI/ECSE programs to provide services to deaf and hard of hearing children and their families. Services may include speech, language and listening training; assistance with hearing aids and other auditory tools; information about cochlear implants; etc. Services are free to children and families who are found eligible for services.

Services for children with low-incidence disabilities, including those who are deaf and hard of hearing, are provided through eight regional contractors throughout the state. This system is called Regional Programs for Low Incidence Disabilities (Regional Programs). Each program hires trained, certified staff to provide the needed specialized services.

Coordination and planning for each region is the responsibility of the local Regional Advisory Council, with representation from local education agencies and parents of children receiving services from Regional Programs. Statewide coordination is provided by a Regional Management Team, consisting of the Regional Program director from the Department of Education, the coordinator of each Regional Program, and the directors of the Schools for the Blind and for the Deaf.

The specialized services provided to children who are deaf and hard of hearing are not generally available through local programs, due to the small number of children per school district. These services include, but are not limited to specially designed instruction in language development; sign language; use of technology for communication, play and social skills; academic areas; assistive technology; and various related services such as audiology, physical therapy and occupational therapy. Consultation and training are provided to local education staff and parents in implementing the Individual Family Service Plan (IFSP). The need for these services is identified through the IFSP process. These plans are developed cooperatively by the Regional Programs, the EI/ECSE programs and the child’s family.
<table>
<thead>
<tr>
<th>Region</th>
<th>Counties served</th>
<th>Regional Program coordinator</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Eastern Oregon Regional Program</td>
<td>Baker, Grant, Malheur, Morrow, Umatilla, Union, Wallowa</td>
<td>Deb Oliver, Umatilla-Morrow ESD, La Grande, OR 97850, <a href="mailto:doliver@umesd.k12.or.us">doliver@umesd.k12.or.us</a>, 541-975-5652, 541-663-8531 fax</td>
</tr>
<tr>
<td>2 Central Oregon Regional Program</td>
<td>Crook, Deschutes, Gilliam, Harney, Jefferson (includes the Confederated Tribes of Warm Springs), Sherman, Wheeler</td>
<td>Paul Andrews, High Desert ESD, Bend, OR 97701, <a href="mailto:pandrews@hdesd.k12.or.us">pandrews@hdesd.k12.or.us</a>, 541-693-5702, 541-693-5701 fax</td>
</tr>
<tr>
<td>3 Southern Oregon Regional Program</td>
<td>Douglas, Jackson, Josephine, Klamath, Lake</td>
<td>Sandra Crews, Southern Oregon ESD, Medford, OR 97501-2793, <a href="mailto:Sandra_Crews@soesd.k12.or.us">Sandra_Crews@soesd.k12.or.us</a>, 541-776-8555, 541-535-2460 fax</td>
</tr>
<tr>
<td>4 Cascade Regional Program</td>
<td>Benton, Coos, Curry, Lincoln, Linn</td>
<td>Jean Orr, Linn-Benton-Lincoln ESD, Albany, OR 97321-3199, <a href="mailto:jean_Orr@lbles4d.k12.or.us">jean_Orr@lbles4d.k12.or.us</a>, 541-812-2640, 541-926-6047 fax</td>
</tr>
<tr>
<td>5 Willamette Regional Program</td>
<td>Marion, Polk, Yamhill</td>
<td>Mary Reid, Willamette ESD, Salem, OR 97302-1533, <a href="mailto:mary.reid@wesd.org">mary.reid@wesd.org</a>, 503-385-4641, 503-385-4879 fax</td>
</tr>
<tr>
<td>Region</td>
<td>Counties served</td>
<td>Regional Program coordinator</td>
</tr>
<tr>
<td>---------</td>
<td>-----------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>6</td>
<td>Multnomah</td>
<td>Robbie Weber</td>
</tr>
<tr>
<td></td>
<td>Clackamas</td>
<td>Portland Public Schools</td>
</tr>
<tr>
<td></td>
<td>Hood River</td>
<td>Blanchard Education Svc. Ctr.</td>
</tr>
<tr>
<td></td>
<td>Wasco</td>
<td>Portland, OR 97227</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:rweber1@pps.k12.or.us">rweber1@pps.k12.or.us</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>503-916-5570</td>
</tr>
<tr>
<td></td>
<td></td>
<td>503-916-5576 fax</td>
</tr>
<tr>
<td>7</td>
<td>Lane</td>
<td>Sue Mathisen</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lane ESD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1200 Hwy. 99N</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eugene, OR 97402-0374</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:smathise@lane.k12.or.us">smathise@lane.k12.or.us</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>541-461-8374</td>
</tr>
<tr>
<td></td>
<td></td>
<td>541-461-8298 fax</td>
</tr>
<tr>
<td>8</td>
<td>Clatsop</td>
<td>Joan Steiner</td>
</tr>
<tr>
<td></td>
<td>Columbia</td>
<td>NW Regional ESD</td>
</tr>
<tr>
<td></td>
<td>Tillamook</td>
<td>5825 NE Ray Circle</td>
</tr>
<tr>
<td></td>
<td>Washington</td>
<td>Hillsboro, OR 97214-6436</td>
</tr>
<tr>
<td></td>
<td></td>
<td><a href="mailto:steinerj@nwresd.k12.or.us">steinerj@nwresd.k12.or.us</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>503-614-1275</td>
</tr>
<tr>
<td></td>
<td></td>
<td>503-614-1440 fax</td>
</tr>
</tbody>
</table>
Tucker-Maxon Oral School provides a comprehensive and developmentally appropriate program for children who are deaf or hard of hearing from birth through fifth grade. Family-centered services consist of home-based and school-based interventions, toddler groups and family support groups.

Blended classrooms of deaf and hearing children are provided from preschool through fifth grade. All classes are taught by two teachers, a teacher of deaf children and a regular educator or early childhood specialist. Each class utilizes two classrooms, a large group room and a small group room, both of which are equipped with sound field amplification. Individual FM systems are also utilized. Onsite audiological services and speech language pathology services support and enhance classroom instruction.

Classes average five deaf children and 12 hearing children. Tucker-Maxon uses an auditory-oral approach and auditory-verbal techniques to teach deaf children to talk. Our children in preschool and elementary classes receive daily individualized instruction in listening, language and speech. Our classes engage deaf children in lively talk with hearing peers, providing them with many opportunities to learn spoken communication as well as to develop literacy and socialization skills.
The Eugene Hearing and Speech Center is a private, non-profit agency that has provided services to deaf and hard-of-hearing children and their families since 1955. We are a comprehensive clinic providing a complete range of diagnostic and rehabilitative services in audiology and speech-language pathology.

Following a diagnosis of hearing loss, family members receive information regarding hearing loss, amplification (hearing aids or cochlear implants), educational and communication approaches, as well as language, speech and auditory development. Our pediatric staff cooperates with each child’s pediatrician and/or otolaryngologist to provide state-of-the-art technology and evidence-based aural rehabilitation and speech-language therapy based on each family’s goals for the child. The Center also collaborates with other community agencies to provide further resources as needed.

Scholarship funds are available for those who qualify. Please contact the Eugene Hearing and Speech Center for an application, or go to our Web site at www.eugenehearingspeech.org. The Eugene Hearing and Speech Center is the leading local provider of hearing and speech-language services, serving all ages throughout Lane County and the southern Oregon area.
This section describes types of hearing loss, how it can occur, types of treatment and other topics about hearing and hearing loss.
Hearing and hearing loss

How does the ear work?
The ear is divided into three main sections: the outer ear, middle ear and inner ear. (See diagram below.) These sections work together to transform sound waves into what we call hearing.

The outer ear catches the sound. The sound travels from the pinna through the ear canal to the tympanic membrane (eardrum).

The middle ear contains the three small bones called the malleus, the incus and the stapes. When the eardrum vibrates, the three bones move, too.

The inner ear contains the cochlea (organ of hearing) and the semi-circular canals (organ for balance). The cochlea contains thousands of tiny sensory cells called hair cells. Some of the hair cells respond to low-pitch sounds, and some respond to high-pitch sounds.

When the middle ear bones move, the hair cells send a message to the auditory (hearing) nerve. The nerve sends information about sound to the brain.

Anatomy of the ear
**Types of hearing loss**

- Conductive hearing loss occurs in the outer or middle parts of the ear. These hearing losses are called “conductive,” because the problem interferes with the conduction of (travel of) sound waves through the outer and/or middle ears. These losses are generally perceived as a decrease in loudness. For example, wearing earplugs creates a temporary conductive hearing loss. Some conductive losses may be temporary (such as ear infections) and respond to medical or surgical treatment. Other conductive hearing losses may need intervention treatments, such as hearing aids for a child born without an outer ear canal.

- Sensorineural hearing loss occurs in the inner ear or auditory nerve. Sensorineural losses are generally perceived as a loss of clarity of sound and/or a decrease in loudness, and are most often permanent. There are many causes of sensorineural hearing loss. Some are genetic in origin, while others happen after an illness, such as meningitis.

- Mixed hearing loss is a combination of conductive and sensorineural hearing losses. For example, a child with a permanent loss may have a temporary loss due to middle-ear fluid.

- Unilateral hearing loss is a hearing loss that occurs in only one ear. (See Page 69 for more information.)

- Bilateral hearing loss is a hearing loss that occurs in both ears.

- Congenital hearing loss means the hearing loss is present at birth.

- Late-onset hearing loss is a hearing loss that happens after birth. A child can be born with normal hearing and then develop a hearing loss.

- Progressive hearing loss is a hearing loss that gets worse over time, in one or both ears.
Types of audiological (hearing) evaluations for infants and children

The purpose of a hearing evaluation is to determine the threshold (softest sound) at which an infant or toddler responds to a variety of frequencies (pitches). Results of the evaluations are used to describe the type and degree of hearing loss that is present. The following are audiological evaluation procedures that can be used with infants and young children.

- Auditory brainstem response (ABR) is a noninvasive test that indicates whether or not sound is being detected. It may be called a BAER or BSER, as well as an ABR. Sensors (electrodes) are placed at several locations on the head and ears. Sounds are presented to each ear, and a computer analyzes the responses measured by the electrodes. The results are used to predict hearing levels. This test, which does not hurt, is most often done while the baby is sleeping.

- Otoacoustic emissions (OAE) Testing uses a soft ear probe placed in the ear canal. Sounds are presented into the ear, and a microphone in the probe records the inner ear responses to the sound.

- Visual reinforcement audiometry (VRA) uses lighted toys to train a child to turn towards a sound source. The sound stimuli are presented to the infant using a speaker system or earphones.

- Conditioned play audiometry is done by teaching a child to respond with some action whenever he/she hears a sound. The child may learn, for instance, to put a peg in a hole or a piece in a puzzle every time he/she hears a sound.

- Behavioral observation audiometry (BOA) is performed by observing the infant’s behavioral responses to sound. For instance, in response to a sound, an infant or young child may smile, open his/her eyes very wide or show some other behavioral change.
Results of an audiological evaluation are usually recorded on a graph called an audiogram.

**Audiogram**
**Degrees of hearing loss**
The various degrees of hearing loss are listed in the table below. Speech and language development varies among individual children with the same degree of hearing loss. All children with the degrees of hearing loss listed in the table would benefit from an amplification system.

<table>
<thead>
<tr>
<th>Degrees of hearing loss</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Minimal loss</strong>&lt;br&gt;16 to 25 dBHL</td>
<td>Minimal loss of some sounds. May have difficulty hearing quiet or distant speech, especially in noisy environments.</td>
</tr>
<tr>
<td><strong>Mild loss</strong>&lt;br&gt;26 to 40 dBHL</td>
<td>Has trouble hearing faint or distant speech and understanding speech in a noisy environment. If undiagnosed, may read at grade levels below those of peers.</td>
</tr>
<tr>
<td><strong>Moderate loss</strong>&lt;br&gt;41 to 55 dBHL</td>
<td>Understands only loud speech. Has difficulty in group discussions. Own speech may have errors. Has vocabulary limitations and deficiencies in language comprehension and usage.</td>
</tr>
<tr>
<td><strong>Moderate - severe loss</strong>&lt;br&gt;56 to 70 dBHL</td>
<td>Hears only very loud speech close to ear. Can identify only loud environmental sounds. May be able to discriminate vowels, but not all consonants. Language development will be seriously deficient if amplification is not provided. Own speech has many errors.</td>
</tr>
<tr>
<td><strong>Severe loss</strong>&lt;br&gt;71 to 90 dBHL</td>
<td>Hears voice only if shouted in ear. Not able to discriminate words without visual cues. If hearing loss is present during first year of life, understanding of spoken language and use of speech will not develop spontaneously unless amplification is provided. Own speech is mostly unintelligible.</td>
</tr>
<tr>
<td><strong>Profound loss</strong>&lt;br&gt;91 dBHL or greater</td>
<td>May hear very loud sounds, but more aware of vibrations than of tonal patterns. Will rely on vision rather than hearing as primary sensory channel for communication. Own speech is unintelligible. Potential candidate for a cochlear implant. Use of a signed language or system may benefit language development.</td>
</tr>
</tbody>
</table>
Different types of hearing technologies

Hearing aids
A hearing aid is an electronic device that amplifies sounds. Hearing aids come in a variety of styles and shapes. Different hearing aids use different technologies to make speech and sounds louder. Although hearing aids may function differently, they all have the following three main parts.
- The microphone picks up the sound from the air and changes the acoustic (sound) signal into an electrical signal.
- The amplifier increases the intensity (loudness) of the electrical signal and makes it louder.
- The receiver (speaker) changes the electrical signal back to an acoustic signal, which is then sent into the ear.

Hearing aids can amplify sound through either analog (electrical processing) or digital (mathematical processing) technology.

Hearing aids are adjusted in one of two ways. Some hearing aids have little screws on the hearing aid case that can be turned to adjust how the hearing aid amplifies sounds. These are called non-programmable hearing aids. Other hearing aids can be adjusted by connecting them to a computer software system. These are called programmable hearing aids. Programmable hearing aids are capable of having multiple channels and/or multiple memories for use in different listening situations. Hearing aids can be adjusted to meet the child's specific hearing loss.
Types of hearing aids — Air-conduction hearing aids

Air-conduction hearing aids conduct sound through the outer ear canal into the ear. The following are types of air-conduction hearing aids.

<table>
<thead>
<tr>
<th>Types of Hearing Aids</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Behind-the-ear (BTE)</strong></td>
<td>These are small hearing aids that are worn behind the ear. They are connected to the outer ear by an earmold (a small plastic piece that holds the hearing aid in place). This is the style of hearing aid most often recommended for infants and children.</td>
</tr>
<tr>
<td><strong>In-the-ear (ITE) hearing aids</strong></td>
<td>These are very small and worn in the outer ear. They are not recommended for infants or very young children.</td>
</tr>
<tr>
<td><strong>Canal hearing aids</strong></td>
<td>These are very tiny and worn in the canal portion of the outer ear. They are not recommended for infants or very young children.</td>
</tr>
<tr>
<td><strong>Body-level hearing aids</strong></td>
<td>The main part of body-level hearing aids looks like a small box or radio, which is worn on the body, usually at waist level. The box contains the microphone and amplifier. A cord attaches the box to the receiver, which is worn in the ear using an earmold.</td>
</tr>
</tbody>
</table>

Examples of air-conduction hearing aids

- **Behind-the-ear (BTE) hearing aid**
- **Canal hearing aids**
- **In-the-ear (ITE) hearing aids**
### Types of hearing aids — Bone-conduction hearing aids

Bone-conduction hearing aids are used most often by people who cannot use an air-conduction hearing aid. For example, a child who is born without an ear canal or who experiences constant drainage from ear infections may wear a bone-conduction hearing aid.

|Traditional| Traditional bone-conduction hearing aids are worn on the head just behind the ear, using a headband and a sound vibrator. They conduct the sounds through the skull bones, rather than the outer ear canal. |
|Bone-anchored| A bone-anchored hearing aid is surgically implanted into the bone behind the ear. This hearing aid conducts sound through the skull bones. |

### Examples of bone-conduction hearing aids

- **Traditional style**

- **Bone-anchored style**
Important facts about hearing aids

**A hearing aid can:**
- Make all sounds in the environment louder (e.g., speech, TV, air conditioner, vacuum cleaner).
- Improve speech and language development for infants and toddlers.
- Improve communication and interaction with family and peers.

**A hearing aid cannot:**
- Cure the child’s hearing loss.
- Help the child hear sounds at frequencies at which there is no hearing.
- Make only speech sounds louder.
- Make sounds clearer if the child’s cochlea is distorting the incoming sounds.

**Choosing a hearing aid**

Which hearing aid is best for infants and young children? Most infants and young children are fitted with two (binaural) behind-the-ear (BTE) hearing aids. In-the-ear (ITE) and canal-type instruments are not recommended for infants or young children for two reasons:
- Due to the instrument’s small size, they are a choking hazard.
- Infants and young children grow so quickly that the custom-made ITE case would need to be replaced very often.

Hearing aids are not a one-time purchase. They may need to be replaced, due to being stepped on, chewed by a family pet or lost. Hearing aids also occasionally require repair. As technology improves, parents may want to try new hearing aids with their child.

It is important to explore many options with your pediatric audiologist before choosing amplification for your child. The selected hearing aid(s) should meet your child’s needs.
What are important features of hearing aids for infants and toddlers?

The hearing aid should:
- Provide sufficient amplification to allow the child to hear speech sounds.
- Have direct audio input (DAI) and microphone-telecoil (M-T) switching options. These options allow the hearing aid to be coupled with other assistive devices. (See the following section, “FM system hearing technology”.)
- Have flexibility in making changes in loudness and pitch so that adjustments can be made as more information is obtained about the child’s hearing levels and responsiveness to sound.
- Have tamper-resistant battery compartments and volume controls. Hearing-aid batteries are toxic and should be monitored closely. They can be harmful if swallowed by infants or pets.

If batteries are swallowed accidentally, call the National Button Battery Hotline at 1-800-222-1222.
Frequency modulated (FM) system hearing technology

Children who use hearing aids often have difficulty hearing speech in a noisy background or when the speaker is at a distance greater than 3 feet. For these situations, a wireless FM system may be beneficial.

An FM system is designed to amplify a speaker’s voice, so that it is louder than any competing background noise. With some FM systems, the child can still hear his/her own voice and environmental sounds. The FM system may be used as the primary amplification system in some cases.

An FM system consists of a microphone (transmitter), receiver, and some type of system to connect the receiver to the child’s ear or hearing aid. The speaker (parent or teacher) wears the microphone/transmitter about 6 to 8 inches from the speaker’s mouth. The microphone sends the signal to the transmitter, which sends it to the receiver. The receiver can be worn by the child in several different ways and may be attached to the child’s hearing aid.
Cochlear implants

What is a cochlear implant?
A cochlear implant is used by children (and adults) who do not benefit from traditional hearing-aid amplification. A cochlear implant is an electronic device that provides electrical stimulation to the remaining auditory nerve fibers. The implant has both internal parts, which are surgically implanted, and external parts, which are worn outside the body.

The surgically implanted parts are the receiver/stimulator and an electrode array. The external parts are a microphone, speech processor and a transmitter coil.
How does a cochlear implant work?
The microphone of the cochlear implant picks up sounds and sends them to electronic circuits inside the speech processor (often worn in a pocket or behind the ear). The speech processor changes sounds into electrical signals, which are sent to the external transmitter coil. The coil emits radio signals, which are picked up by the implanted receivers. The receiver/stimulator sends the electrical signals to the electrode array, which has been implanted in the cochlea. The electrodes stimulate the acoustic nerve, which carries impulses to the brain where they are interpreted as sound.

Which children can use a cochlear implant?
Whether your child can be a candidate for a cochlear implant is based on many different factors. Various audiological, medical and psychological criteria need to be reviewed by a team to determine if your infant or child can be considered for a cochlear implant. Team members should include the parents, other family members and professionals from the implant center. The team may include the surgeon; a teacher of the deaf or hard of hearing; an audiologist; a speech and language pathologist; a psychologist or counselor; and other specialists as needed.

Cochlear implant surgery is a very specialized procedure. A child needs intensive habilitative therapy after receiving a cochlear implant. See below for the list of cochlear implant specialists in Oregon.

The following are considerations for cochlear implants in young children.

- **Age** — the child may be as young as 12 months for profound sensorineural hearing loss.
- **Hearing aid use** — the child has worn appropriately fitted high-power hearing aids and received intensive aural rehabilitation for at least three months.

**Cochlear implant centers in Oregon**

**Oregon Health & Science University (OHSU)**
3181 S.W. Sam Jackson Park Road
Suite 250, Physicians Pavillion
Portland, OR 97239-3098
503-494-4394
503-494-1772 (fax)
E-mail: cochlear@ohsu.edu

**Wilson Ear Clinic**
911 N.W. 18th Avenue
Portland, OR 97209
503-227-3666

**Legacy Holladay Park**
1225 N.E. Second Avenue,
Suite 305
Portland, OR 97232
503-233-6068
Mailing address:
P.O. Box 3950
Portland, OR 97208
Topics related to hearing loss

Other topics related to diagnosis of hearing loss.


Topics related to hearing loss

Deafblindness
The ability to communicate and learn language is based largely on a child’s ability to access visual and auditory information. If these two sensory channels are impaired, children often receive distorted, fluctuating, confusing and meaningless information.

According to the National Information Clearinghouse on Children Who Are Deaf-Blind, people who are deafblind experience the world very differently than others.

“For persons who can see and hear, the world extends outward as far as his or her eyes and ears can reach. For the young child who is deafblind, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. Such children are effectively alone if no one is touching them. Their concepts of the world depend upon what or whom they have had the opportunity to physically contact.”

The impact of deafblindness is so profound that the federal government has set aside grants for every state to provide technical assistance to families and professionals working with children who are deafblind. Techniques for children who are partially or totally blind or deaf do not meet the critical needs of children who are deafblind. For example, children who are visually impaired can still use their hearing in order to communicate or learn to travel independently; children who are deaf can still use their vision to acquire language and to travel independently. Children who are deafblind have to learn other ways to communicate and to access the world around them. They need new ways of providing and receiving information.

Recent evidence of the brain’s ability to change propels the need for early identification of deafblindness. Providing children who are deafblind the earliest possible intervention allows them maximum time to practice. They can also more efficiently access the world and communicate with people around them.

If you suspect your child has both vision and hearing problems, call or e-mail Oregon’s federally funded program. The Oregon Deafblind Project will connect you with a regional consultant who is knowledgeable about deafblindness and can provide you with technical support or train personnel in your organization. The services are provided at no cost.

For More Information
Oregon Deafblind Project
Western Oregon University (TRI)
345 N. Monmouth Ave.
Monmouth, OR 97361
503-838-8328
E-mail: ayerl@wou.edu
**Usher syndrome**

Usher syndrome is three genetic conditions involving both hearing loss and retinitis pigmentosa (RP), a progressive degenerative eye disease.

The audiograms of children with Usher syndrome can serve as a red flag. In Type 1, children are born deaf and have a “corner audiogram” with responses only to very loud, low tones. Night blindness in infancy or early childhood can occur.

In Type 2, children are born hard of hearing with a sloping sensorineural loss from mild loss in low frequencies to severe-profound loss in high frequencies. These children can experience blind spots by late childhood or teens. They could be legally blind by early adulthood.

In Type 3, the onset of hearing loss can happen from 0 to 40 years old. The loss progresses rapidly to profound deafness. It has a ski-slope audiogram with speed bump. There is also a balance disturbance that can be progressive.

One of the first signs of retinitis pigmentosa is difficulty seeing clearly at night. The next sign is the inability to see peripherally in any lighting conditions. Changes in lighting also cause visual problems for people with retinitis pigmentosa.

All types of Usher syndrome are autosomal (not sex linked) recessive conditions. This means that both parents are asymptomatic carriers. Neither parent knows that he or she is a carrier until they have a child with Usher syndrome. Parents find out they are carriers only when their child is diagnosed. Usually they have never heard of the condition and are offered little information or support.

Among children who are born profoundly deaf, 3 to 6 percent can be expected to have Usher syndrome Type 1. Among children born hard of hearing, Usher syndrome Type 2 probably occurs at the same rate. Schools do not perform vision screenings for retinitis pigmentosa routinely, resulting in under-identification of students with Usher syndrome.

**Why early diagnosis is important**

An early diagnosis of Usher syndrome allows parents to consider genetic counseling and testing for other children in the family. Early identification affects medical decisions, educational decisions/services and social implications for the students as well as the family.

It is essential that these students receive the accommodations and/or modifications that are necessary to provide them optimal access to information in all environments.
Communication skills for these students need to be a constant consideration. Students must begin developing the skills or mindset they will need to develop certain skills in preparation for the progressive loss of their vision and/or hearing. The student can receive counseling and support to prepare him or her for the future. It is a traumatic event for a student to be diagnosed with Usher syndrome at any time, but especially as he or she is about to graduate from high school. Having this knowledge when the child is young gives the child and family time to deal with this loss gradually.

**For more information about Usher syndrome:**

DB-LINK at The National Consortium on Deaf-Blindness  
Phone: 1-800-438-9376  
TTY: 1-800-854-7013  
www.tr.wou.edu/dblink  
www.nationaldb.org

Otitis media
Otitis media (or middle-ear infection) is an inflammation in the middle ear that is usually associated with the buildup of fluid. The fluid may or may not be infected.

Symptoms of otitis media may include:

- Fever,
- Ear pain,
- Pulling or scratching at the ears,
- Inattentiveness,
- Wanting the television or radio louder than usual,
- Unexplained irritability or behavioral changes,
- Fatigue.

Otitis media frequently occurs in children. In fact, otitis media is the second most common health problem in preschool children. Only the common cold occurs more often. This is because the Eustachian tube in children, which connects the middle-ear space to the back of the throat, is smaller and more nearly horizontal (flat) than it is in adults. Therefore, it can be blocked more easily by conditions such as large adenoids and infections. When the Eustachian tube is blocked, fluid can develop in the middle-ear space.

Otitis media can cause hearing loss
You can think about otitis media as if you are talking to a person who is underwater. Sound is muffled because the transfer of sound vibrations through liquid is not efficient. Fluid in the middle ear causes a similar sensation.

Otitis media can cause a conductive hearing loss and it is usually temporary. When otitis media occurs over and over again, it can damage the eardrum, the middle-ear bones or even the inner ear. If otitis media lasts a long time, in some cases it can cause a permanent sensorineural hearing loss.

A child with a permanent hearing loss also can have otitis media. The otitis media can cause an additional hearing loss for that child. In that case, the child may not be hearing speech sounds even with his/her hearing aids.
Hearing loss due to otitis media can cause speech and language problems

Children learn spoken language by hearing other people talk. Any hearing loss can interfere with the ability to understand speech. Fluctuating (changing) hearing loss due to otitis media can have a significant effect on a child’s ability to develop speech and language.

Otitis media without infection can be a special problem, because the child may not show pain or have a fever. Sometimes weeks or months can go by before parents suspect a problem. However, it is important to remember that even if there is fluid without an infection, a child’s hearing can still be affected.

Otitis media can be treated medically

Otitis media is often treated with antibiotic medication. Sometimes antibiotics clear up the infection, but the fluid remains in the middle ear. The fluid can remain in the ear over a long period. When this happens, tympanostomy tubes may be considered as a treatment. (A tympanostomy tube is a small tube placed in the eardrum.) The tube allows the fluid to drain out of the middle ear and into the ear canal. Your primary care professional will work with you to decide the best treatment for your child. This may include a referral to a pediatric otologist (ear doctor).
Genetics of hearing loss

Hearing loss can have many different causes. Some hearing losses occur because of infections such as meningitis. Some result from taking certain medications. Those types of causes are called environmental. Other hearing losses may be the result of genetics (heredity). A combination of environmental factors and genes can also cause a hearing loss.

In about 60 percent of cases of hearing loss, the cause is genetic. There are different types of genetic hearing loss. Sometimes a genetic hearing loss is part of a “syndrome.” This means that the child with a hearing loss may have another condition, such as a vision problem. Some syndromes associated with hearing loss are Usher syndrome and Pendred syndrome. Other genetic hearing losses are “non-syndromic.” Children with non-syndromic hearing loss usually have no other significant medical conditions.

Recent advances in medicine have allowed families to learn more about some of the genetic causes of hearing loss. Genetic consultation and evaluations are now available at some clinics. They can help parents, who may want to know the cause of their child’s hearing loss.

Genetic evaluation

A team of health professionals usually conducts the genetic evaluation. The team includes a geneticist, who is a physician trained to recognize signs of a genetic condition, and a genetic counselor, who has either a master’s degree or Ph.D. in genetics. The full genetic evaluation includes a family history, physical examination, medical examination and genetic testing.

For more information about genetic counseling and evaluation, you may contact one of the following genetic clinics:

<table>
<thead>
<tr>
<th>Oregon Health &amp; Science University</th>
<th>503-494-8307</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child Development and Rehabilitation Center (CDRC)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Legacy Emanuel Hospital &amp; Health Center</th>
<th>503-413-4156</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Genetics</td>
<td></td>
</tr>
<tr>
<td>Prenatal Diagnosis &amp; Counseling</td>
<td>503-413-1122 or 1-800-452-7032 x31122</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Kaiser Permanente Northwest (members only)</th>
<th>503-331-6593 or 1-800-813-2000 x16-6593</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Genetics</td>
<td></td>
</tr>
<tr>
<td>Prenatal Diagnosis &amp; Counseling Cancer Genetic</td>
<td></td>
</tr>
<tr>
<td>Counseling, Risk Assessment and Testing</td>
<td></td>
</tr>
</tbody>
</table>
Unilateral hearing loss

A unilateral hearing loss is one that occurs in only one ear. The degree (amount) of hearing loss in that ear can range from mild to profound. A unilateral hearing loss can be caused by a problem in the outer, middle or inner ear. The causes of unilateral hearing loss are similar to those of hearing loss in both ears (i.e., illness, injury or genetics).

A child with normal hearing in at least one ear usually hears well in most situations. However, young children with a unilateral hearing loss may be at risk for speech and language delays and/or later academic problems. We do not know which individual children are at risk. We also do not know at what age the problems may arise.

Many children with a hearing loss in one ear do well in school. However, some children with a unilateral hearing loss are at risk for failing a grade in school. These children may show problems with attending to information and instructions. They may also have problems with the following:
- Hearing sounds directed toward the poorer ear;
- Locating the source of the sound;
- Understanding speech or directions in a noisy environment such as a classroom.

If your child has a unilateral hearing loss, it is important that he/she be tested by an audiologist. The audiologist can help decide if a hearing aid or other listening device would help your child. Not all children with a unilateral hearing loss will benefit from hearing aids or listening devices.

A child with a unilateral hearing loss should also be seen by an otolaryngologist, a physician who specializes in diseases of the ear. The doctor can determine if the hearing loss can be treated medically. The doctor also can decide if the hearing loss is associated with other health problems.
**Intervention guidelines for children with a unilateral hearing loss**

**Strategies for listening**
- Limit background noises as much as possible when speaking with your child.
- Remember to speak so that your child’s good ear can hear you.
- Use assistive listening devices and/or hearing aids, as appropriate.

**Strategies for safety**
- Remember your young child may not always hear sounds coming from the side with the hearing loss.
- You may need to watch your child in hazardous situations to help him/her be aware of sounds.
- As your child grows, teach him/her to use his vision, as well as the good ear, to watch for cars and other dangers.

**Strategies for protecting hearing**
- Use earplugs to protect your child’s hearing from loud sounds (i.e., power tools, firecrackers).
- Monitor your child closely for ear infections. Obtain medical attention promptly if your child has an ear infection.
- Have your child receive regular hearing tests, as recommended by your audiologist or physician. If you think your child’s hearing has changed, schedule a hearing test immediately.

**Complete early intervention (EI) services for infants with hearing loss**
Services for infants with hearing loss and their families can be provided best using a team approach. The team includes your child’s primary care provider, audiologist and early intervention specialist. Parents are the central part of this team. It is important that you discuss your child’s strengths and needs with each team member.

In order to help your child, it is important first to know how your child learns and develops. The early intervention team can assist in coordinating the appropriate services your child may need. The team will want to know how your child functions in certain developmental areas, such as motor skills (movement) and language skills.
In order to assist you in obtaining early intervention services for your child and family, we have developed a list of recommendations.

**Recommended early intervention services for infants/toddlers with hearing loss**
- Complete medical examination/evaluation;
- Audiological services and hearing-aid fitting/use;
- Vision examination;
- Examination by an ear, nose and throat physician;
- Language and speech intervention;
- Referral for counseling regarding cochlear implants, as appropriate (see Page 58);
- Referral for genetic counseling, as appropriate (see Page 68);
- Complete developmental evaluation.
This section provides information regarding funding resources for hearing aids, as well as other hearing technologies. The programs listed here are divided into public agencies and private organizations. Please contact each program for its individual eligibility requirements and application procedure.
Funding resources for hearing technologies

Financial assistance information for parents regarding hearing aids and amplification

Public agencies

Oregon Department of Human Services
Office of Medical Assistance Programs (OMAP)
500 Summer Street, N.E.
Salem, OR 97301-1079
General information
1-800-527-5772
TTY – 1-800-375-2863
www.dhs.state.or.us/healthplan

Oregon Health Plan (OHP) 1-800-699-9075
OHP Application Center 1-800-359-9517
www.oregon.gov/DHS

Supplemental Security Income (SSI)
1-800-772-1213
or call your local Social Security Office
www.ssa.gov

Early Hearing Detection and Intervention (EHDI) Loaner Hearing Aid Program

The Oregon EHDI Program has a Loaner Hearing Aid Bank to ensure all children who need hearing aids have immediate access to them. The hearing aids are to be used on a temporary basis for any child with hearing loss from birth to three years of age who is receiving early intervention services. There is no cost for the hearing aids that can be loaned for up to 6 months (requests for extensions will be considered). Families can access the Loaner Hearing Aid program by completing an application packet. For more information or an application call 1-888-917-HEAR or online at www.healthoregon.org/ehdi.
Private organizations

KEX Kids Fund
Portland and surrounding listening areas for KEX radio station
503-292-4073

Oregon Lions Sight & Hearing Foundation
The following toll-free number is the general contact for the statewide Lions Sight & Hearing Foundation. Ask for the patient services program manager for hearing aids.
1-800-635-4667
1410 S.W. Morrison Street, Suite 760
Portland, OR 97205

Blanche Fischer Foundation
503-819-8205 in Portland
www.bff.org (Web site has a link for direct e-mail)

The HIKE Fund, Inc.
c/o Hike Board Exec. Sec.
10115 Cherryhill Place
Spring Hill, FL 34068
352-688-2579

Hearing Foundation
HEAR NOW Program
6700 Washington Avenue South
Eden Prairie, MN 55344
1-800-648-4327
www.sotheworldmayhear.org

Oregon State Grange
643 Union Street, N.E.
Salem, OR 97301
503-316-0106
503-316-0109 fax

Other private funding may be available through civic organizations in your community (i.e., Eagles, Optimists). Ask your early intervention programs and consultants for assistance.
It is our hope that this resource guide has provided you with the tools you need to answer many of your questions. If there are topics that you would like to investigate further, we encourage you to use our list of organizations and services, books, videotapes and Web sites as a resource. We hope it proves useful.
Resources

Books

A Journey into the Deaf-World
by Harlan Lane, Robert Hoffmeister and Ben Bahan
This book addresses questions such as: What is Deaf culture all about? How are Deaf children raised and educated? And how should they be? What do signed language and Deaf Culture have to offer the Deaf child -- and hearing people? What can we learn from Deaf societies in other lands? How does technology help (and hinder) Deaf people? How do Deaf people integrate into the larger society? The book is rich in examples from the lives of Deaf people and a synthesis of the latest research findings concerning the deaf world.

Auditory-Verbal Therapy for Parents and Professionals
by Warren Estabrooks, M.Ed., 1994
This is an easily understood guidebook for both parents and teachers. It provides the initial information that parents need to start helping their infant or toddler learn to listen with hearing aids or cochlear implants, and to develop beginning vocal and speech skills. Each step-by-step teaching and learning process is spelled out.
Published by A.G. Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, DC 20007-2778
202-337-5220
202-337-5221 (TTY)
www.agbell.org

Caring for Young Children: Signing for Day Care Providers and Sitters
by H. Collins, 1993
This 32-page booklet has the basic signs for feelings, directions, activities, foods, bedtime, discipline and comfort-giving.
Published by Garlic Press
Eugene, Oregon
541-345-0063
www.garlicpress.com
**Choices in Deafness: A Parent’s Guide to Communication Options**  
*Edited by Sue Schwartz, 1996*

This book includes the primary communication approaches used with deaf and hard of hearing children. Each approach is described by an expert, with personal stories by families utilizing the approach. It is clear and easy to understand.

Published by Woodbine House  
6510 Bells Mill Road  
Bethesda, MD, 20817-1636  
1-800-843-7323  
www.woodbinehouse.com

**Deaf in America: Voices from a Culture**  
*by Carol Padden and Tom Humphries*

Through the use of folklore, stories, poetry, jokes, and the authors explain how deaf culture works, what it means to its members, how they define themselves within it, and how they interact with the world outside. This book provides rare insight into this universe of silence and the joy and satisfaction that many deaf people have in their lives.

**Facilitating Hearing and Listening in Young Children: Early Childhood Intervention Series**  
*by Carol Flexer, Ph.D., 1999*

This book provides information about how to create an “auditory world” for children. It contains a wealth of information about all aspects of hearing loss.

Published by A.G. Bell Association for the Deaf  
3417 Volta Place, N.W.  
Washington, DC 20007-2778  
202-337-5220  
202-337-5221  
www.agbell.org

**For Families Guidebook: Helping Your Young Deaf or Hard of Hearing Child Learn to Listen and Communicate**  
*by Valerie Schuyler and Jayne Sowers, 1998*

This is a parent-friendly guidebook and video that covers key topics parents need during the first couple of years with their infant or toddler with hearing loss. It describes the emotions related to the discovery of the hearing loss, first steps for families, how to use hearing aids, cochlear implants, language, learning through play, developing speech and listening skills — a wonderful tool for parents to use to help their baby learn to communicate. Illustrative videotapes are included.

Published by Butte Publications  
Hillsboro, Oregon  
1-866-312-8883  
www.buttepublications.com
My Turn to Learn: A Communication Guide for Parents of Deaf or Hard of Hearing Children
by S. Lane, L. Bell and T. Parson-Tylka, 1997
This is an excellent guidebook for both parents and teachers to use with young children. It describes all of the major techniques used to help young deaf and hard of hearing children learn to listen and to communicate. Each technique is clearly described and illustrated with drawings and several examples. These are the important techniques that make learning more efficient, faster and more fun.
Published by The Elks Family Hearing Resource Centre
B.C. Canada
604-584-2827
604-584-9108 (TTY)
www.bcfamilyhearing.com

Not Deaf Enough: Raising a Child Who is Hard of Hearing with Hugs, Humor and Imagination
by Patricia Candlish, 1996
This sensitive and personal book was written by the parent of a child with mild-to-moderate hearing loss. It details the family’s experience with the diagnosis, support and education of their youngest child, and contains a wealth of information.
Published by A.G. Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, DC 20007-2778
202-337-5220
202-337-5221 (TTY)
www.agbell.org

Sign with Your Baby: How to Communicate with Infants Before They Speak
by Joseph Garcia, 1999
Although the intended population for this book and video is parents and caregivers of typically hearing babies, it is a good starter for families wanting to teach two-way communication through sign language to their deaf or hard of hearing baby. It can be used with babies in the early months of life and is clear, positive and fun.
Published by Northlight Communications
Mukilteo, Washington
1-877-744-6263
www.sign2me.com
The Baby Is Listening
by Warren Estabrooks and Judith Marlowe, 2000
This book (with video) is a compilation of important information parents and professionals need to know about learning through hearing. The accompanying videotape is filled with examples of games and routines to play with babies and young children to develop their listening skills.
Published by A.G. Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, DC 20007-2778
202-337-5220
202-337-5221 (TTY)
www.agbell.org

The Silent Garden: Raising Your Deaf Child
by Paul Ogden, 1996
Ogden, a university professor who has been deaf since birth, has written a powerful book just for parents on the essential needs of their young deaf or hard of hearing child within the family. He addresses common concerns of parents and spells out ways families can support the child’s needs for information, communication and love. Frequently rated as a “favorite” by parents, the first five chapters have also been translated into Spanish.
Distributed by Butte Publications
Hillsboro, Oregon
1-800-312-8883
www.buttepublications.com

When Your Child Is Deaf: A Guide for Parents
by David Luterman, 1991
Written by an audiologist who is also a family counselor, this book is written for families to help them cope with the responsibility of raising a child who has a hearing loss. Parents will find helpful information on the emotions surrounding the identification of the hearing loss, on parenting a deaf or hard of hearing child, on addressing other family concerns, and on technical topics such as hearing aids and education options.
Published by A.G. Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, DC 20007-2778
202-337-5220
202-337-5221 (TTY)
www.agbell.org
DVDs

Signing Time DVD series
This DVD series invites babies and children of all ages to “Come sign with us!” in a fun and memorable way. The series teaches ASL signs you can use everyday.

Videotapes and audiotapes

Dreams SPOKEN Here
This free video (available in English, Spanish and Chinese) explores oral deaf education, focusing on the early years.
Oberkotter Foundation Film Project
1-877-672-5332
www.oraldeafed.org

Families with Deaf Children: Discovering Your Needs and Exploring Your Choices
This videotape contains interviews with parents about their feelings related to the discovery of their child's deafness, choices they have made and their positive views of their children's abilities to succeed. It is a good starting point for family discussion and decision-making.
Boys Town Press
14100 Crawford Street
Boys Town, Nebraska 68010
1-800-282-6657
www.boystownpress.org

Families with Hard of Hearing Children
This video helps parents of children diagnosed with a partial hearing loss know what's ahead. It follows two families in their search for answers and has useful information on working with audiologists and school personnel.
Boys Town Press
1400 Crawford Street
Boys Town, Nebraska 68010
1-800-282-6657
www.boystownpress.org
Sign with Me:
Volume 1—Building Conversations;
Volume 2—Building Concepts;
Volume 3—Positive Parenting
Mary Pat Moeller, M.S., and Brenda Schick, Ph.D.
This series of video/workbook packages can teach the whole family to sign and communicate with the deaf and hard of hearing infant or toddler. Guidelines for effective communication strategies for infants and young children are also included. Each volume contains two videotapes and a workbook. These sets can be ordered in American Sign Language or in Manually Coded English.
Boys Town Press
14100 Crawford Street
Boys Town, Nebraska 68010
1-800-282-6657
www.boystownpress.org

Sound Hearing: Or...Hearing What You Miss
This is a CD and booklet that illustrates for normally hearing people what speech sounds like to individuals with hearing loss.
Published by Garlic Press
Eugene, Oregon
541-345-0063
www.garlicpress.com
Web sites

www.agbell.org
Alexander Graham Bell Association for the Deaf and Hard of Hearing
This Web site will lead you to a wealth of information for parents on a large number of topics. There are numerous publications available, a national conference and many services.

www.babyhearing.org
Boys Town National Research Hospital and National Institute on Deafness and Other Communication Disorders
This site is filled with wonderful information and is designed especially for parents of infants identified with hearing loss.

www.deafchildren.org
American Society for Deaf Children (ASCD)
This is the Web site for a national organization run by and for parents of children with hearing loss. The organization has a toll-free hotline for parents, a national conference for families and many other services.

www.handsandvoices.org
Hands & Voices
This is a dynamic organization for families of children with hearing loss. It is run by parents for parents. The Web site offers much helpful information.

www.cuedspeech.org
Cued Speech is a visual communication system consisting of mouth movements of speech combined with specific handshapes. This association promotes and supports the effective use of Cued Speech for communication, language acquisition and literacy.

www.listen-up.org
This Web site specializes in information for the deaf and hard of hearing.
National advocacy groups and associations: Who they are and what they offer

Alexander Graham Bell Association for the Deaf and Hard of Hearing (A.G. Bell)
3417 Volta Place, N.W.
Washington, DC 20007-2778
202-337-5220 (voice)
202-337-5221 (TTY)
202-337-8314 (fax)
E-mail: info@agbell.org
www.agbell.org
The association emphasizes the use of speechreading, residual hearing and processing spoken/written language.

American Society for Deaf Children (ASDC)
1-800-942-2732 (voice/TTY)
www.deafchildren.org

American Speech-Language Hearing Association (ASHA)
1-800-638-8255
www.asha.org
ASHA is a national organization whose mission is to ensure that all people with speech/language/hearing disorders have access to quality services to help them communicate effectively.

Beginnings For Parents of Children Who Are Deaf or Hard of Hearing
P.O. Box 17646
Raleigh NC 27619
919-850-2746 (voice/TTY)
www.ncbegin.org
Beginnings’ mission is to provide emotional, informational and technical support to parents of children who are deaf or hard of hearing, deaf parents with hearing children, and professionals serving those families.

Cued Speech Association Affiliate and Resource/Training Center
1-800-459-3529 V/TTY
www.cuedspeech.org
Cued Speech workshops are offered regularly throughout the western region. Center-based intervention is available to local families. The National Cued Speech Association offers family vacation camps every summer.
John Tracy Clinic
806 W. Adams Boulevard
Los Angeles, CA  90007
1-800-522-4582 (voice/TTY)
213-748-5481 (voice)
www.johntracyclinic.org
Provides free services worldwide to families of preschool children with hearing loss with emphasis on furnishing a spoken language environment for children.

National Association for the Education of Young Children (NAEYC)
Washington, DC
1-800-424-2460
www.naeyc.org
The National Association for the Education of Young Children is an organization of early childhood educators who are dedicated to improving the quality of programs for children birth through third grade.

National Association of the Deaf (NAD)
Silver Spring, MD
301-587-1788 (voice)
301-587-1789 (TTY)
http://www.nad.org
The NAD's mission is to promote, protect and preserve the rights and quality of life of deaf and hard of hearing individuals.

Oregon organizations and services

CaCOON
1-800-452-3563 (Portland)
1-800-637-0700 (Eugene)
CaCOON is a program for families who have children with special health needs. CaCOON provides services for children birth to age 21 years who have health conditions that may require assistance for medical, educational, vocational and social needs.

Family Voices
503-494-7657
www.familyvoices.org
Family Voices’ national and state organizations actively pursue the mission of improving health care for children and youth with special health care needs through their projects and activities. There are both national and local state projects and activities.
Oregon School for the Deaf
1-800-853-1224
503-378-3825 V/TTY
VP#: 1-866-588-2204
www.osd.k12.or.us
Oregon School for the Deaf is a public school with no cost to families. There are day and residential options, serving Deaf and Hard of Hearing students ages 5-21. We are located in Salem and offer a comprehensive standardized education. OSD provides direct instruction from teacher to student in smaller sized classes, in American Sign Language, to make the educational experience visually-based and completely accessible.

Hands & Voices of Oregon
503-802-5301
info@handsandvoices.org
www.handsandvoices.org
Hands & Voices of Oregon (HVO) is a non-profit group that offers support to all families with children who are deaf/hard of hearing regardless of communication choice. We model parent/professional collaboration to enable deaf/hard-of-hearing children to reach their highest potential. We are a resource for parents and professionals offering information and support. Please let us know how we can serve you.
As a family member of a child who is deaf or hard of hearing, you have probably been introduced to a lot of terminology that is new or unfamiliar. This section of the resource guide aims to identify and define common terms.
Glossary

**auditory brainstem response (ABR)**
A non-invasive test that measures auditory responses at the level of the brainstem in response to auditory stimuli. This test can indicate whether or not sound is being detected, even in an infant. This test may also be referred to as BAER or BSER. AABR refers to automated ABR screening devices.

**acoustics**
Pertaining to sound, the sense of hearing or the science of sound. Often used to refer to the quality of the sound environment.

**acquired hearing loss**
A hearing loss that is not present at birth. Sometimes referred to as adventitious loss.

**advocacy**
The act of ensuring that a child receives appropriate services and intervention. Parents advocate for their children by actively participating in the decision-making process to determine individualized goals.

**American Sign Language (ASL)**
A visual-gestural-spatial language in which the placement, movement, and expression of the hands and body are part of the language. It has a complete grammar system different from English. ASL is considered by the Deaf Community to be the natural language of people who are deaf.

**Americans with Disabilities Act (ADA)**
A federal law that bans discrimination based on disability in the areas of public accommodation, state and local government services, employment, transportation and telecommunications. All public schools must comply with the ADA.

**assistive alerting and communication devices**
Term used to describe equipment or systems that are available to help people who are deaf or hard of hearing increase, maintain or improve communication (i.e., TTY, assistive listening devices). They also allow people who are deaf or hard of hearing to function independently within their environment and society (i.e., vibrating alarm clocks and pagers, flashing-light smoke detectors).
audiologist
A licensed health care professional who holds at least a master’s degree in audiology and is a specialist in evaluating and diagnosing hearing and balance problems. Audiologists provide rehabilitative services, such as hearing aid fitting and follow-up services. Audiologists also can provide aural habilitation to promote optimal use of a child or adult’s residual hearing (remaining hearing). A pediatric audiologist specializes in the assessment of infants and fitting of hearing aids for infants and children.

aural habilitation
Therapy designed to help a person who has a hearing loss make more effective use of his/her remaining (or residual) hearing. This therapy may be done by licensed audiologists, speech-language pathologists, or a certified teacher of the deaf or hard of hearing.

auditory neuropathy (auditory dys-synchrony)
An abnormality in the auditory system caused by improper firing of auditory nerve cells (dys-synchrony). This affects the ability to understand speech signals clearly. A hearing loss may be present or absent.

babbling
Term used to describe an infant’s first use of speech sounds.

bilingual/bicultural (bi-bi)
Being fluent in two languages and comfortable in two cultures. For a person who is deaf, this terminology refers to a person who is fluent in both American Sign Language and English and comfortable in both the Deaf Culture and the Hearing Culture.

closed caption
A process in which the text version of what is being said on a TV or video is either encoded in the video or encoded in real time (for news broadcasts, etc.) and printed at the bottom of the television screen, when the “caption” option is activated. By law, TVs that are 13 inches or larger and manufactured after 1993, must have closed caption capability.
**cochlear implant**
An electronic device that stimulates nerve endings in the inner ear (cochlea) in order to receive and process sounds, including speech. A microphone, a speech processor (miniature computer that changes sound waves into special coded signals) and a transmitter (coil that sends coded signals to internal parts) are worn externally. A small receiver (changes coded signals into electrical pulses) and an electrode array (carries decoded electrical impulses to the hearing nerve) are surgically implanted within the head. The electrode array is surgically placed within the cochlea. The small receiver is implanted in the head right behind the ear.

**congenital hearing loss**
Hearing loss present at birth or associated with the birth process, or that develops in the first few days of life.

**deaf**
A hearing loss that is so severe that the child is unable to process linguistic information through hearing alone. (See also “Deaf Culture.”)

**Deaf Culture**
A culture is generally defined as a system of values, beliefs and standards that guides a people’s thoughts, feelings and behaviors. Culture is learned, shared and constantly changing. Some of the central components of Deaf Culture include the use of American Sign Language, healthy social interaction with other individuals who are Deaf and involvement in Deaf organizations.

**deafblindness**
Developmentally and educationally significant combined loss of vision and hearing (See also Page 63.)

**decibel (dB)**
The unit of measurement of sound. The higher the number value of the decibel level presented, the louder the sound.

**earmold**
Small plastic piece that fits into the ear. The earmold helps hold the hearing aid in place and is custom-made for the child’s ear.

**early intervention (EI)**
This term most commonly refers to federally funded services for children from birth through 3 years of age. Children who have a disability, including hearing loss, may be eligible for early intervention (EI) services, including home visits, family training, counseling, special instruction and therapy. Some communities also have private early intervention programs.
Early Childhood Special Education (ECSE)
This term most commonly refers to federally mandated, state-provided services for children, aged 3 through 5 years. Children who have a disability or developmental delay, including hearing loss, may be eligible for ECSE services including home visits, family training, counseling, special instruction and therapy. Sometimes these services are provided through a group setting such as a preschool placement.

eligibility
A child must be determined eligible for Early Intervention or Early Childhood Special Education services based on specific disabilities and/or levels of functioning in different areas of development (i.e., speech, motor, hearing). There are both federal and state guidelines that determine eligibility requirements.

feedback
The whistling sound made when amplified sound goes back into the microphone. In a hearing aid, feedback can occur when an earmold does not fit well and the amplified sound goes back into the hearing-aid microphone. There are additional causes for feedback, and persistent feedback should be discussed with your parent advisor or audiologist.

fingerspelling
Using a visual, manual form of the English alphabet to spell out words. Fingerspelling is done using fingers and handshapes for the different letters of the alphabet.

frequency modulation (FM) system
An assistive listening device that is designed to keep the speaker’s voice audible in the presence of background noise. One type of FM system consists of a microphone/transmitter (worn by the speaker) and a receiver (worn by the child). The signal is transmitted from the speaker to the child using an FM signal (like a radio).

gain
The amount of amplification provided by the hearing aid. For example, a child with unaided hearing at 70 dBHL who, when amplified hears at 30 dBHL, is experiencing a gain of 40 dBHL from the hearing aid.

genetic counseling
Can help families determine if the cause of the child’s hearing loss is inherited. (See also “genetic hearing loss”.)
**genetic hearing loss**
Hearing loss that is inherited from one or both parents. The hearing loss can be part of a syndrome (meaning the baby has other health/developmental concerns) or non-syndromic (meaning that the baby has no other health/developmental concerns).

**hard of hearing**
Term used to describe a person who has a hearing loss, as in, “My friend Joe is hard of hearing.” This term is most often used for children with mild, moderate or severe hearing losses.

**hearing age/listening age**
Hearing age (or listening age) is measured from the time the child begins wearing hearing aids or a cochlear implant consistently. For example, after a child has worn a hearing aid for one year, his listening age will be 1.

**hearing aid**
An electronic device that amplifies sound and directs it into the ear. A hearing aid consists of a microphone, an amplifier (makes the signal louder) and a receiver (speaker). Sound usually enters the ear through an earmold worn in the ear.

**Individuals with Disabilities Education Act (IDEA)**
A federal law that establishes policies for comprehensive services for infants and children with disabilities from birth through 21 years of age. Part C of IDEA outlines programs for infants and toddlers birth to 3 years. Part B of IDEA covers children 3 years to 21 years of age.

**inclusion**
Refers to the process of providing services for infants and children with disabilities in settings with children who are developing typically. (See also “least restrictive environment” and “natural environment.”)

**individual education plan (IEP)**
The IEP is a document that outlines the special education and related services for children with disabilities who are aged 5 to 21 years. The plan is developed by a team, which includes parents, administrators, teachers and special services personnel specific to each child’s needs. The plan includes educational goals and objectives, modifications to the regular curriculum, daily schedule, support services, educational setting and other information as required by law.
**Individual Family Service Plan (IFSP)**
Plan that outlines the outcomes, strategies and services for children with disabilities who are age birth to 5 years. A team, which includes the parents and professionals who are specific to each child’s needs, develops the plan. The plan also includes location, amount of time, the people who will provide the services and the criteria that will be used to determine if the outcomes are achieved.

**Interpreter**
A person who facilitates communication between people who do not use the same language, by translating from one language to another.

**Language**
A shared code, used by a group of people that determines what words mean and the rules for how words are combined and used. Language can be spoken, signed or written. “Receptive language” refers to our ability to understand the information communicated by others. “Expressive language” refers to our ability to share information with others.

**Manually Coded English (MCE)**
This method uses a visual (signed) form of the English language. English is visually represented (coded) through manual signs and fingerspelling. There are a number of systems for Manually Coded English, and each has its own rules and variations. Examples of Manually Coded English include Signing Exact English (SEEII) and total communication.

**Natural environment**
Defined by the Individuals with Disabilities Education Act (IDEA) as, “Settings that are natural or normal for the child’s age peers who have no disabilities. To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate.”

**Otitis media**
The medical term for a middle-ear infection. Children who have recurring otitis media may experience fluctuating hearing loss and may be at risk for speech and language delays. Fluid may be present with or without infection and may cause temporary hearing loss, which can evolve into permanent hearing loss.

**Otolaryngologist**
A physician who specializes in medical problems of the ear, nose and throat. Sometimes referred to as an ENT (ear-nose-throat).

**Otolologist**
A physician who specializes in medical problems of the ear.
**postlingual hearing loss**
Hearing loss that occurs following the acquisition of speech and language.

**prelingual hearing loss**
Hearing loss that is present at birth or occurred prior to development of speech and language.

**real ear measurement**
A test that measures how effectively sound is amplified by the hearing aid for an individual child. During this test a small device (probe microphone) is placed in the ear canal while the hearing aid and earmold are being worn. The probe microphone measures how much sound the hearing aid is sending into the ear. A computer analyzes the results.

**Relay Service/Relay Network**
Relay Service/Relay Network is a service that involves an operator “relaying” conversation between a TTY/TDD user (generally a person with a hearing loss and/or speech disorder) and a hearing/speaking individual using an ordinary, non-adapted phone.

**sign babble**
Infants who are hearing put sounds together (babble) before they talk. Infants who are exposed to sign language put handshapes together (sign babble) before they sign.

**simultaneous communication**
A communication system in which spoken English and its manually coded (signed) version are used at the same time. The term “total communication” may at times be used to describe simultaneous communication.

**speech**
Generally used to mean the expression of language through the spoken word. The term “speech sounds” refers to the individual consonant and vowel sounds that make up a language such as English.

**speech awareness threshold (SAT)**
This is the faintest level at which an individual detects speech 50 percent of the time.

**speech banana (speech zone) on the audiogram**
The area on an audiogram where most conversational sounds (vowels and consonants) of spoken language occur. This area is called the “speech banana,” because of the shape this area forms on the graph.
**speech-language pathologist**
A speech-language pathologist is a licensed health care professional who specializes in the evaluation and treatment of speech, language and voice disorders. This may include treatment of children whose speech or language problems are the result of a hearing loss.

**speech reception threshold (SRT)**
This is the faintest level at which an individual can correctly identify a list of two syllable words (i.e., hotdog, ice cream) 50 percent of the time.

**speechreading (lipreading)**
The use of lip and mouth movements, facial expressions, body language and context to help understand speech.

**telecommunication devices (TTY/TDD)**
TTY=Teletypewriter. TDD= Telecommunication Device for the Deaf. These are electronic devices that allow the deaf and hard of hearing to communicate using a text telephone system.

**total communication**
In this communication system, the word “total” refers to the use of any form of communication that will enable the child to learn language. Manually Coded English is one part of the system, which also includes speech, listening through amplification, print and speechreading. The term “total communication” may at times be used to describe simultaneous communication.

**tympanometry**
This test is used to measure the mobility of the eardrum. It is not a test of hearing, but provides information on how well the ear canal, eardrum, Eustachian tube and middle-ear bones are working. The results of tympanometry are printed on a graph called a tympanogram.
As a family member of a child who is deaf or hard of hearing, you have probably been introduced to a lot of terminology that is new or unfamiliar. This section of the resource guide aims to identify and define common abbreviations and acronyms.
### Abbreviations and Acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAA</td>
<td>American Academy of Audiology</td>
</tr>
<tr>
<td>AABR</td>
<td>automated auditory brainstem response</td>
</tr>
<tr>
<td>AAP</td>
<td>American Academy of Pediatrics</td>
</tr>
<tr>
<td>ABR</td>
<td>auditory brainstem response</td>
</tr>
<tr>
<td>ASL</td>
<td>American Sign Language</td>
</tr>
<tr>
<td>ALD</td>
<td>assistive listening device</td>
</tr>
<tr>
<td>AO</td>
<td>auditory-oral</td>
</tr>
<tr>
<td>ASHA</td>
<td>American Speech-Language Hearing Association</td>
</tr>
<tr>
<td>AV</td>
<td>auditory-verbal</td>
</tr>
<tr>
<td>BAER</td>
<td>brainstem auditory evoked response</td>
</tr>
<tr>
<td>BI-Bi</td>
<td>bilingual and bicultural</td>
</tr>
<tr>
<td>BOA</td>
<td>behavioral observation audiometry</td>
</tr>
<tr>
<td>BSER</td>
<td>brainstem evoked response</td>
</tr>
<tr>
<td>BTE</td>
<td>behind the ear</td>
</tr>
<tr>
<td>CaCOON</td>
<td>nursing care coordination</td>
</tr>
<tr>
<td>CDRC</td>
<td>Child Development and Rehabilitation Center (at Oregon Health &amp; Science University)</td>
</tr>
<tr>
<td>CI</td>
<td>cochlear implant</td>
</tr>
<tr>
<td>CIC</td>
<td>completely in the canal</td>
</tr>
<tr>
<td>dB</td>
<td>decibel (loudness)</td>
</tr>
<tr>
<td>DMAP</td>
<td>Division of Medical Assistance Programs</td>
</tr>
<tr>
<td>DPOAE</td>
<td>distortion product otoacoustic emission</td>
</tr>
<tr>
<td>ECSE</td>
<td>Early Childhood Special Education Program</td>
</tr>
<tr>
<td>EHDI</td>
<td>Early Hearing Detection and Intervention Program</td>
</tr>
<tr>
<td>EI</td>
<td>early intervention</td>
</tr>
<tr>
<td>ENT</td>
<td>ear, nose and throat</td>
</tr>
<tr>
<td>ESD</td>
<td>Education Service District</td>
</tr>
<tr>
<td>Hz</td>
<td>hertz (cycles per second, pitch)</td>
</tr>
<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
</tr>
<tr>
<td>IEP</td>
<td>individual education plan</td>
</tr>
<tr>
<td>IFSP</td>
<td>Individual Family Service Plan</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Definition</td>
</tr>
<tr>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>ITC</td>
<td>in the canal</td>
</tr>
<tr>
<td>ITE</td>
<td>in the ear</td>
</tr>
<tr>
<td>MCE</td>
<td>Manually Coded English</td>
</tr>
<tr>
<td>OAE</td>
<td>otoacoustic emission</td>
</tr>
<tr>
<td>OHP</td>
<td>Oregon Health Plan</td>
</tr>
<tr>
<td>OSD</td>
<td>Oregon School for the Deaf</td>
</tr>
<tr>
<td>POAD</td>
<td>Post-Otitis Auditory Disorder</td>
</tr>
<tr>
<td>PTA</td>
<td>pure tone average</td>
</tr>
<tr>
<td>SAT</td>
<td>speech awareness threshold</td>
</tr>
<tr>
<td>SEE</td>
<td>Signed Exact English</td>
</tr>
<tr>
<td>SHHH</td>
<td>Self Help for Hard of Hearing People, Inc.</td>
</tr>
<tr>
<td>Sim-Com</td>
<td>simultaneous communication</td>
</tr>
<tr>
<td>SRT</td>
<td>speech reception threshold</td>
</tr>
<tr>
<td>TC</td>
<td>total communication</td>
</tr>
<tr>
<td>TEOAE</td>
<td>transient evoked otoacoustic emission</td>
</tr>
<tr>
<td>VRA</td>
<td>visual reinforcement audiometry</td>
</tr>
</tbody>
</table>