When a child has been diagnosed with hearing loss, parents may deal with many emotions: grief, anger, shock and maybe even denial. Focusing on practical matters such as medical insurance can be tough. But it’s necessary.

A 2003 study by the Centers for Disease Control and Prevention estimated that hearing loss would cost an affected person an average of $383,000 over his or her lifetime (Honeycutt et al., 2003, 2006). As parents move through the emotions that diagnosis brings and read those types of statistics, the next feeling might be one of panic: “How will I pay for treatment?” This guide to insurance and hearing loss will make navigating a course to listening and spoken language a little easier for your child.

Understand Your Insurance

The first thing you should do is check your insurance policy for any hearing benefits or specific exclusions. This will help you avoid unexpected bills because you were not aware of network limitations or that a certain procedure was not covered.

“Your insurance policy may be very dull reading, but it is worthwhile,” says Robert C. Fifer, Ph.D., director of audiology and speech-language pathology at the University of Miami Mailman Center for Child Development. “Make sure you have a copy of your policy,” he adds. “And if you don’t have one, call the company to get a copy. It represents the contract between your family and the insurance company. You need to know what to expect and what not to expect. And that’s for any child with special needs.”

Julibeth Jones, Au.D., CCC-A, FAAA, agrees. She owns her own practice, Jones Institute for Rehabilitative Audiology in Vestavia Hills, Ala., contracts for Huntsville Hospital for Women & Children in Huntsville, Ala., and is well-versed in insurance issues in both settings. “You have to be prepared to chase down paperwork,” she says. “You’d like to think you could focus on treatment concerns, but the reality is you’re going to have to deal with bureaucratic details.”

Testing, Testing

When researching specific coverage, ask your audiologist or speech-language pathologist exactly what tests or therapy will be conducted. Get the diagnosis codes and procedure codes that will be used in the billing process. Many insurers need these medical codes to determine whether a service is covered by a particular policy. Jones explains that, as part of the Health Insurance Portability and Accountability Act (HIPAA) law, diagnosis and procedure codes are a standardized way of letting insurance companies know what kind of testing is done and why. It’s a universal language for the medical field.

Fifer adds, “When the appointment is coming up, we try to predict which procedure code and diagnosis code will be used. We do this to make sure that the audiologist is in-network and that the procedures are covered by the insurance company. If the answer is no to either, we will call the family and ask whether they want to pay for the service personally or find another audiologist who is covered under their policy.”

Learning more about your policy and asking questions early can save you money and give you peace of mind down the road.
On the Case

If you’ve read your policy and still do not understand all of your benefits and exclusions, you may want to contact you or your spouse’s human resources department, or the company through which you obtained insurance. “It’s your human resources department’s responsibility to help advocate on your behalf,” Jones explains. “They are the liaison between you and the insurance company.” Also check to find out if your insurer offers a case manager. A case manager can help you understand what is covered under your policy, and many can help you coordinate with providers.

“Case management is meant to be supportive,” says Christine Crowe, director of specialty case management at Cigna, a global health service company. “We help families understand how their benefits apply, and we make sure they are connected with good community resources.” Crowe says it’s important to share your personal information and any medical history with your case manager. “This helps build a foundation of support and allows us to reach out to physicians if there are questions,” she explains.

In addition to providing the diagnosis and procedure codes, you may want to ask your human resources liaison or insurance case manager some of the following questions. If they do not immediately know the answer, they should be able to find someone who does:

- Is my provider in-network for your plan?
- Are there any pre-certification or pre-authorization requirements?
- What is my deductible?
- What will my co-pays be?
- Can you help estimate my out-of-pocket expenses?
- Do I have a maximum allowable clause? And what does that mean?
- Does my plan cover diagnostic testing?
- Do I have coverage for auditory brainstem response (ABR)?
- Do I have coverage for tympanometry, otoacoustic emissions (OAE), or visual reinforcement audiometry (VRA)?
- Does it cover hearing aid fitting?
- Does it cover hearing aids and equipment testing?
- Do I have limits on the number of visits?
- If I have visit limits, do they include speech and audiology together? Or separately?
- Does my insurance cover cochlear implant services, including the implant device, surgery and device programming?
- Is a cochlear implant or bone-conduction implant considered a prosthetic? Is it covered that way?
- Does it cover follow-up cochlear implant programming and auditory-verbal therapy and/or speech-language pathology services?
- Does it cover cochlear implant accessories and related equipment?

Document and Organize Everything

Because you will be consulting your policy information often, you may want to consider creating an organization system for all of your documentation. For easy access, you should have all of your child’s records, your medical insurance policy and any notes you have on each item in one place. If you prefer hard copies, invest in a three-ring binder and keep all your paperwork in it. If you are more digitally inclined, scan your policy, records and any notes to your computer and begin an electronic document file.

Whenever you speak with someone about your insurance policy or your child’s treatment and therapy, take copious notes. Be sure to include the date and time, whom you spoke with, and what he or she said. Documenting everything and having it all in one place will make it easier to provide a reference when needed.

Early Intervention

In addition to insurance, there may be other options in obtaining coverage for services. The Individuals with Disabilities Education Act (IDEA), passed by Congress in 1975 and revised several times since, ensures that children with disabilities have the opportunity to receive a free, appropriate public education like other children.

IDEA is divided into four parts, and Part C deals with children from birth to age 3. Part C mandates early intervention services for infants and toddlers who have a delay or disability in one or more of the following developmental categories: physical (reaching, rolling, crawling, walking), cognitive (thinking, learning, solving problems), communication (talking, listening,
understanding), social/emotional (playing, feeling secure, happy), and self-help (eating, dressing).

According to the National Dissemination Center for Children with Disabilities (NICHCY, 2011), “early intervention services are specialized health, educational and therapeutic services designed to meet the needs of infants and toddlers [from birth to age 3] who have a developmental delay or disability and their families.” Some states also include children who are at-risk for developing delays if they do not receive intervention services.

Although early intervention services are part of a federal law, states are given discretion in establishing criteria, so eligibility for Part C varies from state to state. “In general, though, children with hearing loss qualify for early intervention services,” says Janet DesGeorges, national outreach director of Hands & Voices, an advocacy organization for children who are deaf and hard of hearing. Indeed, a web search of early intervention programs across the country confirms that most children with hearing loss do qualify for services.

DesGeorges says early intervention services are meant to not only provide services for children, but also provide support for families. “I think sometimes people think of early intervention as just the actual professional services children receive. But I think of it as encompassing family support, information and everything a family needs to make sure their child thrives.”

The NICHCY website also lists the possible intervention services your child might receive (NICHCY, 2011).

**Some Caveats**

Another thing to keep in mind, Fifer explains, is that early intervention, by federal law, is the payor of last resort. “If a child has Medicaid, Medicaid must be billed. Any cost [for approved services] left over after Medicaid has been billed [will be covered by] Part C,” he says. “If a family has insurance, parents do have the right to block access to it in order to avoid depleting their annual or lifetime cap on coverage. In this case, Part C becomes the payor of first resort.”

Due to budget constraints in many states, Part C officials are taking a close look at expenditures. “For the sake of accountability, many states require a denial from insurance companies before they will cover services,” Fifer says. “Of course, this varies from state to state, but the motivation is to make Part C completely accountable for every dollar spent.”

**Your Child’s Needs**

Although your child may receive many services at no cost, if you feel those services are not adequate for your child, you have the right to request another provider or service. DesGeorges says parents must ask themselves several questions: “Are the services being offered the services that meet the unique needs of my child?” or “Do the providers have expertise and knowledge of issues surrounding children who are deaf and hard of hearing and our preferred communication modality?” If the services and professionals provided are not working for your child, you have the right to request services that will.

Although services vary greatly from state to state, Part C is a resource every family should make use of. “It’s free, and you don’t have to worry about insurance,” explains Annette Forseter, an educational audiologist and the first point of contact for families signing up for Part C in the D.C. area. “It’s a good way for families to access services, many of which are provided in their own communities.”

**Medicaid, Other Programs**

Even if you can’t afford health insurance, medical care may be available to you through Medicaid or the federally funded Children’s Health Insurance Program (CHIP; CMS, 2011).

Medicaid, a federal program, is for individuals and families of low-income who meet certain eligibility requirements. The program is administered by individual states, so criteria and eligibility will vary. According to the Centers for Medicare & Medicaid Services, which administers the program, Medicaid covers diagnosis and treatment for hearing loss, including hearing aids (CMS, 2005). Indeed, Fifer says, “In some ways, Medicaid offers better benefits than private insurers. Medicaid in most states will pay for hearing aids for most little ones. However, the program will typically cover only one cochlear implant, if they cover cochlear implants at all. Again, it varies tremendously from state to state.”
Additionally, you might qualify for CHIP, which is also federally funded and state administered. This program is a complement to Medicaid and covers many of the same services. It is for low-income families who don’t qualify for Medicaid and who can’t afford other health insurance (Kaiser, 2009). Like Medicaid, states are allowed to set their own eligibility requirements. Jones notes that many CHIP programs cover hearing aids and offer a sliding fee scale as a way to further help families.

If you think your child might qualify for Medicaid or CHIP coverage, contact your state Medicaid or CHIP office. Visit www.benefits.gov/benefits/browse-by-state and click on your state to find information on what programs your state offers and the contact information for each.

**Intervention Timeline**

In addition to considering the specifics of medical insurance coverage, parents should also be mindful of the timeline for diagnosis, treatment and development of listening and spoken language. The Joint Committee on Infant Hearing, made up of representatives from pediatrics, audiology, speech-language pathology and otolaryngology, including the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell), states that all infants should be screened by 1 month of age and if they do not pass, that diagnostic testing be done by 3 months of age (JCIH, 2007). All babies with confirmed hearing loss should begin intervention and receive appropriate amplification (if listening and spoken language is the communication choice) by 6 months of age.

Early identification and treatment of a hearing loss offers the best chance for a child to learn to hear and talk. Birth to age 3 is a critical time in a child’s language development when auditory pathways to the brain are being created. If they go unused, those pathways will be allocated for other processes (Gilley et al., 2009).

“In the absence of sound, the brain reorganizes itself to receive input from other senses, primarily vision,” says Carol Flexer, Ph.D., LSLS Cert. AVT, an auditory development expert and professor at the University of Akron. “When this happens, you lose auditory capacity.” Flexer explains that when intervention begins in the first six months of life, it helps children master developmental skills as close as possible to the normal biological timeline. Also, she adds, “The earlier children are identified and treated, the fewer services they’ll need throughout their life.”

If choosing a listening and spoken language outcome, the first step will be to provide your child with amplification in order to access sound. And when it is time to add amplification and speech-language services, all the work that went into understanding your insurance policy and early intervention processes will begin to pay off because you already know what your policy covers and how to access services.

**Getting Aided**

Several states now mandate insurance coverage for hearing aids for children (see a list of states). In addition, some states, including Arizona, Colorado, Delaware, Florida, Indiana, Kansas, Maryland, Massachusetts, Missouri, Nebraska, New York, North Carolina, Ohio, Oklahoma, Texas, Virginia, and Wisconsin, offer hearing aid loaner banks so children can get access to sound while parents are working through insurance options.

Hear Now, a national nonprofit organization, has a loaner program, as does Miracle Ear’s Children’s Foundation. In addition, hearing aid manufacturer Oticon offers a national loaner bank, accessible through hearing practitioners. The Hearing Charities of America’s website also offers an extensive list of resources for accessing hearing aids.

**Cochlear Implants, Bone-Conduction Implants**

“If your child is not showing adequate progress [with hearing aids], it’s time to start thinking about a cochlear implant, which opens a whole new chapter of insurance coverage,” says Fifer.

Depending on the type and severity of the hearing loss, cochlear implants or bone-conduction implants (BAHAs) may be an option. Food and Drug Administration (FDA) guidelines support cochlear implantation at 12 months of age and older, when appropriate. However, families should begin investigating cochlear implants long before a potential surgery. This means necessary evaluations, medical discussions and insurance authorizations would be in place if you decide to take that route, allowing implantation as close as possible to age 12 months.
If your insurance covers cochlear implants or BAHAs, it will most likely require pre-authorization and a letter of medical necessity from your child’s surgeon and/or audiologist. In the letter of medical necessity, the surgeon and/or audiologist details the medical reasons your child is a good candidate for an implant. Jones explains that pre-authorization asks the insurance company to look at the policy and confirm that the treatment proposed by your child’s team is going to be covered. “It’s so you can have some confidence that you’re going to have coverage for a very expensive surgery,” she says. “In the best circumstance, your insurance company’s authorization letter will tell you what’s covered, at what rate, and give you a feel for the cost.”

Jones says parents must ask their insurance company what criteria it uses to establish whether a procedure is medically necessary, and go through the criteria point by point in the letter of medical necessity to be sure they have met each guideline when seeking coverage for a cochlear implant or BAHA.

Even if your policy excludes hearing aids, it may still cover cochlear implants and BAHAs. “Both cochlear implants and BAHAs are generally considered as prosthetics, not hearing aids,” Jones says. “They are likely covered under the durable medical equipment part of the policy.” As always, check your policy for specific coverage.

Learning to Hear and Speak

In order for your child to benefit from hearing aids and/or cochlear implants, it is best to engage the services of a professional who is trained and experienced in the development of listening and spoken language for infants and young children with hearing loss. These individuals come from the field of audiology, speech-language pathology or education of the deaf, some of whom hold the credential as a Listening and Spoken Language Specialist (LSLS). Check with your insurance provider to determine whether this intervention is covered. It may fall under speech and language therapy, or it could fall within a section of your policy for learning how to use a prosthetic device. Also, many policies require physician orders for therapy and audiology services, so be sure to keep your child’s pediatrician informed about intervention.

As Fifer notes, many insurance companies may be reluctant to cover treatment for disorders that are congenital rather than acquired. “A rule of thumb where insurance will provide more benefits is if you had an ability and lost it through an illness or injury,” Fifer says. “Insurance will provide benefits to restore that ability, but they don’t really like to cover services to help you acquire something that you didn’t have. … Many view therapy as in perpetuity for a child with hearing loss, and insurance companies like to be able to fix things with a finite set of therapy sessions.”

This is why it is crucial to understand your coverage before you begin therapy to avoid expensive surprises down the road. If a specific treatment or therapy is excluded, speak with your employer about adding it to your company’s health policy. The American Speech-Language-Hearing Association (ASHA)’s website features resources on how employers can add these benefits to their policies. ASHA also offers a helpful document called “Making Sense of Your Insurance Plan” that explains the language and what to look for when studying your policy.

After Care Coverage

It’s not enough to have hearing aids or cochlear implants and appropriate therapy, you also must plan for after-care costs, such as programming the device, repairs and maintenance, and service contracts and warranties for the device. “Just because the wholesale cost of an implant is upward of $30,000 doesn’t mean follow-up care will be covered,” Fifer says. “You have to seek authorization for after care after surgery as well. Another issue is whether insurance will cover one implant or two, if it will cover one first and a second one later, or both at the same time. And, of course, all the variables differ by each respective company.”

Once your child has a hearing aid or cochlear implant, the device will have to be programmed to meet your child’s specific needs (ASHA, 2011; Boswell, 2011). The audiologist will connect the hearing aid or cochlear implant processor to a computer and program the device to the most appropriate settings for your child. These sessions will continue at varying intervals as your child becomes used to using his or her hearing device(s).

In addition, your child’s equipment will eventually need repairs and maintenance, you will have to buy batteries and warranties, and you’ll be responsible for associated costs that often aren’t taken into consideration at the start of intervention.
“As a parent advocate, while insurance may be the last thing on your mind, it comes to the forefront very quickly,” says DesGeorges. It is important to budget for expenses such as a warranty for the implant device or insurance to cover loss and damage of the processor.

Adds Fifer, “Many times insurance will cover reprogramming of a cochlear implant, but will not cover repair and maintenance of hearing aids. That cost is typically borne by the family. And speech-language therapy is an ongoing proposition that insurance tends not to cover long term.”

Families may be left with the balance. Check to see if your company offers a benefit, sometimes called a flexible spending account, that allows you to set aside pre-tax money to help cover the costs of batteries, repairs and maintenance, ear molds, FM systems and other equipment parts. Some of these accounts are for medical expenses only, while others cover dependent care (IRS, 2010). Check with your human resources department to find out which kind your company offers and whether it can be used for these hearing expenses. Warranties and loss and damage insurance for cochlear implants are not an eligible expense for most flexible spending accounts.

**Constant Contact**

Once the paperwork seeking coverage has been submitted, maintain contact with your case manager or other insurance company representative. Request a time frame for when they will respond.”Set aside time to follow up,” Jones says. “Make sure paperwork is getting to the right place at the right time. Ask when you can expect a response. Follow up, follow up, follow up. Advocate for your child to get what he or she needs in a timely matter. There are probably going to be insurance roadblocks and unexpected answers that will pile on to the emotional upheaval you’re already feeling,” she adds, so Jones suggests giving yourself some downtime as well.

**Step by Step**

Understandably, the amount of information being thrown at you can be overwhelming. But it’s important to learn as much as possible about your insurance benefits and exclusions as well as other programs available for your child. Knowledge is power and you’re going to need both in the days ahead. There are many parents who have been where you are. Just take it step by step, question by question, day by day. To paraphrase an ancient Chinese proverb, “A journey of a thousand miles begins with just one step.” And with that first step your child will be on the way to acquiring listening and spoken language.

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