

Rhode Island Resource Guide for Families of Children who are Deaf or Hard of Hearing

OFFICE OF FAMILIES RAISING CHILDREN WITH SPECIAL HEALTH CARE NEEDS 2014 :: RHODE ISLAND DEPARTMENT OF HEALTH



The purpose of this guide is to provide families with current information and resources about health and educational opportunities for children from birth through age 21 who have hearing loss. The Rhode Island Department of Health, Office of Special Health Care Needs does not endorse any particular intervention or educational model. To our knowledge, the resources listed are current and accurate. Inclusion of a resource does not reflect a recommendation; omission of a resource is not intentional. The information is provided so that you, the parent or caregiver, can make educated decisions for your child.

Dear Parents,

Learning that your child is deaf or hard of hearing may have been unexpected for you as a parent. One of your first concerns may be how this will affect your child's future. You may also want to know what you should do to make sure that your child receives all the opportunities you want for him or her. There are people who can help, new technologies, advances in research, and many community services and supports available to help you on this gratifying journey with your child.

You are not alone. Each year in the United States, about 12,000 babies are born with hearing loss. Ninety percent of these children are born to parents with normal hearing. There are many successful deaf and hard-of-hearing individuals in this country. You are your child's greatest advocate. Remember that children who are deaf or hard of hearing are limited only if they are viewed as having limitations.

The Rhode Island Resource Guide for Families of Children who are Deaf or Hard of Hearing was created in response to requests from families for information and resources to help them understand their child's unique growth, development, and educational options.

The Office of Special Health Care Needs in our Division of Community, Family Health, and Equity is dedicated to providing families with support, guidance, and encouragement regarding their children's care. We recognize the important role of families as partners with professionals in the health care of their children. Our goal is to assist you in this role.

Sincerely,

Michael Fine, MD Director of Health



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Answers to Families' Frequently Asked Questions

If you have just learned that your child is deaf or hard of hearing, you may be experiencing many different feelings and unsure of where to turn. You may be wondering what the future will bring and what opportunities exist for your child. You may also want to know how you will communicate with your child.

Special services are available for you, your family, and your child, and you should begin looking for them as soon as possible. This is very important so that your child can get off to a good start in developing language.

Families often ask some of the following questions when they first learn about their child's hearing loss. Contact information for agencies that might be able to respond to your questions in more detail can be found in the Resources sections at the back of this guide. See Resources by Topic for a list of resources organized according to the order of questions in this section.

GENERAL QUESTIONS

HOW WAS MY CHILD IDENTIFIED?

The Rhode Island Newborn Hearing Screening Program supports early identification and timely and appropriate intervention to prevent or minimize developmental delays due to hearing loss.

Per Rhode Island General Law § 23-13-13, newborn hearing screening is a mandated program in Rhode Island. Prior to discharge from the birthing hospital a quick, harmless, and non-invasive hearing screening is performed by a technician or nurse, and results are reviewed and interpreted by an audiologist. The results may indicate a need for an additional screening. Parents receive a phone call from the staff to come back for this screening at the hospital. The baby's doctor is notified of this by mail.

When results suggest the baby has an actual hearing loss, the Newborn Hearing Screening Program helps coordinate referral and follow up to assure the best and earliest possible intervention.

REFERRAL PROCESS Newborn screened at birth prior to hospital discharge T Newborn Hearing Screening Program ensures rescreens if necessary Newborn Hearing Screening Program refers infant to an Audiologist Audiologist diagnoses hearing loss V Audiologist orders hearing aids Audiologist May Refer Infant to: Ear, Nose, and Throat Doctor Otologist (Ear Specialist) Genetic Counselor Early Intervention

HEARING SCREENING AND

ANSWERS TO FAMILIES FREQUENTLY ASKED QUESTIONS

ACCEPTANCE It is perfectly normal to have mixed feelings when your child is diagnosed with a hearing loss. You are uncertain of the future for your child and your family. Parents handle this news in different ways. Some parents keep their feelings to themselves while others may want to talk to other parents, family, or friends for support. It is normal to feel angry and hurt. Please remember that your child is still the same child as before he or she was diagnosed with a hearing loss. Your child still loves you and needs you. Part of being a parent is being there for your child. Even though your child may be different, your child is still wonderful and will take you on a journey that you never dreamed of.

WHERE DO I START?

Now you have been informed that your child has a hearing loss. Your audiologist may refer you to one of Rhode Island's Early Intervention (EI) programs. You may also call any EI agency directly. Rhode Island's EI programs help families support the growth and development of infants and toddlers who have a developmental disability or delay in one or more areas. This includes children who are deaf or hard of hearing. EI programs may also assist in connecting you with the support of other families.

Your EI service coordinator or a teacher of the deaf can provide you with contact information for the Rhode Island Hearing Assessment Program Hearing Resource Specialist. The Hearing Resource Specialist can help you access community resources. The Hearing Resource Specialist can also connect you with other families who have children with hearing loss.

Other parents can:

- ► Share experiences they have had with professionals and Early Intervention programs.
- ▶ Tell you about people and information sources they have found useful.
- Share their feelings related to parenting a child with hearing loss and how their feelings have changed over time.
- Help you better understand your child's special healthcare needs.

DO I HAVE TO PAY FOR EARLY INTERVENTION?

Early Intervention is available for all eligible children from birth through age three, regardless of ability to pay. Health insurers who are licensed in Rhode Island are required to pay for EI services. There is no direct cost for families.



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ARE THERE MANY CHILDREN WITH HEARING LOSS? AM I ALONE IN THIS?

You are not alone. There are many children who are deaf or hard of hearing. Approximately one child out of every thousand is born deaf. More than 90% of these children have parents who hear, so less than 10% have parents who are deaf themselves. There are many different causes of hearing loss in children, such as illnesses during pregnancy, viruses, accidents, and heredity.

ARE THERE ANY SUPPORT GROUPS FOR PARENTS OF INFANTS WHO ARE DEAF OR HARD OF HEARING?

There are support groups available in Rhode Island that you can easily join. Some of these groups are held during the daytime, and some are held in the evening. Resources are provided at the back of this guide or families can contact the Rhode Island Parent Information Network (RIPIN) for more information.

QUESTIONS ABOUT COMMUNICATION

WHAT DOES MY CHILD'S HEARING LOSS MEAN FOR HIS OR HER LANGUAGE AND SOCIAL DEVELOPMENT?

Most parents have had no personal experience with hearing loss, so it is helpful to connect with people who can help you learn what you need to know. All children do not have the same kind of hearing loss. The effects of hearing loss vary from child to child. There are many resources to help you understand what your child can hear, and what it means for your child's language and social development. See the Resources section of this guide for specific agencies that can help.

HOW CAN I UNDERSTAND MY CHILD'S EARLY ATTEMPTS TO COMMUNICATE WITH ME?

Whether your child can hear or not, most infants will first communicate by making sounds, smiling, crying, and using gestures like reaching and looking. Parents recognize these behaviors as meaningful and reinforce these early attempts to communicate. Communicate with your child with your smiles, hugs, and facial expressions, and by looking at each other, looking at things together, and playing together. Making eye contact is especially important for infants with hearing loss.

HOW DO I GET MY CHILD'S ATTENTION?

There are several approaches you can try. Try calling your child's name using a normal tone of voice or tap your child gently on the shoulder and wait for a response. You can start signing to get your child's attention any time. You can also move into your child's field of vision and wait for your child to look at you.

WHEN CAN I COMMUNICATE WITH MY CHILD?

Parents can begin to communicate with their child as soon as the child is born. It is important that parents continue communicating with their child the same way they had before hearing loss was diagnosed and add visual cues for additional information.

HOW WILL I BE ABLE TO COMMUNICATE WITH MY CHILD?

Currently, there are various opportunities for helping young children who are deaf or hard of hearing learn language. Children may benefit from a variety of communication approaches. It is important to ask a lot of questions and gather information so you can meet the unique needs of your child. Strong family involvement and a supportive environment are the foundation to communicating with the child, however this communication occurs.

WHAT IS THE DIFFERENCE BETWEEN SPEECH AND LANGUAGE?

According to the American Speech Language Hearing Association (ASHA), there is an important difference between speech and language.

Language is made up of socially shared rules that include:

- ▶ what words mean and how the same word can have different meanings,
- ▶ how to make new words by adding endings, and
- ▶ how to put words together and use them to communicate an idea.

Speech is the verbal means of communicating. Speech consists of:

- ▶ articulation (how speech sounds are made),
- ▶ voice (using our vocal cords and breathing to produce sound), and
- ▶ fluency (the rhythm of speech).

Sign language is a visual means of communication. Signs consist of making language visible to the eye through the use of hands, arms, body posture, and facial expression.

Acquiring language supports healthy cognitive development. Language is a brain function. We create language to express our inner thoughts and feelings, make sense of ideas, communicate with others, and maintain relationships. Hearing loss may interfere with the natural development of language unless steps are taken to enable the child to learn language. Specialized professionals who are knowledgeable about deafness and hearing loss can support you as you help your child develop language.

WHO CAN HELP ME DEVELOP MY CHILD'S SPEECH AND LANGUAGE SKILLS?

Your child's doctor, Early Intervention Programs, and the Parent Infant Partners Program located at the Rhode Island School for the Deaf can share the milestones for language development and how this development can be supported for children who are deaf or hard of hearing. (See the Local Resources Section at the back of this guide for more information on the Parent Infant Partners Program). Your child's audiologist or a speech language pathologist can help you identify resources to teach speech to your child.

HOW CAN I TEACH MY CHILD TO SPEAK IF SHE CAN'T HEAR?

Hearing children generally develop speech and spoken language naturally, without conscious effort. More deliberate planning will be necessary for the young deaf or hard-of-hearing child to acquire effective language. The key for language development, whether it is spoken language or a visual language such as American Sign Language (ASL), is for the child to be able to get regular exposure to and to practice the language of the environment. Currently, there are many opportunities for enabling young children who are deaf or hard of hearing to develop speech and visual languages. Your child's audiologist, speech language pathologist and professionals who teach sign language (found in the Local and National Resources sections at the back of this guide) can help you learn activities that promote speech and language development.

WHERE CAN I LEARN TO COMMUNICATE WITH MY YOUNG CHILD IN SIGN LANGUAGE?

Research has shown that early exposure to sign language increases brain development; it does not prevent speech development. Rhode Island has several resources for learning American Sign Language (ASL). These are listed in the Local and National Resources sections at the back of this guide. There are Internet sites that can get you started.

SIGNING WITH YOUR BABY (FROM WWW.SIGNINGBABY.COM)

THERE ARE SEVERAL ADVANTAGES TO SIGNING WITH YOUR BABY. INFANTS TAUGHT SIGN LANGUAGE:

- $\ensuremath{\text{\tiny *}}$ Can communicate wants and needs to their caregivers at an early age.
- » Will have an earlier understanding of the English language.
- » May learn to speak earlier.
- » Could have an above-average ability later in life to learn a new language.

PARENTS WHO SIGN WITH THEIR BABY MAY EXPERIENCE:

- » Lower frustration levels (for both you and your baby) because your baby can communicate with you.
- » Deeper bonding with your baby because you have greater insight into your baby's mind.
- » A higher level of trust from your baby because he or she knows that you understand what he or she is trying to tell you.
- » Satisfaction.What a great feeling it is to know that you can effectively communicate with your preverbal infant.

QUESTIONS ABOUT AUDIOLOGY

WHERE CAN I GET MY CHILD'S HEARING TESTED?

All children born in Rhode Island have their hearing screened after birth while they are still in the hospital. You can contact the Rhode Island Hearing Assessment Program or talk to your child's doctor about the screening results. You can also contact a licensed audiologist who has experience testing infants and toddlers, listed in the Local and National Resources sections at the back of this guide.

QUESTIONS ABOUT HEARING AIDS

HOW CAN I KEEP MY CHILD'S HEARING AIDS IN HIS EARS?

Many parents encounter this issue. There are a few things you can check. Always communicate concerns with your child's audiologist.

On a regular basis, check the ear mold to make sure it is comfortable, and be sure your child does not have an ear infection. If your child is healthy and there is nothing wrong with the hearing aids, try putting the hearing aids in when the child is preoccupied and/or doing an activity that he or she enjoys. For example, some toddlers are more inclined to keep their hearing aids in during lunch, because their hands are occupied with finger food and they are enjoying their meal. You could try two-sided tape or huggies as well. You could also contact your audiologist, another parent, or a support group for more suggestions.



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The more consistent a parent is in inserting the hearing aids, the more the infant or toddler will get used to them. As your child grows and develops, you will be able to discuss together when the hearing aid needs to be adjusted and why your child wants or does not want to wear them. Try not to worry if your child goes through a period in school when he or she feels self-conscious about having hearing aids. With support and self confidence, your child will eventually be able to see the benefit of hearing aids and choose to wear them at the appropriate times.

HOW DO I PAY FOR MY CHILD'S HEARING AIDS?

Your audiologist and/or Early Intervention provider will guide you. They will contact your health insurance company first. There are also several foundations and organizations that may help you find financial aid for purchasing hearing aids.

HOW SHOULD I CHECK MY CHILD'S HEARING AID TO MAKE SURE IT WORKS?

There are a number of ways that you can check to make sure the hearing aid is working properly. It is important for parents to become familiar with how the hearing aid sounds so they will recognize when it needs to be repaired. Your child's audiologist can teach you how to check the hearing aid daily.

MY CHILD'S HEARING AIDS ARE ALWAYS BUZZING. HOW CAN I STOP THIS?

Your child's ear mold may be loose and need to be readjusted, the ear mold may be too small and need to be replaced, or there could be a problem with the hearing aid. As your child grows, he or she will need new ear molds. You can contact your child's audiologist to have new ear molds made or to have your child's hearing aid checked.

WHERE CAN I PURCHASE HEARING AID BATTERIES?

Batteries can be purchased in drug stores, at audiology clinics, through hearing aid dealers, or at department stores.

CAN I DONATE MY CHILD'S HEARING AIDS WHEN THEY ARE NO LONGER BEING USED?

There are several agencies that collect used hearing aids, repair them, and loan them out to other children. Loaner hearing aids can be useful when a child's hearing aid is being repaired.

WHO DO I CONTACT FOR INFORMATION ABOUT A COCHLEAR IMPLANT?

There are several agencies in Rhode Island that can refer you to hospitals in the New England area where cochlear implant surgery is done. Currently in Rhode Island, the Audiology and Speech Pathology center located at Hasbro Children's Hospital is where young children can get cochlear implant surgery. See the "Hearing Technology" section of this guide for more information on cochlear implants.

QUESTIONS ABOUT ADDITIONAL RESOURCES FOR DEAF AND HARD-OF-HEARING INDIVIDUALS

WHERE CAN I MEET DEAF ADULTS?

You can contact the Commission on the Deaf and Hard of Hearing or the Rhode Island Association of the Deaf to get a calendar of events where you can meet deaf adults in a social environment.

WHERE CAN I FIND HELP ACCESSING ASSISTIVE DEVICES?

Your child's audiologist, TechACCESS of Rhode Island, and Early Intervention are among the resources that can help you find assistive devices.

WHERE CAN I GET CAPTIONED MOVIES?

The National Association for the Deaf provides free loans of educational and entertainment open-captioned CD-ROMS and videos for people who are deaf or hard of hearing.

WHAT KIND OF WORK WILL MY CHILD BE ABLE TO DO?

There are many resources to help your child learn more about different types of jobs, skill requirements, and job training. See the Resources by Topic section at the end of this guide for a listing.

There are no educational, job, or career limitations for your child because he or she is deaf or hard of hearing. For inspirational stories by deaf people who have achieved careers as pilots, doctors, and ministers around the world, visit the "No Barriers" website at https://deafnation.com/joelbarish/ and visit www.raisingdeafkids.org

WILL MY CHILD LEARN TO DRIVE?

Statistics have shown that people who are deaf or hard of hearing are among the safest drivers on the road. See the Resources by Topic section at the end of this guide for agencies that can help you access special accommodations, which may be needed for the driver's test.

EITAN'S STORY BY LEE VILKER

Two years ago, my wife, Ronitte, and I found out that our son, Eitan, had a hearing loss. He was four years old then. Looking back, it was one of the most difficult and painful times of our lives.

Both of us had dealt with illness and even death of family members in the past, but nothing can prepare you for the pain and shock of learning that something is wrong with your



child. We are programmed to protect our children from all danger. It was simply unimaginable to us that our child could have a disability that would likely impact the rest of his life.

It is difficult for even the best experts to diagnose certain types of hearing loss in children. My advice to anyone going through the diagnosis period is to listen to your gut. You know your child better than anyone else, and if you suspect something is wrong, you're probably right. Don't stop pursuing the issue until you are satisfied that the right conclusion has been reached.

I am a federal prosecutor who makes a living being tough – or at least appearing so – to career criminals. Yet for months after learning that my son had a hearing loss and needed hearing aids, I was unable to hold back my tears and broke down in front of strangers. But, this period somehow ended. My wife and I reached a level of acceptance that I didn't think was possible. The pain that accompanied the knowledge that our child had a disability gradually diminished, although it never disappeared.

For anyone going through this now, please know it will get better. You will realize that our sense of hearing, though significant, represents just one small piece in the total picture of who we are. Your child is still wonderful. You are still going to receive so much joy from him or her. And your child's life is not ruined. It just feels that way now. But that feeling will end.

At the time, everyone was telling me that things could be worse, we'll get through it, and Eitan will be fine. I can't tell you how little those words helped me at the time. Yet that is what I am trying to tell you now. You have to get through the first few months, and then you'll see that everything really is okay.

What helps you get through it is realizing how amazing your child is. He or she will adjust one hundred times faster than you will. You will see him or her happy, playing with friends, and going on with his or her life as if nothing has changed. All the important things are just as they were before. Your kid is great and the two of you love each other more than words can express. It just takes time to get to that point. You can't rush it. But you will get there.

Learning that your Child is Deaf or Hard of Hearing

HEARING SCREENING FOR NEWBORNS

Learning that your child is deaf or hard of hearing can be overwhelming. Although all newborn babies are screened for hearing loss, children can develop a hearing loss at any stage in life. Depending on your child's age, he or she may have been diagnosed by the methods described in this section. What lies behind us and what lies ahead of us are tiny matters compared to what lives within us. ~ Ralph Waldo Emerson

In 1993, Rhode Island became the first state in the nation to mandate hearing screening for all newborn babies under the Universal Newborn Hearing Screening Program. Since then, the Rhode Island Hearing Assessment Program (RIHAP) has provided hearing screenings for every infant born in Rhode Island. All birthing hospitals in Rhode Island participate in this program. For more information about the Universal Newborn Hearing Screening Program in Rhode Island, visit www.health.ri.gov/newbornscreening/hearing/for/parents/

A trained nurse or a skilled screener performs the hearing screening before your baby leaves the hospital using one or two methods (described below). The screening does not hurt the baby and usually takes anywhere from less than 10 minutes to 30 minutes. Results are reviewed and interpreted by an audiologist (trained hearing specialist) and become part of your baby's medical record. If the results are unclear and the screening tests need to be repeated, you will be notified by a member of the RIHAP staff within one month after discharge. You may also get a call if the audiologist recommends further testing. Your child's doctor may also be notified.

The methods used to screen newborns in the hospital include Otoacoustic Emissions (OAE) and Automated Auditory Brainstem Response (AABR).

OTOACOUSTIC EMISSIONS

The most common screening method for newborns is called Otoacoustic Emissions (OAE). A probe with a tiny microphone and earphone is placed in the baby's ear. The earphone gives off a series of quiet clicks. If the baby's cochlea (hearing organ located in the inner ear) is healthy and free of fluid, it will produce an echo, which is picked up by the microphone. When a baby has hearing loss or excess fluid in the ear, no echo can be measured. If the baby passes the OAE, the screening is over. If the baby does not pass the OAE, a second screening method, called the Automated Auditory Brainstem Response, is used.

AUTOMATED AUDITORY BRAINSTEM RESPONSE

Another screening method, Automated Auditory Brainstem Response (AABR), uses small bandaid-like sensors placed on the baby's head. Sound is then introduced to the ear(s) using

small earmuffs. The sensors pick up responses from the hearing nerve and display them on a screen. This method usually lasts less than 15 minutes. If the baby does not pass this test, further tests are necessary to determine whether there is an actual hearing loss.

OTHER DIAGNOSTIC TESTS

Even if your child passed the newborn screening tests at the hospital, he or she may have developed a hearing loss after the newborn period. There are tests that audiologists use to diagnose hearing loss in children. The type of test used depends on the age of your child and the type of information that the audiologist needs to check your child's hearing. These tests are not painful for your child.

AUDITORY BRAINSTEM RESPONSE

The Auditory Brainstem Response (ABR) is a diagnostic test similar to AABR, but it gives more detailed information about the amount of hearing loss in both ears and the effect the hearing loss will have on the child's ability to communicate. Using this method, an audiologist is also able to determine the type of hearing loss (see section 4 of this guide, "Causes and Types of Hearing Loss," for types of hearing loss), if any, that your child has. In children older than three months, sedation (having the child be asleep) may be required in order for this test to be completed successfully, as it may take up to three hours.

BEHAVIORAL TESTS: VISUAL REINFORCEMENT AUDIOMETRY AND CONDITIONED PLAY AUDIOMETRY

These are hearing evaluations used with children who are old enough to respond to sounds either by turning their head or by playing a simple game, such as dropping a block into a container. Behavioral tests measure the amount of hearing loss and can help in locating the problem, whether in the middle ear, inner ear, or some combination. Behavioral tests also provide information about how the hearing loss will affect your child's ability to communicate. Behavioral testing sometimes indicates that hearing aids may help a child.

TYMPANOMETRY

Tympanometry is used to test if your child's middle ear, rather than inner ear, is working normally. During the test, a small probe is placed in the child's ear, and the air pressure is gently changed. If the middle ear is clear, the eardrum will gently move away from the probe and then return to normal. If there is fluid in the middle ear, the eardrum will not move. The results are presented in a diagram called a tympanogram.

ACOUSTIC REFLEXES

Typically, muscles in the middle ear contract in response to loud noises. When a child has normal hearing, these muscle contractions, called acoustic reflexes, are present. However, a child with a hearing loss or middle ear fluid may not have these reflexes. Acoustic reflexes are tested with a probe placed in the child's ear. The probe makes beeping sounds in order to produce acoustic reflexes.

A FAMILY'S STORY

Steve and Michelle, both profoundly deaf, had their first son, Kyle, in July 2004. They learned of his deafness after he failed the newborn hearing screening at Kent Hospital. Soon after, he had a follow-up appointment with an audiologist at Women & Infants Hospital. where his hearing loss was confirmed. The whole family benefits from resources provided by the Rhode Island Commission on the Deaf and Hard of Hearing, the Rhode Island School for the Deaf Family Guidance Program (currently known as Parent Infant Partners), and Early Intervention services in Warwick. Early Intervention provides a sign language facilitator to Kyle in his daycare setting. The sign language facilitator has helped Kyle develop a large vocabulary of signs. In January 2006, the family welcomed a new addition, Luke. He failed the newborn hearing screening at Kent Hospital and will have a follow up appointment with an audiologist at Women & Infants. The whole family uses American Sign Language as their primary language in the home.



WHO CAN HELP?

In addition to your child's pediatrician or primary care provider, there are many different types of professionals and resources that your family may use if your child does not pass a hearing screening test. Rhode Island uses a team approach, where specialists work together to provide care and resources for your child. You may also want to meet and interact with other families who have children with hearing loss. Families provide each other with valuable information and support.



As you move forward you will build a

support team of professionals who will be current with the latest technologies and have experience working with very young deaf and hard-of-hearing children. Some of these professionals will become a regular part of your family's life. You may wish to interview several professionals or seek recommendations from other parents with deaf and hardof-hearing children. Things to consider in choosing your team members include their willingness to listen to and value your input as parents and also to support your choices for your child. Additionally, these professionals need to communicate effectively with each other to provide your family with an effective team.

The following list identifies some of the professionals who might be part of your team. The needs of your child and your family will drive the decision as to who becomes part of your team, which may change as your child grows and develops. There may be professionals that you do not need when your baby is 2 months old, but decide would be helpful to your child and family when your child is 12 months old.

The most important member of the team is you. Professionals will come and go in your child's life but you, the parent, will be your child's best advocate and offer the most support.

PEDIATRIC AUDIOLOGIST

The Audiologist is the professional who evaluates your child's hearing. If amplification is recommended, he or she will discuss appropriate options for your child. Some audiologists are members of cochlear implant teams. (See the "Hearing Technology" section of this guide for more information on cochlear implants.) It is very important to find an audiologist who has experience testing infants and toddlers.

SOME QUESTIONS TO ASK YOUR AUDIOLOGIST PRIOR TO THE APPOINTMENT

Do you have experience assessing infants and toddlers?

(Testing infants and toddlers is very different than testing adults or even older children.)

How much experience do you have fitting infants with hearing aids?

Do you work with several different hearing aid manufacturers?

SOME QUESTIONS TO ASK YOUR AUDIOLOGIST DURING THE APPOINTMENT

How will this type/degree of loss impact my child's speech, language, and learning?

What type of amplification do you suggest and why?

What are the advantages and disadvantages of different types of amplification?

How often will my child need equipment adjustments and how much will it cost (such as new ear molds, new maps for cochlear implant, or even batteries)?

How soon do you recommend fitting hearing aids on an infant or young child?

Do you work with several different hearing aid manufacturers?

SOME QUESTIONS FOR YOUR AUDIOLOGIST DURING SUBSEQUENT APPOINTMENTS

What will my child hear with the hearing aids or cochlear implant?

What if my child rejects the hearing aids or cochlear implant?

PEDIATRICIAN OR PRIMARY CARE PHYSICIAN

The primary care physician is the doctor responsible for coordinating your child's overall healthcare. It is important to have a doctor who will listen to your concerns and make appropriate referrals. Your doctor will be in touch with other professionals who will work with you and your child.

OTOLARYNGOLOGIST (EAR, NOSE, AND THROAT SPECIALIST [ENT]) OR OTOLOGIST (EAR SPECIALIST)

If you are referred to an otolaryngologist, this doctor will examine your child to determine if there are medically treatable conditions causing the hearing loss or surgical interventions appropriate for your child. This professional may order additional tests.

TEACHER OF THE DEAF

A teacher of the deaf is a certified teacher with the knowledge and skills to teach deaf and hard-of-hearing students. This professional is also qualified to talk with parents about hearing loss, language development, technology/amplification, audiological testing, communication options, and transition.

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SOME QUESTIONS FOR A TEACHER OF THE DEAF

What modes of communication as a teacher of the deaf are you trained for?

Do you have experience working with young children who are deaf or hard of hearing?

Are you fluent in American Sign Language?

Are you trained in how to work with children who have cochlear implants?

How can you develop my child's language skills necessary for transition to school?

SPEECH/LANGUAGE PATHOLOGIST OR SPEECH THERAPIST

The speech language pathologist is a professional who specializes in spoken language development. This individual should have expertise in working with children with hearing loss.

SOME QUESTIONS AS YOU LOOK FOR A SPEECH THERAPIST

Do you have experience working with deaf and hard-of-hearing young children?

Do you understand amplification? Have you had experience working with a young child with a cochlear implant (if this is a concern for your family)?

What is your approach regarding communication? (It is important to find a therapist who will respect and support your decisions regarding the communication strategies you are using with your child. If you are signing at home, does the therapist know American Sign Language?)

How can you help develop my child's language skills necessary for transition to preschool?

How can you help develop my child's auditory skills?

What will occur during a therapy session?

AMERICAN SIGN LANGUAGE INSTRUCTOR

This professional works collaboratively with other service providers to involve family and community members in the language learning process. If your family chooses to include American Sign Language (ASL) to communicate early with your child, you may decide to add an ASL educator to your team. The instructor will teach your family how to communicate using ASL in your daily routines and may also facilitate connections to other deaf and hard-of-hearing adults in Rhode Island.

DEAF/HARD-OF-HEARING ADULT ROLE MODEL

Many families find it helpful to meet deaf and hard-of-hearing adults who work, raise families, and contribute to their communities. These individuals can share educational, social, and cultural experiences and perspectives and model different means of communication. They have the personal experience to help your family create successes with your child and lessen some of your concerns about your child growing up with a hearing loss. Through their examples, children can understand that there are no limits to what they can achieve.

OTHER THERAPISTS

In addition to hearing loss, your child may need help in other areas of development that require the expertise of another therapist. Some of the frequently utilized services are those of an occupational therapist (OT), physical therapist (PT), or vision therapist.

RHODE ISLAND PARENT INFORMATION NETWORK (RIPIN)

The Rhode Island Parent Information Network (RIPIN) is a non-profit organization that provides the direct linkages for parents and children with special healthcare needs in Rhode Island to obtain the critical services and supports needed in the areas of healthcare and education. RIPIN recruits and hires parents who have children with special needs to support other parents in Early Intervention, pediatric offices and other community settings. There is a RIPIN Resource Specialist placed with the Rhode Island Hearing Assessment Program. This Resource Specialist is the parent of a child who is deaf or hard of hearing and is able to provide parents with many resources, supports and connections. Parents may also call RIPIN's Resource Center with any questions or concerns regarding accessing services and supports for themselves or family members with specials needs.

RHODE ISLAND EARLY INTERVENTION PROGRAM

Early Intervention is a comprehensive and coordinated system of home and communitybased services and supports for families of infants and toddlers with developmental disabilities or delays. The purpose of Early Intervention is to:

- 1. enhance the developmental functioning of infants and toddlers with special needs and
- 2. enhance the capacity of families to meet the special needs of their infants or toddlers.

PARENT INFANT PARTNERS

Parent Infant Partners (PIP), located at the Rhode Island School for the Deaf, is designed specifically for infants and children with hearing loss and their families. Its staff of family educators has specialized knowledge and experience in the field of deafness and hearing loss and its effect on communication.

CEDARR FAMILY CENTERS

CEDARR stands for Comprehensive Evaluation, Diagnosis, Assessment, Referral, and Reevaluation. CEDARR Family Centers can provide families of children with special healthcare needs with information, clinical expertise, and connection to community supports, and assistance to help them meet the needs of their child and family. The services available through CEDARR Family Centers will vary depending on the goals and needs of the child and family. They may include assistance obtaining basic services and supports, specialized clinical evaluations, family care coordination, and supports for home and community participation.

MEDICAL ASSISTANCE PROGRAM

The Medical Assistance Program, also called Medicaid, is a program created by Congress in 1956 under the Social Security Act. Medicaid programs are jointly funded by the federal and state governments and are administered by each individual state.

Rhode Island Medicaid provides publicly funded healthcare services and supports for people with disabilities and special needs who can not afford or otherwise obtain the assistance they need to optimize their health and lead productive lives. These services may be available across the life course and, depending on a person's needs, may include comprehensive healthcare, premium assistance, and/or long-term services and supports. In Rhode Island, the Rhode Island Executive Office of Health and Human Services is the state agency responsible for administering the Medical Assistance Program.

Within Medicaid is a program for children from birth to age 21 called the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT). Under this program, children must receive screening and diagnostic services as well as medically necessary treatments, which may not be available under the state's Medicaid plan but are allowed under federal Medicaid law. The EPSDT Program ensures that Medicaid benefits for children are the same across the delivery systems.

Children with special healthcare needs may qualify for Medicaid due to a disability or condition through RIte Care/RIte Share or the Katie Beckett Program. For more information on Rhode Island Medicaid coverage and eligibility, see www.eohhs.ri.gov/Consumer/ConsumerInformation/Healthcare/PeoplewithSpecialNeedsandDisabilities.aspx.

Please see the Local and National Resources section at the end of this guide for additional programs and resources that may benefit your family.

Causes and Types of Hearing Loss

One of the greatest discoveries a man makes, one of his great surprises, is to find he can do what he was afraid he couldn't do. ~Henry Ford

There are many different causes of hearing loss. Some children may have inherited a hearing loss. Often hearing loss comes from illness, ear infections,

or certain medications. However, in some cases, there may be no obvious explanation for hearing loss, and the cause may never be known.

Hearing loss can be a temporary problem caused by a blockage in the outer or middle ear, or it can be caused by nerve damage that will not go away. A hearing loss may even be a combination of these things. How your child's hearing loss will affect his or her language development and growth depends on many things. If the hearing loss can be resolved medically, quick treatment is important. If the hearing loss is permanent, there are many resources available to support families.

HOW THE EAR WORKS

Understanding the ear and how it works will help you understand your child's hearing loss and can help you seek the best possible care and services for him or her.

When sounds enter the ear, a chain reaction of vibrations occurs. These vibrations create electrical signals or messages, which are sent by the nerves in the ear to the brain. Because we have two ears, the difference between sounds entering each ear creates a stereo effect. This helps the brain know where the sounds are coming from and what kinds of sounds they are.

THE PARTS OF THE EAR

The ear is made up of three parts, which include the outer ear, middle ear, and inner ear.

The outer ear is the part that we see and includes the ear canal. The ear canal is like a tunnel, which ends at the eardrum (or tympanic membrane). Sounds travel through the ear canal and cause the eardrum to vibrate.

The middle ear contains the eardrum and three tiny bones called the hammer (malleus), anvil (incus) and stirrup (stapes). These bones form a small bridge that hangs across a space in the middle ear. Eardrum vibrations cause the three middle ear bones to vibrate. These vibrations then cause fluid in the inner ear (cochlea) to move.

The inner ear (cochlea) is snail-shaped and filled with fluid. It contains thousands of sensitive hair cells that have tiny hair-like structures at the top of each cell. The movement of the fluid in the inner ear causes the hair-like structures to move. When this occurs, the hair

cells create electrical signals that are picked up by the auditory nerve and sent to the brain. The brain interprets these electrical signals as sounds.

THE ROLE OF GENETICS IN HEARING LOSS

Genetic testing is optional and may be recommended to help understand the cause of your child's hearing loss. Your child will have a physical exam, and you will be asked about your family history. A doctor, nurse, or technician will take a sample of cells from your child's inner cheek by using a small, soft brush. The sample will be used to check for several gene changes that are known to cause hearing loss. If a gene change is found, you (and any other family members who may be affected) will be offered genetic counseling services. The counselor will explain how genetics could affect you, your child, and other family members. For example, the genetic test may show that the hearing loss may increase over time. This information may help you make decisions now about your child's future.

RISK FACTORS FOR HEARING LOSS

Sometimes the cause of hearing loss is known. Other times a cause cannot be identified. However, there are several known "risk factors" for hearing loss. A risk factor is a condition or event that often is connected with hearing loss. Risk factors can sometimes help predict hearing loss in a child, but not always. If your child has a risk factor, he or she will not necessarily have a hearing loss. Also, if your child does not have any risk factors, he or she



could still have a hearing loss. Nearly half of all infants with hearing loss do not have any risk factors to explain their hearing loss.

Hearing loss has happened in a high number of children who have the following conditions or risk factors:

- A family history of childhood hearing loss
- A mother who had an infection during pregnancy (for example, measles or certain viral infections)
- ▶ Birth defects of the head and neck (such as cleft palate or ear deformities)
- Low birth weight
- ▶ Extreme yellowing of the skin (jaundice) at birth, requiring a blood transfusion
- Meningitis
- ▶ Use of certain strong antibiotics to fight infection during the newborn period
- Use of a respirator for more than five days following birth
- Exposure to loud noises multiple times
- Multiple ear infections

WELCOME TO HOLLAND

BY EMILY PERL KINGSLEY ~ I am often asked to describe the experience of raising a child with a disability – to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you are going to have a baby, it's like planning a fabulous vacation trip – to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say, "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you never would have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

The pain of that will never, ever go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

TYPES AND DEGREES OF HEARING LOSS

There are several different types of hearing loss. In addition, there are different degrees of hearing loss that range from minimal to profound. An explanation of each of these types and degrees of hearing loss follows.

CONDUCTIVE HEARING LOSS

Conductive hearing loss is the result of a problem affecting the outer or middle ear. In most cases, conductive hearing loss is not permanent and can be treated either medically or surgically. Common causes of conductive hearing loss include ear infections, excess wax, fluid in the middle ear, or parts of the middle ear that did not form correctly.

SENSORINEURAL HEARING LOSS

Sensorineural hearing loss is the result of a problem in the inner ear affecting the nerve that deals with hearing called the auditory nerve. Sensorineural hearing loss cannot be corrected, but can usually be treated with the use of hearing aids or cochlear implants. Sensorineural hearing loss usually occurs in both ears, but one ear may be more affected than the other. Common causes of sensorineural hearing loss include a family history of hearing loss, certain medications or infections that the mother had during pregnancy, or other problems around the newborn period (see Risk Factors for Hearing Loss, above).

MIXED HEARING LOSS

Mixed hearing loss is the result of problems in both the inner ear and the outer or middle ear (sensorineural and conductive hearing loss together). With mixed hearing loss, the conductive loss may be managed with medical treatment, but the sensorineural loss will not go away and may be managed with hearing aids.

UNILATERAL HEARING LOSS

Hearing loss in only one ear is called unilateral hearing loss. It can be conductive, sensorineural, or mixed. It may be difficult for a child with unilateral hearing loss to know where sounds are coming from and to hear in noisy environments.

PROGRESSIVE HEARING LOSS

Progressive hearing loss is hearing loss that happens over time. It can be conductive, sensorineural, or mixed. Infants who are able to hear at birth may lose their hearing gradually. In other words, passing the newborn hearing screening does not mean an infant will always have normal hearing.

FLUCTUATING HEARING LOSS

Fluctuating hearing loss changes often by becoming more or less severe. Sometimes conductive hearing loss can be fluctuating.

SYNDROMES & HEARING LOSS

Syndromes are groups of symptoms or characteristics that, taken together, identify a certain disease or condition. Some syndromes are associated with hearing loss. If hearing loss is detected early, specialists may be able to test for certain syndromes that may not be identifiable by appearance alone. Two examples of such syndromes are Usher's Syndrome, which is associated with progressive vision loss, and Jervell and Lange-Nielsen Syndrome, which is associated with heart defects.

AUDITORY NEUROPATHY

Auditory neuropathy is a less common condition in which sound enters the inner ear normally, but the transmission of signals through the auditory nerve from the inner ear to the brain is impaired. People with auditory neuropathy may have normal hearing, or they may have hearing loss ranging from mild to profound. Typically, people with auditory neuropathy have trouble understanding speech clearly, especially if there is a lot of background noise. They may be able to hear sounds but may have difficulty understanding spoken words. Risk factors of auditory neuropathy include a family history of hearing loss or health problems at birth, such as mild jaundice or prematurity.

The following chart shows the various degrees of hearing loss and the potential effects of the loss. Your child's audiologist will be able to give you more information about types and degrees of hearing loss.

DEGREE OF HEARING LOSS	POTENTIAL EFFECTS
MINIMAL	The child may have difficulty hearing quiet or distant speech, especially in noisy places.This can impact speech and language development.
MILD	The child can hear most speech sounds but is likely to miss parts of words, especially those that contain "s", "f", and "th." This can impact speech and language development. With the proper amplification device, the child is likely to understand all spoken words, even from a distance.
MODERATE	Without an amplification device, the child may miss 50–100% of speech sounds. This will affect speech development.The proper amplification device should allow the child to hear most sounds at closer distances.
MODERATELY SEVERE	The child cannot understand words, unless they are very loud. Appropriate services and regular use of an amplification device will determine his or her ability to understand speech and develop language.
SEVERE	Without amplification, the child may be aware of loud voices near his or her ear. Spoken language will not develop normally without therapy. With an amplification device, the child may be able to hear many sounds of speech and identify environmental sounds, such as car horns.
PROFOUND	The child is aware of sound vibrations more than actual words. He or she may rely on sight rather than hearing as the primary means of communication and learning.The child's speech will not develop normally without amplification and therapy.

AUDIOGRAMS

Hearing test results are often shown on an audiogram. An audiogram is a graph or picture of a person's hearing. The audiogram will show the degree or severity of hearing loss in each ear. The audiologist will help explain your child's audiogram to you, so you understand what it says about your child's hearing. More information about how to read an audiogram is available on the American Academy of Audiology's website at www.audiology.org/ consumer/guides/uya.php



EAR INFECTIONS AND HEARING LOSS

Ear infections, or otitis media, are the most common illness in children and can cause shortterm hearing, speech, and language problems. If an ear infection is left untreated, problems can become more serious. Ear infections are usually painful and affect the whole ear, but especially the middle ear. Children with sensorine ural hearing loss can also have middle ear infections.

SIGNS OF EAR INFECTIONS

It is not always easy to know if your child has an ear infection. If your child is not old enough to talk, you may have to look for other signs that there is a problem, such as:

- Pulling at the ears
- Crying more than usual
- ▶ Fluid draining from the ears
- Not reacting to quiet sounds
- ► Trouble sleeping
- ► Fever
- Trouble keeping balance

WHAT ARE EAR INFECTIONS?

Ear infections usually happen when viruses or bacteria get inside the middle ear space. They often happen as a result of another illness, such as a cold.

When a child has a cold, the eustachian tubes, which are located inside the ear, can become swollen, inflamed, and clogged with fluid and mucus. If the fluids plug the openings of the eustachian tubes, air and fluid get trapped inside the middle ear.

Adenoids are groups of cells that fight infections and are located in the throat, at the base of the eustachian tubes. Adenoids can become infected and swollen and can also block the openings of the eustachian tubes, trapping air and fluid.

DIFFERENT TYPES OF EAR INFECTIONS

There are two main types of ear infections, called acute otitis media and otitis media with effusion. Acute otitis media happens when the middle ear is infected and swollen, and fluid is trapped inside the ear. Otitis media with effusion can happen when clear fluid remains in the ear after the initial infection is over.

TREATMENTS FOR EAR INFECTIONS

When there is an acute otitis media, your child's doctor may prescribe an antibiotic drug and sometimes a pain reliever. The antibiotic should be taken until the end of the prescription period. Most healthcare providers will schedule a follow-up visit to check to see if the infection is gone. Because there are many bacteria that can cause ear infections, some infections cannot be cured with just one antibiotic. As a result, your child may have to try several different antibiotics to cure the infection. After the infection goes away, fluid may remain in the middle ear for several months, but it often disappears after three to six weeks.

If the fluid remains for more than three months and is connected with hearing loss, many healthcare providers suggest putting tubes in the ears in order to drain the fluid. This operation is usually done by an Ear, Nose, and Throat (ENT) doctor. While the child is asleep under general anesthesia, a small metal or plastic tube is placed in the eardrum. The tube helps dry out the middle ear and keeps the air pressure in the middle ear even. The tubes normally stay in the eardrums for six to twelve months and usually come out on their own. Your child's hearing should return to normal once the fluid is removed with the tubes. Some children may need to have the operation again if the ear infection comes back.



Amplification and Hearing Technology

A parent understands what a child does not say. ~anonymous

Hearing aids are designed to make sounds louder in order to make sounds that were previously not heard by your child audible. Hearing aids cannot fix hearing loss like glasses fix vision impairments, so your child may also need some special services and programs, such as Early Intervention, Parent Infant Partners, and Special Education. Your child's audiologist can give you more information about these programs and services.

There are three main types of assistive listening technology your family may want to consider in managing your child's hearing loss: hearing aids, FM Systems, and cochlear implants.



HEARING AIDS

A hearing aid is a battery-operated device that amplifies (increases) sound. A hearing aid can best help most sensorineural hearing loss and some types of conductive hearing loss.

The selection of a hearing aid is one of the first important decisions that a family may have to make. In recommending a hearing aid, the

audiologist will consider factors such as your child's degree of hearing loss, the hearing aid's function, and what types of special hearing technology will be used in your child's school.

Finding the correct hearing aid for a baby with hearing loss is an important step. Language learning begins within the first months of a baby's life. It is important for babies with hearing loss to start using hearing aids as soon as possible so that they can hear speech. Hearing aids may be small, but they are complicated devices. If you are a parent or caregiver of a child with hearing loss, you need to learn about how hearing aids work so you can help your child.

Your child's audiologist will discuss which technology will work best for your child's specific hearing loss. The hearing aid will make some pitches of sound louder than others, depending on the type of the hearing loss. Your audiologist uses the hearing aid's internal controls or computer programming to adjust the sound for your child's needs. How much your child benefits from hearing aid use depends on a variety of factors, such as degree of hearing loss, age of hearing loss identification, and how much and how often your child wears his aids. Even if your child does not show a response to sound when he first starts using hearing aids, it does not mean that he will not benefit from them. It may take time for him to learn what to do with this new information. The more your child wears his or her aids, the more opportunities he or she will have to learn from the sounds heard. Use of amplification is particularly important during the early years when the brain is developing rapidly and it is easier to develop auditory skills.

HOW HEARING AIDS WORK

Hearing aids receive sound through a microphone and send the sound to the ear through a speaker. All hearing aids, regardless of style, are made with the same basic parts. These include a microphone, tone



hook, earmold, volume control, on/off switch, and battery compartment.

The microphone picks up sounds outside the body and sends them to a processor that makes sounds louder.

The tone hook is a small plastic piece that hooks over and behind the child's outer ear. The amplified sound is carried to the earmold through the tone hook.

The hearing aid consists of a microphone, amplifier, and a receiver that boosts sounds. There are different kinds of hearing aids, but babies are usually fit with behind-the-ear (BTE) aids. BTEs are uniquely suited to the needs of young children as the molds are separate and can easily be replaced to accommodate rapidly growing ears. They are not easily damaged and come in bright colors that young children like. Some children with permanent conductive hearing losses or single-sided deafness may be fit with bone-anchored hearing aids (BAHA). Your audiologist will make recommendations for the most appropriate hearing aids for your child.

The earmold holds the hearing aid in the child's ear and directs sound into the ear canal. The earmold fits the shape of your child's ear and stops sound from coming back out of the ear. Earmolds are made from a mold or impression of your child's ear. They are made from soft materials and fit in the outer ear and ear canal. Over time, the earmold will need to be replaced because the shape of your child's ear will change with age. Also, the plastic can shrink or harden with time.

TYPES OF HEARING AIDS

There are several types of hearing aids, and each offers different advantages.

Behind the Ear (BTE) Hearing Aids are used for all types of hearing loss. A BTE hearing aid has all of its parts in a curved plastic case that fits behind the ear. Amplified sound comes out of the case and into a clear plastic tube, which goes through the earmold into the ear canal. This type of hearing aid can also work with other devices such as an FM assistive device through a telecoil. A telecoil is a small magnetic coil contained in the hearing aid that improves sound during telephone calls.

Canal aids are used for mild to moderately severe hearing loss. These aids fit into the ear canal. They are available in two sizes: In the Canal (ITC) and Completely in the Canal (CIC). The ITC hearing aid is made to fit the size and shape of the ear. The CIC hearing aid is mostly hidden in the ear canal. Because of the small size of canal aids, these aids may be difficult to adjust or remove.

In-the-Ear (ITE) Aids: All parts of the aid are contained in a shell that fills in the outer part of the ear. These aids are larger than canal aids and, for some people, may be easier to handle than smaller aids.

FITTING HEARING AIDS

Fitting a child with a hearing aid is different than fitting an adult, so it is important to work with an audiologist who has pediatric expertise. Unlike adults, young children aren't able to say how well the hearing aids are working. It is very important that your child has the best hearing aid possible while his or her speech and oral language skills are developing.

Hearing aids must be fit individually for each child. Even if your child has different degrees of hearing loss in each ear, your child's audiologist will almost always recommend hearing aids for both ears. Two hearing aids are needed to support the child's language and speech development.

The audiologist will show you how to put your child's hearing aids on and how to take care of them. Also, the audiologist will teach your child how to pay attention to and identify sounds. This is necessary because the sounds your child will hear with the hearing aids will be different from what he or she hears without them. It will take practice for your child to recognize familiar and new sounds. This process may require several visits with the audiologist and an early interventionist.

TESTING THE HEARING AIDS

The audiologist will test the hearing aids while your child is wearing them to determine the best setting. The most important goal for the audiologist is to make speech loud enough for your child to hear.

After the testing is completed, the audiologist will discuss how your child's hearing will be affected by the hearing aids, and what the family can expect as the child gets used to them. Your child may need several more appointments with the audiologist to make sure that the hearing aids are working properly.

Real-Ear-to-Coupler-Difference

For children under six months of age, a special probe microphone technique called Real-Ear-to-Coupler-Difference (RECD) can be used to test a hearing aid. During this test, a small, soft microphone is placed in the child's ear next to the earmold to allow the audiologist to determine how much sound is delivered to the child's ear. The audiologist uses RECD measures before fitting the hearing aid directly on the child to avoid the problem of too much sound from the hearing aid or inaccurate volume settings. RECD testing is one of the most recent developments in hearing aid evaluation for young children.

THE FOLLOWING CLEANING AND CARE TIPS WILL HELP KEEP YOUR CHILD'S HEARING AIDS AND BATTERIES WORKING PROPERLY. HEARING AIDS » Protect hearing aids by keeping them dry » Keep hearing aids away from heat and chemicals » Clean the earmolds and hearing aids with a dry tissue » Do not use any chemicals on the earmolds or hearing aids » Put the hearing aids in the case or special moisture removal kit when not in use » Be careful not to bend the plastic tubes or wires » Remove hearing aids when bathing or swimming » Take the hearing aids off at bedtime » Keep the hearing aids out of the reach of pets BATTERIES Hearing aid batteries last for approximately one to two weeks depending on the type of hearing aid and how long your child wears it each day. Batteries can be purchased at audiology clinics, drug stores, grocery stores, and department stores. IF THE HEARING AID IS NOT WORKING PROPERLY, CHECK TO SEE IF: » Battery is dead » Battery is in the right position and the battery door is closed » Earmold opening is free of wax » Plastic tubing is not bent or twisted » Hearing aid is in the "on" position » If the hearing aid still does not work, do not try to fix it yourself. Take it to your child's audiologist. HERE ARE SOME TIPS FOR CARING FOR A HEARING AID'S BATTERIES » Remove the battery when the hearing aid is not in use » To test the battery, use a hearing aid battery tester » Do not remove the paper tag on the battery until ready to use » Keep extra batteries on hand and store in a cool, dry place

Probe Microphone Test

For young children, the best method of hearing aid testing is called probe microphone testing. Similar to the RECD test, a small, soft microphone is placed next to the ear mold to measure the amount of sound that is carried to the child's ears. Probe microphone measures allow the audiologist to determine how much speech will be heard with different types of hearing aids. It also can be used to compare aided and unaided hearing, different hearing aid settings, and different listening conditions. Because young children have much smaller ear canals than adults, it is important to take these measures to avoid discomfort and further damage to the child's hearing.



PAYMENT AND INSURANCE FOR HEARING AIDS

The audiologist or Early Intervention Program can provide you with information regarding payment and insurance for your child's hearing aids. If you have health insurance, it will be accessed for payment first. Your health insurance may cover lost or damaged hearing aids. Insurance policies vary, so check with your health insurance company for coverage guidelines. Hearing aids come with one-year standard warranties. As insurance companies do not typically pay for additional warranties, you can purchase extended warranties through companies that specialize in hearing aid insurance or sometimes through the hearing aid manufacturer.

There may be assistance available to help you pay for hearing aids. For children who do not have insurance or whose insurance does not cover hearing aids, Shriners of Rhode Island Charities Trust can help cover the costs of hearing aids, earmolds, and repairs every 3 years until the child is 18. (See the Local and National Resources sections of this guide for contact information.)

A law was passed in Rhode Island requiring most private insurance companies to cover the cost of hearing aids up to \$400 per aid every 3 years. RI General Law § 5-49-3 states that a receipt is required to be furnished to a person supplied with hearing aids. The receipt shall contain language that verifies that the client has been informed about the benefits of audio switch technology, including increased access to telephones and assistive listening systems required under the "Americans with Disabilities Act of 1990", and section 504 of the Rehabilitation Act of 1973. The client shall be informed that an audio switch is also referred to as a telecoil, t-coil, or t-switch.
FM SYSTEMS

Hearing aids keep getting better. But hearing aids alone do not make listening easier in all situations. The things that can interfere with listening are background noises, distance from a sound, and reverberation or echo. People with normal hearing also have problems hearing when listening from a distance. Background noise and echo are a problem for everyone. People with hearing loss have even more problems than people with normal hearing when trying to listen in these difficult situations.

Babies and young children are listening in difficult situations every day. Some examples are listening in the car, at day care, playing outside or at the park, and watching television. The best way to hear better in all of these situations is to remove background noise and to have a short distance between the speaker and the listener. Most people do not talk with each other while they are standing three to six inches apart. You could not talk this closely in a car or while your child is playing at the park. Background noises usually cannot be removed or changed. Because of this, there are devices designed to make it easier to hear in difficult situations. The device used most often today is the Frequency Modulated or FM system. An FM system is a device that works together with hearing aids to bring the sound of someone's voice directly to your child's ears. The speaker wears a wireless transmitter/microphone that transmits an FM radio frequency signal to a receiver worn by the child, usually coupled to the hearing aids. FM systems give your child consistent access to the speaker's language (especially in noisy places or at a distance). They give the child better and more consistent auditory input, so that he or she can better develop speech and language at this critical early stage. These systems are helpful in any environment where there may be a lot a background noise or when the speaker is not directly in front of the child.

WHERE SHOULD FM SYSTEMS BE USED?

In the past, FM systems were only used in schools. They helped students listen in noisy and reverberant classrooms. Many pediatric audiologists now recommend that FM systems be used at home. There are ear-level receivers and lightweight microphones and transmitters that are easy to use in everyday listening situations.

There are other benefits to using FM systems at home. Home use of FM systems can give a baby or young child more consistent speech and language exposure. For example: a mother and child are both in the kitchen, but the mother is working at the stove or sink and her back is turned to the child. If the child is using an FM system he or she can easily hear what the mother is saying no matter where the mother moves. When babies start to crawl and walk, the listening distance between the child and his or her parent can change quickly. Children often do not look at a person that is speaking. They might be busy playing or exploring while people are talking to them. An FM system keeps the listening distance close no matter what the child is doing. Children report that using the FM system gives them a feeling of security when they are at a distance from their parents, such as in the grocery store or on a family outing. This may help children develop self-esteem and independence.

Research shows that children learn a lot of language by overhearing conversations. This overhearing helps children learn new words and grows their understanding of how to use language. Children with hearing loss may miss opportunities to overhear if people are talking more than one meter away or if it is noisy. Using the FM with a hearing aid can give a child more opportunities to overhear some conversations.

COCHLEAR IMPLANTS



Cochlear implants are devices that can provide sound for people who receive little or no benefit from hearing aids. Hearing aids make sounds louder. However, for children and adults who have severe to profound hearing loss, making sounds louder may not be enough to allow the ear to process sound. A cochlear implant may be more successful than hearing aids in some cases, because it bypasses the damaged sense organ of hearing (cochlea) and directly stimulates the hearing (auditory) nerve, which sends signals to the brain. Part of the cochlear implant includes tiny electrodes that

are surgically inserted into the cochlea. The cochlear implant converts sound into electrical signals that go to the auditory nerve.

A cochlear implant is made up of inner and outer parts. The inner part is surgically implanted and includes a receiver and a tiny electrode array.

The external portion, shown in the picture below includes a speech processor that is connected to a headpiece by a cord. The headpiece has a transmitting coil that sends the signal from the speech processor to the internal part of the cochlear implant. It magnetically

attaches to the surface of the head behind the ear at the spot where the internal portion of the implant is located.

Intensive follow-up therapy is required to help your child understand the many new sounds that are heard with the implant. Cochlear implants are not a "cure" for hearing loss. The FDA (Food and Drug Administration) has approved cochlear implants for adults and also for children who are profoundly deaf at age 12 months, and for those with severe hearing loss at age 24 months.



CRITERIA FOR COCHLEAR IMPLANTATION IN CHILDREN

The criteria for determining who can benefit from cochlear implants have changed a great deal since the devices were first introduced. In general, it is recommended that a child be appropriately fit with hearing aids and use them for three to six months before determining implant candidacy. In cases of meningitis, a shorter hearing aid trial may be recommended, or the trial may be waived as bony growth in the cochlea following meningitis may create problems for implantation. In a few cases of meningitis, the physician may proceed with implantation prior to the child reaching 12 months of age. This is to insure adequate insertion of the electrodes into the cochlea, before the bony growth fills the cochlea.

No medical contraindications

Included in the list of contraindications are things such as an absence of the auditory nerve; medical conditions or developmental delays that would severely limit participation in oral communication; and active middle ear infections.

High motivation, positive family environment, and realistic expectations

These are all important factors in a child's performance with the cochlear implant. Children should be in a rehabilitative or educational setting where the development of auditory (listening and speaking) skills is emphasized. Rehabilitative or educational environments that encourage auditory skill development are likely to have a positive effect on the speech and language progress in children.



Getting an Early Start with Learning

There are no seven wonders of the world in the eyes of a child. There are seven million. ~Walt Streightiff

All children regardless of their hearing levels need to acquire structured language as early as possible. All children younger than age three who are diagnosed with hearing loss are referred by their audiologist to

Early Intervention. A child's ability to learn language can be improved by these services, so it is important to get your child involved as soon as possible. The public education system can provide your child with the services he or she needs after age three. It is recommended that families with a child who is deaf or hard of hearing provide all language opportunities, including sign language, speech, or other modalities, for the best outcome for their child to learn and acquire language. This decision will require commitment from your family and professionals on your child's team. The level at which one child with moderate hearing loss successfully discriminates speech (tells the words apart) may be different for another child with moderate hearing loss. It is important for parents to keep this variability in mind, so they do not think they are doing something wrong if their child does not discriminate speech as well as another. You should also get to know other parents of deaf children and deaf adults in the community. Family Voices at the Rhode Island Parent Information Network can help put families in touch with other families. (See the "Local Resources" section at the back of this guide for contact information.)

EARLY INTERVENTION

Early Intervention works with families to support the developmental functioning of infants and toddlers with special needs. Families can self-refer their child to EI or referrals may come from the child's pediatrician or audiologist.

The EI provider is only in the home for a limited time, but the child's family is there forever. This is why it is important for EI to support the family as they learn new skills and interventions to use with their child.

PARENT INFANT PARTNERS

A child's audiologist, Early Intervention (EI) provider, pediatrician, or other professional can refer the child to Parent Infant Partners (PIP). Parent Infant Partners at the Rhode Island School for the Deaf provides support, guidance, and information to families of children who are deaf or hard of hearing. Parent Infant Partners staff work in partnership with EI staff to address the family's needs. As with EI, it is the family's choice to participate in Parent Infant Partners.

Hearing loss specialists at Parent Infant Partners offer a range of support and training tailored to the individual needs and choices of families. This includes helping families:

- Become confident as their child's primary caregiver;
- Understand information on infant hearing loss, which can be confusing and conflicting;
- Recognize the best methods of communicating with their infants;
- Make decisions about approaches to communicating;
- ▶ Learn to support language development through using American Sign Language;
- Discuss appropriate amplification devices and technology to enhance early hearing experiences;
- Identify their child's progress through in-depth observations and assessments designed specifically for deaf and hard-of-hearing children;
- Connect to other families; and
- Meet deaf adult role models.

Helping children with hearing loss is often different than helping other children who need special education. The PIP understands the emotions of families trying to make difficult decisions about their child's communication needs. The mission of the PIP is to provide families with guidance and information that will help them make decisions and advocate for their children. The PIP emphasizes the importance of helping families establish communication with their infants as soon as possible, and helps parents optimize both visual and/or auditory pathways for learning language.

PROGRAM REFERRAL

Rhode Island has a Comprehensive Child Find System (Level One) to ensure that all infants and toddlers in the state who are eligible for Early Intervention services are identified, located, and evaluated through universal screening and direct referrals, and public awareness.

All babies born in Rhode Island are screened at birth for specific congenital conditions and disorders under the Rhode Island Department of Health's Universal Newborn Screening Program. A follow-up in-home screening is offered through the First Connections Home Visiting Program to families of children identified as "at risk" for developmental delays. The First Connections program is administered by the Rhode Island Department of Health. Children in need of additional services are referred to Early Intervention.

Direct referrals to Early Intervention can be made by family members, guardians, primary care physicians, and community agencies for infant and toddler screening, evaluation, and assessment to determine eligibility for services.

FROM EARLY INTERVENTION TO SPECIAL EDUCATION

When your child turns 28 months old, your EI Service Coordinator will ask you to sign a release so that she may share your child's information with the local school department, also called the LEA, or local education agency. Your Service Coordinator will schedule a transition conference meeting with you and the LEA representative, to be held around the time the child is 30 months old. You may also want to include other members of your child's team in this meeting, such as an educational



audiologist, speech/language specialist, or anyone else involved in your child's care. You should receive a letter from the Rhode Island Hearing Assessment Program before the meeting that includes suggestions to help you develop the best plan for your child.

If your child is older than three years of age, you can contact your school district's Early Childhood or Child Outreach office for a screening and more information on options available in your district.

Between 30-35 months of age, the LEA will convene both an Evaluation Team meeting to review the referral and an Evaluation Team meeting to determine eligibility for special education. Your presence at these meetings is critical. If your child is eligible, an Individualized Education Program (IEP) Meeting will be scheduled. If your child is ineligible for special education, the transition team will help you locate appropriate community resources that may continue to support your child's development as stated in his or her Transition Plan. At the IEP meeting, the team, including you, will set goals and identify services to help your child attain those goals. The team will determine the frequency of services and placement (if appropriate) where your child will receive the services. The team will complete referrals to other community resources, and your child will be discharged from EI.

All families of children eligible for Medical Assistance should be informed about CEDARR Family Centers at an appropriate time during their experience in EI. With a parent's permission, the EI Service Coordinator can initiate a referral for the child to CEDARR. A child does not need to be in special education to access CEDARR services, but does need to be enrolled in a Medicaid program.

A number of publications have been written to guide families through the transition process. These are provided to families by their Service Coordinators and are available on the Paul V. Sherlock Center on Disabilities at Rhode Island College's website, http://www.ric.edu/ sherlockcenter/index.html

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The school district shall document a history of the child's response to scientific, research based interventions before referring the student for a special education evaluation. This process does not prohibit direct referral for a special education evaluation evaluation at any time by a parent or school district representative.

The IEP Process



SPECIAL EDUCATION

Congress enacted the Individuals with Disabilities Education Act (IDEA) based on its finding that "disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities." Rhode Island establishes state regulations for implementing IDEA. These rules are designed to ensure a free, appropriate public education for children with disabilities, protect the rights of children with disabilities and their parents, and assist agencies to provide for the education of children with disabilities, and to assess and ensure the effectiveness of these efforts. The Rhode Island Department of Education (RIDE) Office of Student, Community and Academic Supports (OSCAS) oversees these state regulations.

If you suspect that your child has a disability, contact the school department of the town you reside in to initiate a special education referral. Within ten school days, an initial evaluation team of qualified professionals, including you as the parent, will meet to determine if evaluations are warranted and, if so, which assessments will be conducted to determine whether your child has a disability and requires (meets eligibility criteria for) special education.

Once a child has been designated as a student with a disability and is eligible for special education and related services, the school district must develop an individualized education program (IEP) within 15 school days. At the least, an IEP team consists of the parent (parents of a child with a disability are expected to be equal participants along with school

personnel in developing and revising their child's IEP), general education teacher, special education teacher, and a district representative. The IEP team must use a variety of sources to determine your child's present levels of academic achievement and functional performance as well as post secondary goals where appropriate. The IEP will document your child's strengths and needs, in need areas, present levels of performance, goals and objectives, specialized instruction, related services which could consist of transportation, speech and language therapy and audiology services, and accommodations. An IEP frequently asked question guide is available through the RIDE website at http://www.ritap.org/iep-faq/player.html.



Your child's IEP must be reviewed at least annually. It can be reviewed sooner if a parent or teacher feels the program and services are not meeting the child's needs. A reevaluation must be conducted and a child's eligibility predetermined every three years, unless the parent and school district agree that a reevaluation is unnecessary.

Parents and school districts must work collaboratively and build trusting relationships in order to productively share decision-making responsibilities. At times differences in opinions and perspectives may occur, and it may be difficult to reach an agreement about a child's IEP. Rhode Island has several resources available to assist parents (see the "Local Resources" section of this guide for contact information).

Children who are not eligible for special education services may be assisted through rights outlined in Section 504 of the Rehabilitation Act of 1973. This law prohibits discrimination on the basis of a disability in programs and activities that receive federal financial assistance. Children with disabilities can receive related services under Section 504 to provide them with an "appropriate education," described in writing in a 504 plan, even if they are not receiving special education services. An "appropriate education" means an education that is comparable to one provided to students who do not have disabilities. For more information, visit the U.S. Department of Education website at www.ed.gov.

YOUR CHILD'S RIGHTS

It is important to understand your rights and your child's rights. Families may find that they sometimes disagree with what professionals advise. If you and your family feel you know better alternatives for your child, you have the right to have these considered by the IEP team. Families are their child's best advocate and may need to be persistent in order to get the services needed. Families may have to make phone calls, write letters, attend meetings, and meet with professionals and doctors. Children or parents who use ASL have the right to access all meetings through sign language interpreters provided by their school district.

There are a number of measures in place to ensure that children and their families receive appropriate services. These include:

- a legal way to resolve complaints you have about procedures or services that you or your child receives,
- ▶ the right to confidentiality,
- the right to accept or decline services proposed for you and your child,
- ▶ the right to examine school or medical records,
- written prior notice (in your native language) regarding your child's identification, placement, and evaluation, and
- ▶ the right to use mediation (legal support) to resolve disputes.

TIPS FOR FAMILIES: THE IEP MEETING

Bring a friend or family member to the meeting with you. It helps to have another person there to listen and take notes.

Go to the meeting prepared. Take information about your child's strengths and needs, what you see at home or in other settings.

Carry written information in a folder or notebook.

The image that you project can make a difference. Dress neatly and appropriately.

Arrive on time. Arriving on time shows that you feel this is an important meeting and that you are ready to conduct business.

Shake hands and acknowledge other people at the meeting as you are introduced to them. If no one begins the introductions, begin by introducing yourself.

Sit with the other team members. Remember that you are a part of the decision making process.

Speak clearly and look at other team members while talking.

Make positive statements such as "I expect...," "I understand...," "My child needs...," "I am concerned that...," "I want to cooperate with you, however, I am concerned that...," "I know that you have many children to care for..."

Ask questions and for clarification of anything that you do not understand.

Remain as friendly as possible. Separate the people from the problems. Keep your emotions in control.

Focus on the issues at hand. Do not be sidetracked by other issues, such as past experiences, lack of available funding, or what "all the other children" are doing.

Make your proposal and expect to get what your child needs. Be flexible enough to accept minor revisions, but be firm about the major issues.

Feel confident enough to end the meeting if it seems that no more progress can be made. Tell the other team members that you would like to continue working with them, and set up another appointment for a fresh start.

Sometimes necessary team members begin leaving the meeting before decisions have been made. If this happens, stop the meeting and reschedule a time when all team members can attend and finish negotiations.

Follow up with a letter to the person who ran the meeting. If you are satisfied, state what the agreements were. If you are not satisfied, explain your position, your understanding of their position, the next course of action, and your timelines.

Remember that you are advocating for the safety, health, well-being, and future of your child. If you do not do it, who will?

Courtesy of the Rhode Island Parent Information Network, Adapted from The Network News

THE FOLLOWING IS A LIST OF FEDERAL LAWS THAT PROTECT THE RIGHTS OF PEOPLE WHO ARE DEAF OR HARD OF HEARING.

Section 504 of the Rehabilitation Act of 1973

This law prohibits discrimination on the basis of a disability in programs and activities that receive federal financial assistance, such as in work and education. Section 504 gives eligible children the right to a free and public education and protects them from discrimination or retaliation in an educational setting. Similarly, Section 504 protects people with disabilities from discrimination in public higher education institutions. For more information, visit the US Department of Education website at www.ed.gov

Americans with Disabilities Act of 1990 (ADA Amendment Act of 2008)

The Americans with Disabilities Act (ADA) protects people with disabilities in private sector employment, public services, public accommodation, transportation, and telecommunications. Under ADA, a person with a disability is one who 1) has a mental or physical impairment that substantially limits that person in a major life activity; 2) has a record of such an impairment; 3) is regarded as having such an impairment.

Individuals with Disabilities Education Improvement Act of 2004

The Individuals with Disabilities Education Act (IDEA) is the federal law that requires that all children be given a free and appropriate public education, with meaningful access to the general curriculum, and high expectations and standards. In 2004, changes were made to IDEA that impact children who are deaf or hard of hearing. The new law is called the Individuals with Disabilities Education Improvement Act of 2004. For more information, visit the US Department of Education website at www.ed.gov or www.nationalparentcenters.org/ index.htm.

- ► *IDEA*, *Part B* refers to the services all states are required to provide to children ages 3 through 21, including access to public education.
- ► *IDEA*, *Part C* refers to the services all states are required to provide to children from birth to age three and their families.
- ► IDEA, Part D refers to support provided to states, schools, teachers, and families to improve results for children with disabilities through research, technical assistance, dissemination of information, and other activities that can be most efficiently carried out at the federal level.

Work Incentives Improvement Act of 1999

The Work Incentives Improvement Act of 1999 was designed to remove barriers and provide incentives for people with disabilities to work. This law expands the availability of healthcare coverage for working people with disabilities and provides such individuals with meaningful opportunities to work.

EDUCATIONAL PLACEMENTS

When it comes to making decisions about your child's education, it is important to explore the options and talk with professionals. If you are not satisfied with the educational setting in your local school district, the first step in discussing alternatives is to request that the school district reconvene the IEP team to review and reconsider your child's plan. The laws about education are designed so that families can re-evaluate their child's educational setting and make appropriate changes with help from the IEP team.



READING TO YOUR DEAF OR HARD OF HEARING CHILD

It is important to read to your child and nurture his or her ability to write when the time is appropriate.

TIPS FOR READING TO YOUR DEAF OR HARD OF HEARING CHILD

- » Choose books both you and your child will enjoy together.
- » Make sure your child sees your face, your signs, and the printed words at the same time.
- » Don't be limited by the words. Expand on the book's ideas.
- » Be dramatic. Play with the signs and exaggerate your facial expressions and movements to show different characters.
- » Talk about the story as you read. Ask your child questions and link ideas in the story with your experiences. Have your child guess what will happen next.
- » Keep your child's attention by gently tapping on his or her shoulder or by giving a gentle nudge.
- » Change the locations where you use sign language. Sometimes sign on the page; sometimes sign on the child; sometimes sign in the usual place.
- » Keep a pad or paper nearby so you can sketch an idea or a cue for your child.
- » Read the story over and over if your child asks. This is an important part of your child's language development.
- » Act out the story after you are finished reading.

The following questions may be helpful for families to ask while learning about an educational setting:

- ▶ What are the school's expectations for a student with hearing loss?
- If there is a program for deaf children, are there opportunities to interact with hearing peers?
- ▶ How much experience does the staff have educating students with special needs?
- What is the school's policy about classroom observations by parents and other team members?
- ▶ Is the staff willing to work with professionals from a different facility?
- Will all of the child's needs be met at the school?
- Does the school offer a variety of therapies like speech, occupational, and sign language therapy?

YOU MAY HEAR THE FOLLOWING TERMS ABOUT EDUCATIONAL PLACEMENTS AT YOUR CHILD'S IEP MEETING.

Inclusion

Inclusion means that the deaf or hard-of-hearing student attends classes with hearing peers, usually in their home school district. The school provides appropriate support services that help the child succeed in school. Some students may need a lot of support, and others may need less. Support services may include speech and language therapy, acoustical accommodations, educational audiological consultation, assistive listening systems, interpreters, note-takers, curriculum and test-taking accommodations, resource services, or physical or occupational therapies. Children who are educated in an inclusionary setting usually communicate with spoken language, an English-based sign language, or cued speech.

Self-Contained Classroom

A self-contained classroom is made up of students with hearing loss or other special needs who are taught by a Teacher of the Deaf or special educator. Often, the class is within a public school with typically hearing children. Children educated in this setting may communicate with spoken language, cued speech, or sign language and cannot have their needs met fully through inclusion.

Partially Included

A partially included student spends part of the day in an inclusionary setting and part of the day in a self-contained classroom or resources area of instruction.

NORTHERN RI COLLABORATIVE (NRIC) AUDITORY/ORAL PROGRAM

The Northern RI Collaborative Auditory/Oral Program is a specialized program in oral deaf education for students with hearing loss who benefit from hearing technology and are learning how to listen and talk as their primary means of communicating and learning. The program's mission is to prepare children to successfully join their hearing peers in general early childhood or elementary classroom settings in their home school districts. Through Early Intervention, Preschool and Elementary Intervention, and Education Outreach, the Auditory/Oral Program offers a continuum of support services for children.

THE RHODE ISLAND SCHOOL FOR THE DEAF (RISD)

RISD is a state-funded school located in Providence (PreK-12) that offers educational programs to deaf and hard-of-hearing students and their families. The School's preschool, elementary, middle, and senior high school programs educate deaf and hard-of-hearing students from birth through secondary school using ASL and English. A full-year Transition Academy (post high school) is also offered to prepare young people for college and further career readiness.

Outreach Services

RISD provides Outreach Services to deaf and hard-of-hearing children in typical classrooms throughout the state. Outreach Services include:

- diagnostic assessment,
- placement evaluation,
- monitoring of academic progress,
- classroom consultation,
- ▶ support groups for students and their families
- ▶ audiological support and consultation, and
- transition services.

In addition, RISD provides the following services for teachers and staff:

- Education and training for teachers and support staff working with deaf and hard-ofhearing students in their classrooms
- ► Training for Special Education Directors and their staff about assistive technology

RISD recognizes the challenges that many deaf and hard-of-hearing children experience in schools. Efforts are made to connect these students and their families with others through group meetings, summer camps, and informal get-togethers. Hearing students often visit their friends at RISD and join them for social activities and athletic events.

Integrated Programs

RISD students benefit from interaction with hearing children and adults in preparation for participation in the greater Rhode Island community. RISD encourages parents to involve their children in a variety of community-based programs at a very early age. RISD pre-school and early elementary classes often work with students and teachers from other schools on projects. As students grow, they are offered more formal academic and vocational programs to supplement their course work.

EAST PROVIDENCE HIGH SCHOOL AND EAST PROVIDENCE CAREER TECHNICAL CENTER

Academic and vocational opportunities are offered to high school students at East Providence High School and East Providence Career Technical Center. Students from different communities learn together in small groups, using resources coordinated by RISD the student's district and involving teachers, interpreters, and tutors.

SHARED PROGRAMS WITH THE LOCAL COMMUNITY

Some students chose to be integrated into schools in their own communities. RISD staff work with schools to coordinate schedules and support services.

TRANSITION INTO HIGHER EDUCATION

It is important to start talking with your child about plans for the future when he or she starts middle school. Exploring career or higher education options early will help your child prepare for his or her transition to independence and adult life. Planning for the transition from school to adult life becomes a central part of your child's IEP beginning at age 14. The goal is for your child to become as independent as possible. Your child should take part in the planning, because his or her input will help make the plan more successful.

HIGHER EDUCATION

Colleges and other institutes for higher learning can provide your child with more career choices and a better future. When researching these places, it is important to find out how they accommodate students who are deaf or hard of hearing with services such as interpreters, note-takers, and tutors.

Assistive Devices: Building Independence

As your child grows and experiences new situations, the goals that you have for his or her future will begin to focus on promoting independence. Many assistive devices are available to increase independence during different stages of childhood and the transition to adulthood.

Ability is what you're capable of doing. Motivation determines what you do. Attitude determines how well you do it. ~Lou Holtz

CLASSROOM TECHNOLOGY

COMPUTER ASSISTED NOTE TAKING (C-PRINT)

A captionist (person specially trained to type very fast and accurately) types the lesson notes on a laptop computer on-site in the classroom. The typed notes are shown on a computer or television screen for the student to read. The student receives a typed copy of the notes.

COMMUNICATION ACCESS REAL-TIME TRANSLATION (CART)

A trained typist records every word in the lesson (exactly as the teacher says) using special equipment on-site in the classroom. The student reads the words on a television screen and receives a printout of the lesson.

VIABLE REAL-TIME TRANSCRIPTION (VRT)

VRT is different from C-print and CART because the trained typist who records the teacher's words works in an off-site location, not in the classroom. The teacher's words are transmitted through a microphone, which is connected to a phone line, which is connected to a VRT provider site where there is a trained person who types out the lesson. The text is transmitted via the Internet back to the classroom and is displayed on the student's computer in real time. Real time means approximately one to five seconds delayed. A transcript of the lesson is provided to the student within 24 hours. VRT is based on the latest technology and eliminates scheduling and traveling costs for an on-site transcriptionist.

FM SYSTEMS

A frequency modulation (FM) system, also called an auditory trainer, is an Assistive Listening Device (ALD). The basic function of this device is to improve the "signal to noise ratio" so that wanted sounds (or signals) are louder and unwanted sounds (or noises) are less loud.

Traditionally, FM systems have been used to help children overcome problems listening in noisy classrooms. With an FM system, the teacher wears a small microphone and transmitter and the child wears a hearing aid and receiver. The sound is transmitted directly from the teacher to the child.

Many pediatric audiologists also recommend FM systems for use outside the classroom on family outings and field trips or while watching television, because background noises, echoes, or distance can make listening difficult. For more information on FM systems, see the "Hearing Technology" section of this guide.

TELEPHONES

AMPLIFIED TELEPHONES

Even with hearing aids, some children will need extra amplification to use a telephone. Amplified telephones make the voices on the telephone louder.



T-SWITCH

A T-switch is a feature on some hearing aids that helps wearers hear better on the telephone. The T-switch allows the wearer to switch between the normal microphone "on" setting to a "T" setting that eliminates background noise so the wearer only hears sounds from the telephone. The "T" setting can also be used with FM systems installed in classrooms, theatres, and auditoriums.

TELETYPEWRITER (TTY)

Understanding voices on the telephone can be difficult for children with severe hearing loss. A teletypewriter (TTY) is a device that allows people who are deaf, hard of hearing, or speech impaired to have phone conversations using typed messages. As your child learns to read and write, a TTY or wireless messaging system can provide him or her with more independence in communicating with friends and family. A TTY is also known as a telecommunications device for the deaf (TDD).

TELECOMMUNICATIONS RELAY SERVICE (TRS)

TRS allows people who are deaf, hard of hearing, or speech impaired to communicate through a communications assistant (CA). The CA is a third party on the phone line who uses TTY or speech to relay messages and responses exactly as they are received from the callers. TRS can be reached by dialing 711 on all phones in the United States. The relay service is free. All relay calls are confidential.

There are two options when using TRS: voice carry-over (VCO) and hearing carry-over (HCO). Voice carry-over allows a person with hearing loss to speak directly to another party and then read the response that is typed by the communications assistant using a telephone typewriter. With hearing carry-over, a person with speech impairment uses a telephone typewriter to communicate and the communications assistant verbally relays the message to the other party. These services allow people with communication disorders to communicate with all telephone users.

For more information on telecommunications relay services, please visit the Federal Communications Commission website at http://ftp.fcc.gov/cgb/dro/trs/con_trs.html

VIDEO RELAY SERVICE

Video Relay Service (VRS) enables people who are deaf or hard of hearing who use American Sign Language (ASL) to communicate with voice telephone users through video equipment, rather than through typed text. The VRS caller, using a television or a computer with a video camera device and high-speed Internet connection, contacts a VRS communications assistant (CA), who is a qualified sign language interpreter. They communicate with each other in sign language through a video link. The VRS CA then places a telephone call to the party the VRS user wishes to call. The VRS CA relays the conversation back and forth between the parties—in sign language with the VRS user, and by voice with the called party.

The VRS CA can be reached through the VRS provider's Internet site, or through video equipment attached to a television. Currently, more than a half dozen providers offer VRS. Like all TRS calls, VRS is free to the caller. A voice telephone user can also initiate a VRS call by calling a VRS center.

INTERNET PROTOCOL (IP) RELAY

Internet Protocol (IP) Relay allows people who have difficulty hearing or speaking to communicate with anyone through an Internet connection. IP Relay is accessed using a computer and the Internet. The first leg of an IP Relay call goes from the caller's computer, or other web-enabled device, to the IP Relay Center via the Internet. The IP Relay Center is usually accessed via a web page. The second leg of the call is from the communications assistant (CA) to the receiving party via voice telephone. The CA can also accept IP relay calls from people with hard-to-understand speech and repeat the calls in an easily understandable form for the called party. There are no additional costs to consumers for IP Relay beyond a computer or other web-capable device and an Internet connection.

KEEPING IN TOUCH WITH OTHERS

TEXT RELAY

Text relay connects people using a textphone with people using a telephone or another textphone. It lets deaf, hard-of-hearing, and speech-impaired people stay in touch with friends and family and call businesses over the phone.

VIDEO REMOTE INTERPRETING

Video remote interpreting is a videotelecommunication service that uses devices such as web cameras or videophones to provide sign language or spoken language interpreting services. This is done through a remote or offsite interpreter, in order to communicate with people with whom there is a communication barrier.

TECHNOLOGY FOR FOR THE HOME

PERSONAL AMPLIFIER

This assistive device connects to a hearing aid and sends sound directly from the television to the hearing aid. The hearing aid must have a direct audio input (DAI) to accommodate this device.

CLOSED CAPTIONING

Closed captioning enables someone who is deaf or hard of hearing to understand what is being said on television by printing the words on the top or bottom of the television screen. Televisions are made with a closed captioning option already included. A television can be switched to the closed captioning setting at any time.

SAFETY/ALERTING DEVICES AND TACTILE AIDS

Alerting devices and tactile aids provide visual or vibratory signals to help people who are deaf or hard of hearing improve their ability to communicate within their surroundings. Special lights that are linked electronically to doorbells, telephones, alarm clocks, or smoke detectors can be used as alerting devices. Wrist vibrators or vibrating beepers and alarms are tactile aids that alert the wearer to speech and other sounds.



Glossary

ABR/AUDITORY BRAINSTEM RESPONSE

A non-invasive test that measures the hearing potential of the auditory nerve from the cochlea through the brainstem. Responses are evoked from an auditory stimulus and are measured in five to seven waveform peaks. The automated version is used for infant hearing screening. A sleep state or sedation is required for infants and toddlers.

ACQUIRED HEARING LOSS

Hearing loss that is not present at birth but develops later in life.

ADVOCACY

The role parents or guardians play in developing and monitoring their child's educational program. Advocating for your child means knowing what rights are assured you by the law and actively participating in the decision-making process to ensure that the services are delivered in line with your goals for your child's development and education.

AMPLIFICATION

The use of hearing aids or other electronic devices to increase the loudness of sounds so that they may be more easily heard and understood.

ASSISTIVE COMMUNICATION DEVICES

Devices and systems which are available to help deaf and hard-of-hearing people improve communication, adapt to their environment, and function more effectively.

These include personal hearing instruments, frequency modulation (FM) systems, infrared, special connectivity devices for telephone, television, computer use, and amplified or visual alarms and signals.

AUDIOGRAM

A graph on which a person's ability to hear different pitches (frequencies) at different volumes (intensities) of sound is recorded.

AUDIOLOGICAL ASSESSMENT

An evaluation of hearing ability that is minimally comprised of pure-tone thresholds and speech and word recognition measurements to determine the type and degree of hearing loss. Additional measures such as acoustic immittance, acoustic reflex, otoacoustic emissions, speech-in-noise, and procedures to identify the need for amplification or verify the fitting of amplification are included as needed.

AUDIOLOGIST

Hearing loss specialists who are qualified to prescribe hearing aids if necessary. Audiologists perform testing and help you understand the results.

AUDITORY DISCRIMINATION

The ability to pick up differences in sounds and words.

AUDITORY NEUROPATHY/DYSYNCHRONY

An auditory disorder that disrupts the synchronous activity of the hearing system. There is high variability in individual effects. The most common complaint is of hearing sounds but not comprehending what is heard. Hearing ranges from normal to severe hearing loss, and some individuals improve over time. Treatment also varies.

AUDITORY NERVE

The nerve in the inner ear that leads to the brain. It is responsible for carrying nerve messages, resulting from sound stimulation, to the brain.

BILATERAL HEARING LOSS

A hearing loss of any degree that is in both ears.

BILINGUAL/BICULTURAL

Knowing or being fluent in two languages and comfortable in two cultures. For a person who is deaf, these words refer to someone who can "speak" both American Sign Language and English and is comfortable in both Deaf and Hearing Cultures.

BIMODAL

Knowing and being fluent in sign language and English. Able to "code switch" as needed.

BINAURAL

Hearing with both ears.

BINAURAL HEARING AIDS

Hearing aids worn on both ears.

COCHLEAR IMPLANT

An electronic device that is surgically implanted in the cochlea of the inner ear. It transmits auditory information directly to the brain, by-passing damaged or absent auditory nerves. Technically, it synthesizes hearing of all sounds, but the wearer requires training to attach meaning to the sounds. This is called auditory "habilitation", or "rehabilitation". Typically, cochlear implant users have severe to profound hearing losses and do not get much benefit from hearing aids. Successful cochlear implant users gain useful hearing and improved communication abilities.

The Food and Drug Administration (FDA) has approved cochlear implants for qualified candidate adults and children starting at age 12 months.

COGNITIVE

Refers to the ability to think, learn, and remember.

CONDUCTIVE HEARING LOSS

Impairment of hearing due to failure of sound to reach the inner ear through the normal air conduction of the outer and middle ear. In children, conductive loss is typically medically correctable, and is most often associated with otitis media. Some children will have permanent conductive hearing loss due to structural abnormalities of the ear such as an absent canal opening (atresia) or as a result of chronic middle ear disease.

CT SCAN

Stands for computerized tomography and sometimes called a CAT scan. It is a medical procedure that combines a series of X-ray views taken from many different angles and computer processing to create cross-sectional images of the body.

CUED SPEECH

A mode of communication using the mouth and hand to visually distinguish the phonemes of English spoken language. There are eight handshapes (cues) indicating groups of consonants and four positions around the face indicating vowel sounds.

DEAF

Spelled with a small "d," it refers to the phenomenon of being audiologically deaf. A child who is audiologically deaf has a hearing loss so severe that he or she cannot adequately process information through hearing, with or without an amplification device.

Spelled with a capital "D," it refers to a specific linguistic and cultural identity, namely a person whose primary language is American Sign Language and who identifies with the Deaf Community.

DEAF COMMUNITY

A group of people who share common interests and a common heritage. They use American Sign Language to communicate and identify as being culturally Deaf.

DEAF CULTURE

Traditions, values, beliefs, heritage, social networks, political goals, artistic expressions, attitudes, and language that are particular to deaf people, stemming from a history of shared experiences and common oppressions.

DECIBEL

Unit of measurement for the loudness of sound. The higher the decibel, the louder the sound.

DEVELOPMENTAL DELAY

A delay in the development of certain skills, such as crawling and talking, by an expected age. Hearing loss may impact a child's language development.

EARMOLD

A custom-made plastic or vinyl piece which fits into the outer ear to connect with a hearing aid.

ELIGIBILITY

A child must be determined eligible for special education services based on specific disabling conditions and an exhibited delay as a result of that condition.

ENT

A medical doctor who specializes in the treatment of problems of the ears, nose, and throat. Sometimes referred to as an otolaryngologist or otologist (see also otologist).

ENVIRONMENTAL SOUNDS

All sounds that take place around us, but not including speech sounds.

FEEDBACK

The whistling sound made when amplified sound goes back into a microphone. In a hearing aid, feedback can occur when an ear mold does not fit well and the amplified sound goes back into the hearing aid microphone. If feedback continues, it should be discussed with the child's healthcare provider.

FM SYSTEM

A hearing assistance device that transmits the speaker's voice via a frequency modulated signal to an electronic receiver worn by the listener. The receiver may be in a hearing aid, earphones or earbuds, or a speaker. The device reduces the problem of background noise interference and the problem of distance from the speaker.

FREQUENCY

Another word to describe the pitch (or highness or lowness) of a sound.

GENETIC HEARING LOSS

Hearing loss that is caused by one of more than several hundred genes that are known to cause hereditary hearing loss (hearing loss passed from parents to their children). About 50-60% of all hearing loss is genetic. The hearing loss can be part of a syndrome (meaning the child has other medical problems) or non-syndromic (meaning the child has no other medical problems).

HARD OF HEARING

A hearing loss that can be permanent or changing, and that affects a person's ability to detect or understand some sounds, including speech. The term "hard of hearing" is preferred by the Deaf and hard-of-hearing community over the term "hearing impaired" when referring to people who have hearing loss and use remaining hearing to communicate.

HEARING AID

An electronic device that amplifies and delivers sound to the ear. The purpose of a hearing aid is to improve speech reception and intelligibility.

HEARING IMPAIRED

Clinical or medical term used to describe a child whose hearing is below the normal range. It is not the term generally preferred by people who have a hearing loss.

HEARING SCREENING

A hearing evaluation that is designed to identify children who require further audiologic testing.

HUGGIES

A device that helps keep hearing aids in place on a child's ear.

IDEA

The Individuals with Disabilities Education Act (IDEA), a federal law that ensures all eligible children with disabilities access to free and appropriate public education. Children who are deaf or hard of hearing are included in IDEA.

INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)

A written document that includes information on the child's present levels of functioning and the family's concerns, priorities, and resources. The IFSP team, which includes the family, will use the IFSP to document the outcomes expected to be achieved for the child and family and the services and support needed to accomplish them. The IFSP is reviewed at least every six months to document progress and assess outcomes.

INTENSITY (OF SOUND)

The loudness of sound, measured in decibels.

INTERPRETER

A person who facilitates communication between hearing and deaf or hard-of-hearing people through interpretation into a signed language, or transliteration of a language into a visual and/or phonemic code.

LANGUAGE

Structured use of symbols by which a group of people communicate. Language can be spoken, written, or signed.

LISTENING AGE

The length of time a child has had the chance to listen and learn either through existing hearing or with a hearing aid or another assistive device. A child with a listening age of one year might be just beginning to use words even though his or her chronological age is older.

MAINSTREAMING

Educational placement of students with disabilities into selected general education classrooms, for some parts of the school day, based on the student's IEP. This placement decision is rooted in the philosophy that children with disabilities should be integrated with their non-disabled peers when appropriate to the needs of the child with a disability. The term differs from inclusion in that inclusion implies that the child is a member of the general education classroom and removed for services only when necessary as determined by the IEP.

MANUAL BABBLING

The early hand shapes used by infants or toddlers who see sign language in their everyday surroundings. As with speech babbling, early manual babbling may not represent any true signs or words. Later manual babbling may be used as part of a young child's beginning communication.

MIXED HEARING LOSS

A combination of conductive and sensorineural components that make up the hearing loss.

MONAURAL

Hearing with only one ear.

MONAURAL AMPLIFICATION

The use of one hearing aid instead of two.

MULTI-DISCIPLINARY ASSESSMENT

An assessment of a child's strengths and needs conducted by two professionals of different disciplines.

NATIVE LANGUAGE

The language spoken in a child's home. This could include American Sign Language (ASL), Spanish, or any other language.

ORAL

A reference to the communication ability of an individual who is deaf or hard of hearing to use spoken language as a modality by which to communicate.

OTOACOUSTIC EMISSION (OAE)

The OAE is a soft sound that is produced by the normal functioning cochlea. The OAE test verifies cochlear function without participation of the child. The procedure is quick and a routine part of assessment for infants and young children suspected of having hearing loss; automated versions are used for infant screening. The test consists of a probe placed in the ear canal that emits an auditory signal and measures the resulting response of the auditory nerve. There are 2 types of OAE tests: transient (TEOAE) and distortion product (DPOAE). OAEs are primarily used to diagnoses sensorineural hearing loss but also provide information about the conductivity of the middle ear system.

OTOLOGIST

A physician who specializes in medical problems of the ear (see also ENT).

PART B

Part B is the section of the Individuals with Disabilities Education Act (IDEA) that refers to special education and support services available to eligible children aged 3 through 21 in the public schools

PART C

Part C is the section of the Individuals with Disabilities Education Act (IDEA) that refers to diagnostic and early intervention services available to eligible children from birth through two years of age and their families.

PITCH

Highness or lowness of sound.

PRE-LINGUAL DEAFNESS

Hearing loss that is congenital (at birth) or develops before learning a language.

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PROGRESSIVE HEARING LOSS

Hearing loss that gets worse over time.

RESIDUAL HEARING

The remaining hearing used by a person with a hearing loss.

SIGN LANGUAGE

Sign language uses the hands, face, and body to express language. There are many sign languages. Some examples are American Sign Language (ASL), Italian Sign Language, and French Sign Language.

SPEECH-LANGUAGE PATHOLOGIST

A professional who works with individuals who have speech and language disorders.

TEACHER OF THE DEAF OR HARD OF HEARING

A person certified by the Rhode Island Department of Education to teach the deaf or hard of hearing.

THRESHOLD (OF SOUND)

The softest level at which sound is heard.

UNILATERAL HEARING LOSS

Hearing loss that affects only one ear or one side of the head or body.

VIDEO RELAY/VIDEO PHONE

Video Relay Service (VRS) is a communication technology where the deaf and hearing consumers are in different locations and are linked through an interpreter provided through a relay center. Users of VRS must have equipment that allows them to send their image to the Relay Center. Once connected, a deaf caller can simply sign a message to the sign language interpreter, who conveys it to the person called. That person, in turn, can reply and the interpreter will transmit the message in sign language back to the deaf caller.

VISUAL REINFORCEMENT AUDIOMETRY (VRA)

A method of assessment in which the child is conditioned to respond to sound using a toy that lights each time he or she hears the sound as reinforcement; used with young children.

Acronyms

AAA

American Academy of Audiology

AABR

Automated Auditory Brainstem Response (a type of hearing evaluation)

ABR

Auditory Brainstem Response (a type of hearing evaluation)

ALD

Assistive Listening Device

ASDC

American Society for Deaf Children

ASHA

American Speech-Language-Hearing Association

ASL American Sign Language

ASSR

Auditory Steady State Evoked Response (a type of hearing test)

AVI

Auditory-Verbal International (a non-profit organization)

BCDC

Boston Center for Deaf and Hard of Hearing Children

BTE

Behind the Ear Hearing Aid

CA

Communications Assistant

CART

Computer Assisted Real-Time Transcription (an assistive device for the classroom)

CEDARR

Comprehensive Evaluation, Diagnosis, Assessment, Referral, Re-Evaluation Family Center

CIC Completely in the Canal Hearing Aid

CMP Captioned Media Program

C-PRINT

Computer Assisted Note Taking (an assistive device for the classroom)

DAI Direct Audio Input (a hearing aid feature)

DCYF

Department of Children, Youth, and Families

DHS Department of Human Services

EI

Early Intervention

ENT Ear, Nose, and Throat doctor

EPSDT Early Periodic Screening, Diagnosis, and Treatment Program

FM Frequency Modulation

(a sensory aid system)

HBTS Home-Based Therapeutic Services

нсо

Hearing Carry-Over (a relay service option)

IDEA

Individuals with Disabilities Education Act

IEP Individualized Education Program

IFSP

Individualized Family Service Plan

IP Internet Protocol Relay

ITC In the Canal Hearing Aid

ITE In the Ear Hearing Aid

NAD National Association of the Deaf

NCHAM National Center for Hearing Assessment and Management

NCSA

National Cued Speech Association

ΟΑΕ

Otoacoustic Emissions (a type of hearing evaluation)

PARI

People Actively Reaching Independence (a non-profit organization)

PASS

Personal Assistant Services and Supports

PIP

Parent Infant Partners

PPEP

Pediatric Practice Enhancement Project

RECD

Real-Ear-to-Coupler-Difference (a type of hearing aid test)

RIAD

Rhode Island Association of the Deaf

RICDHH

Rhode Island Commission on the Deaf and Hard of Hearing

RIDE

Rhode Island Department of Education

RIHAP Rhode Island Hearing Assessment Program

RIPIN Rhode Island Parent Information Network

RISD

Rhode Island School for the Deaf

SHHH

Self Help for Hard of Hearing People

SSI

Supplemental Security Income

тс

Total Communication

TDD

Telecommunications Device for the Deaf

TLC

The Learning Center for Deaf Children

TRS

Telecommunications Relay Service

ттү

Teletypewriter

vco

Voice Carry-Over (a relay service option)

VRA

Visual Reinforcement Audiometry (a type of hearing evaluation)

VRS

Video Relay Service

VRT

Viable Real-Time Transcription (an assistive device for the classroom)

Local Resources

ADOPTION SUBSIDY

Children in Adoption Subsidy may qualify for Medical Assistance. The Adoption Subsidy Program is administered through the Department of Children, Youth and Families (DCYF).

Rhode Island Department of Children, Youth, and Families Adoption Services Unit 101 Friendship Street, Providence, RI 02903 Phone: 401-254- 7021 Website: www.dcyf.ri.gov

ASL ACADEMY

ASL Academy is a language program designed to bring students all the way to fluency. Its teaching approach builds progressive skills to allow students to reach that goal. ASL Academy's approach aims to take the shortest route to putting information into students' long-term memory.

391 Main St, Pawtucket, RI 02860 Phone: 401-722-1022 Website: www.aslacademy.org

ASSISTIVE TECHNOLOGY ACCESS PARTNERSHIP (ATAP) REHABILITATION CENTER

ATAP is a statewide partnership of organizations and agencies, each with a targeted assistive technology focus, working together to provide information and improve access to assistive technology for individuals with disabilities. ATAP works closely with other state advocacy projects.

40 Fountain Street, Providence, RI 02903 Phone: 401-421-7005 ext 421 TTY: 401-421-7016 Fax: 401-222-3574 Website: www.atap.ri.gov

BOSTON CENTER FOR DEAF AND HARD OF HEARING CHILDREN (BCDC)

BCDC is an interdisciplinary clinical and research group within the Department of Otolaryngology and Communication Disorders at Boston Children's Hospital. The clinical team includes specialists in psychology, audiology, education, medicine, speech and language, psychiatry, and communication. BCDC provides comprehensive evaluation and consultative services to deaf and hard-of-hearing infants, children, and teenagers, and their families. BCDC coordinates evaluations, referrals, research, guidance, and information for families.

Boston Children's Hospital at Waltham 9 Hope Avenue, Waltham, MA 02453 Phone: 781-216-2215 TTY: 781-647-8913 Website: www.childrenshospital.org

BRIGHT STARS

Bright Stars helps families in Rhode Island access quality child care, early learning, and school-age programs.

535 Centerville Road, Suite 301 Warwick, Rhode Island 02886 Phone: 401-739-6100 Fax: 401-739-6101 Website: www.brightstars.org

BRISTOL COMMUNITY COLLEGE

Bristol Community College offers classes in American Sign Language.

777 Elsbree Street, Fall River, MA 02720 Phone: 508-678-2811 Website: www.bristol.mass.edu

BROWN UNIVERSITY

Brown University offers classes in American Sign Language.

Center for Language Studies PO Box 1982 Providence, RI 02912 Phone: 401-863-3043 Website: www.brown.edu

CEDARR FAMILY CENTERS OF RHODE ISLAND

CEDARR (Comprehensive Evaluation, Diagnosis, Assessment, Referral, Re-Evaluation) Family Centers offer families information on specific disabilities, clinical expertise, referrals to community supports, and assistance for their children with special healthcare needs. There are four CEDARR Family Centers in Rhode Island that serve families statewide:

About Families 203 Concord Street, Suite 335 Pawtucket, RI 02860 Phone: 401-365-6855 Website: www.aboutfamilies.org

Empowered Families CEDARR 1471 Elmwood Ave. Cranston, RI 02910 Phone: 401-383-3669. 888-881-6380 Website: www.empoweredfamilies.org

Families First CEDARR Center Hasbro Early Intervention 335R Prairie Ave, Providence, RI 02905 Phone: 401-444-7703

Solutions CEDARR 134 Thurbers Avenue, Suite 102 Providence, RI 02905 Phone: 401-461-4351, 800-640-7283 Website: www.solutionscedarr.org

CLARKE SCHOOLS FOR HEARING AND SPEECH

Clarke offers educational assessment, planning, and resources for deaf or hard-of-hearing children from birth through age 21. Clarke also provides audiological services, including assistive listening devices, and residential and day school for preschool through eighth grade students.

47 Round Hill Road, Northhampton, MA 01060 Phone: 413-584-3450 TTY: 413-584-3450 Fax: 413-584-8273

1 Whitman Road, Canton, MA 02021 Phone: 781-821-3499 TTY: 781-821-3904 Fax: 781-821-3905 Website: www.clarkeschools.org

COMMUNITY COLLEGE OF RHODE ISLAND

Community College of Rhode Island offers classes in American Sign Language.

400 East Avenue, Warwick, RI 02886 Phone: 401-825-1000 Website: www.ccri.edu

DUAL SENSORY IMPAIRMENT PROJECT PAUL V SHERLOCK CENTER ON DISABILITIES RHODE ISLAND COLLEGE

The Dual Sensory Impairment Project provides family and professional support, coordination of services, information, technical assistance, and training to children with dual sensory impairments, from birth through 22 years of age.

Paul V. Sherlock Center on Disabilities Rhode Island College 600 Mount Pleasant Avenue, Providence, RI 02908 Phone: 401-456-8072 TTY: 401-456 8773

EARLY INTERVENTION PROGRAM (EI)

Early Intervention is a comprehensive and coordinated system of home and communitybased services and supports for families of infants and toddlers with developmental disabilities or delays. The purpose of Early Intervention is to:

- 1. enhance the developmental functioning of infants and toddlers with special needs and
- 2. enhance the capacity of families to meet the special needs of their infants or toddlers.



EARLY INTERVENTION PROGRAM (EI)

Children's Friend & Service

621 Dexter Street Central Falls, RI 02863-2603 Phone: 401-721-9200, Fax: 401-729-0010

Community Care Alliance

245 Main Street Woonsocket, RI 02895-3123 Phone: 401-766-0900, Fax: 401-766-8737

Easter Seals, RI

213 Robinson Street Wakefield, RI 02879 Phone: 401-284-1000, Fax: 401-284-1006

Family Service of RI

134 Thurbers Avenue Providence, RI 02905-4754 Phone: 401-331-1350, Fax: 401-277-3388

The Groden Center

30 Livingston Street Providence, RI 02904 Phone: 401-525-2380, Fax: 401-525-2382

Hasbro Children's Hospital

765 Allens Ave Suite 110 Providence, RI 02905 Fall 2014 Hasbro EI is moving to: 335R Prairie Avenue All other information is the same Phone: 401-444-3201, Fax: 401-444-8507 Referral line: 444-3201

Developing Dreams

at the James L. Maher Center 120 Hillside Avenue Newport, RI 02840-1227 Phone: 401-848-2660, Fax: 401-847-9459 Seven Hills Rhode Island 178 Norwood Ave. Cranston, RI 02905 Phone: 401-921-1470, Fax: 401-762-0837

J. Arthur Trudeau Memorial Center 3445 Post Road Warwick, RI 02886 Phone: 401-823-1731, Fax: 401-823-1849 25 West Independence Way Kingston, RI 02881 Phone: 401-284-1980, Fax: 401-284-1979

Looking Upwards, Inc. 2974 East Main Road Portsmouth, RI 02871 Mailing Address: PO Box 838 Portsmouth, RI 02871 Phone: 401-293-5790, Fax: 401-293-5796

Meeting Street

1000 Eddy Street Providence, RI 02905 Phone: 401-533-9100, Fax: 401-533-9102 Referral line: 401-533-9104 RI Early Intervention, Lead Agency

Executive Office of Health and Human Services Center for Child and Family Health

Hazard Building #74 74 West Road Cranston, RI 02920 Part C Coordinator and Chief, Family Health Systems: Brenda DuHamel Phone: 401-462-0318

EXECUTIVE OFFICE OF HEALTH AND HUMAN SERVICES (EOHHS)

In Rhode Island, EOHHS oversees programs and services for children, adults, and families including Early Intervention, Medical Assistance, and CEDARR.

74 West Road, Cranston, RI 02920 Phone: 401-462-5300, 800-244-8700, Spanish: 401-462-1500 TTY: 401-462-3363 Website: www.eohhs.ri.gov

FAMILY VOICES AT RHODE ISLAND PARENT INFORMATION NETWORK

Family Voices offers information and education about ways to improve healthcare for children with disabilities and chronic conditions. The Family Voices network includes families, coordinators in each state and region, and a national staff. Members of the network serve on local, state, and national boards and task forces; as staff for state health agencies or parent organizations; and as advisors to private and public health systems and research projects. Their mission is to bring the family perspective into policy discussions and decisions.

1210 Pontiac Avenue, Cranston, RI 02920 Phone: 401-270-0101 Fax: 401-270-7049 Toll-Free: 800-464-3399 Website: www.ripin.org

GALLAUDET UNIVERSITY REGIONAL CENTER

Gallaudet University Regional Center offers several programs for families. The Family Sign Language Program offers deaf or hard-of-hearing tutors to visit a family's home. The goal of this program is to introduce family members to Sign Language, enabling them to communicate with their child at the earliest age possible. The Shared Reading Project (SRP) is designed to teach parents and caregivers how to read to their deaf and hard-of-hearing children using American Sign Language, and to use strategies to make book sharing most effective.

Northern Essex Community College 100 Elliott Way, Haverhill, MA 01830-2397
GOVERNOR'S COMMISSION ON DISABILITIES

The Commission's goal is to ensure that all people with disabilities are given the opportunities to exercise their rights and responsibilities as Rhode Island citizens and that each person with a disability is able to reach his or her maximum potential in independence, human development, productivity, and self-sufficiency. The Commission is responsible for ensuring that state agencies comply with the state and federal disability rights laws. The Commission acts as a mediator in solving disability discrimination complaints and explores options for resolving the complaints.

John O. Pastore Center 41 Cherry Dale Court, Cranston, RI 02920-3049 Phone: 401-462-0100, Fax: 401-462-0106 TTY: 401-462-0101 Website: www.disabilities.ri.gov

HASBRO CHILDREN'S HOSPITAL COCHLEAR IMPLANT PROGRAM

A cochlear implant is a device that provides stimulation directly to the auditory nerve, bypassing damaged hair cells in the cochlea that prevent sound from reaching the nerve. An implant does not result in "restored" hearing for the recipient, but does allow him or her to perceive sounds.

Audiology and Speech Pathology 115 Georgia Avenue, Providence, RI 02905 Phone: 401-444-5485 Website: www.hasbrochildrenshospital.org/Cochlear_Implant_Program.html

HEALTH INFORMATION LINE

The Health Information Line at the Rhode Island Department of Health is a toll-free service providing answers to questions and referrals to programs and services that improve the health of families. Available to callers from Rhode Island in English and Spanish, Monday-Friday from 8:30am to 4:30pm.

Phone: 401-222-5960 / RI Relay 711

THE LEARNING CENTER FOR DEAF CHILDREN (TLC)

The Learning Center for Deaf Children serves deaf and hard-of-hearing students from infancy through high school. TLC is comprised of three schools—a comprehensive Parent/Infant through High School program in Framingham, MA; a satellite program in Randolph, MA, which was established in 1994 to better serve the southeastern region; and Walden School, a therapeutic treatment program for deaf students with severe emotional, behavioral, or developmental disturbances.

848 Central Street, Framingham, MA 01701 Phone: 508-879-5110 TTY: 508-879-5110 Website: www.tlcdeaf.org

MEETING STREET

Meeting Street provides services such as occupational, physical, speech, auditory integration, and sensory integration therapies on an out-patient basis.

1000 Eddy Street, Providence, RI 02905 Phone: 401-533-9100 Fax: 401-533-9101 EI: 401-533 9104 Website: www.meetingstreet.org

MEMORIAL HOSPITAL OF RHODE ISLAND, AUDIOLOGY DEPARTMENT

The Audiology Department at Memorial Hospital offers hearing aid prescription and fitting, instruction in use and care of hearing aids, communication skills training, and assistive listening devices for telephone, television, and general alert.

111 Brewster St., Pawtucket, RI 02860 Phone: 401-729-2022 or 401-729-2316 Fax: 401-729- 2680 Website: http://www.mhri.org/ss_plugins/content/content.php?content.8004

NEIGHBORHOOD HEALTH PLAN OF RHODE ISLAND

Neighborhood Health Plan of Rhode Island offers a specialized care management program for children with special healthcare needs. Through this program, children with special healthcare needs, who do not have other health insurance coverage, may be eligible for Medicaid through SSI, Katie Beckett, or Adoption Subsidy.

299 Promenade St., Providence, RI 02908 Phone: 401-459-6000, 800-963-1001 Fax: 401-459-6066 Website: www.nhpri.org

NEW ENGLAND CENTER FOR HEARING REHABILITATION (NECHEAR)

NECHEAR is a rehabilitation facility designed to meet the needs of infants, children, and adults with hearing loss and their families. Auditory-verbal techniques are used to facilitate the acquisition of spoken language, thus following full integration into communities. NECHEAR staff has expertise in implementing rehabilitation programs and supporting mainstream education for infants, children, and prelingual adults with cochlear implants.

354 Hartford Turnpike (Rte 6), Hampton, CT 06247 Phone: (860) 455-1404 Fax: (860) 455-1396 Website: www.nechear.com

NORTHERN RI COLLABORATIVE (NRIC) AUDITORY/ORAL PROGRAM

The Northern RI Collaborative Auditory/Oral Program is a specialized program in oral deaf education for students with hearing loss who benefit from hearing technology and are learning how to listen and talk as their primary means of communicating and learning. The program's mission is to prepare children to successfully join their hearing peers in general early childhood or elementary classroom settings in their home school districts. Through Early Intervention, Preschool and Elementary Intervention, and Education Outreach, the Auditory/Oral Program offers a continuum of support services for children.

Orchard Farms Elementary School 1555 Scituate Avenue, Cranston, RI 02921 Phone: 401-270-8725 Website: www.nric-ri.org

PARENT INFANT PARTNERSHIP

The Parent Infant Partnership at the Rhode Island School for the Deaf is a program for families with children who are deaf or hard of hearing. It provides consultation services from trained professionals in the field of deafness and hearing loss. The Parent Infant Partnership provides all families with the support, guidance, skills, and information needed to make decisions and advocate for their child. The staff and parents work together to develop programs that are tailored to meet the individual needs of each child and family.

Rhode Island School for the Deaf 1 Corliss Park, Providence, RI 02908-1795 Phone: 401-222-3525 Website: www.rideaf.net

PEDIATRIC PRACTICES ENHANCEMENT PROJECT (PPEP)

PPEP is an initiative sponsored by the Rhode Island Departments of Health and Human Services to support primary care pediatric and family practices dedicated to serving children with special healthcare needs and their families. PPEP provides parent consultants from the Rhode Island Parent Information Network (RIPIN) in selected practices to help families access information, resources, and community services, including CEDARR. Participating practices include:

Bald Hill Pediatrics

315 Commonwealth Ave Warwick, RI 02886 Phone: 401-615-2299

Dr. Robert Burke Hasbro Children's Hospital, Lower Level 593 Eddy Street, Providence, RI 02903 Phone: 401-444-8448

Center for Southeast Asians Xong Yang 270 Elmwood Ave Providence, RI 02907 Phone: 401-274-8811 x12

Coastal Waterman Pediatrics

900 Warren Ave East Providence, RI 02914 Phone: 401-421-6481

East Greenwich Pediatrics

1377 South County Trail, Suite 2B East Greenwich, RI 02818 Phone: 401-884-8900

Dr. Cheryl Flynn 2 Wake Robin Road Lincoln, RI 02865 Phone: 401-333-1656 Fax: 401-333-3104 Hasbro Children's Rehabilitation Center

765 Allens Ave. Suite 200 Providence, RI 02903 Phone: 401-432-6806

Hillside Family Medicine 727 East Avenue

Pawtucket, RI 02860 Phone: 401-725-6160

Narragansett Bay Pediatrics 70 Kenyon Ave Wakefield, RI 02879 Phone: 401-789-5924

Park Pediatrics, Inc 801 Park Ave Cranston, RI 02910 Phone: 401-274 6575

Partnering with Parents Women & Infants Hospital (NICU) 300 Richmond St Providence, RI 02903 Phone: 401-274-1122

Patient & Family Centered Care 593 Eddy Street Providence, RI 02903 Phone: 401-274-1122

Pediatric Associates, Inc. 450 Veterans Memorial Pkwy #10 East Providence, RI 02914 Phone: 401-438-6665

Rhode Island Hearing Assessment Program, Women & Infants Hospital

134 Thurbers Ave. Suite 215 Providence, RI 02905 Phone: 401-453-7750

Rhode Island Hospital/ Hasbro Children's Hospital, Asthma Program

Annex Bldg. #316 593 Eddy Street Providence, RI 02907 Phone: 401-444-2955

South County Pediatric Group, Inc.

4979 Tower Hill Road Wakefield, RI 02879 Phone: 401-789-6492

St. Joseph Hospital, Asthma Program 23 Peace Street Providence, RI 02907 Phone: 401-456-4310, 401-222-4040

Samuels Sinclair Dental Center Rhode Island Hospital Shirley A. Spater, DMD 593 Eddy Street

Providence, RI 02903 Phone: 401-444-5284 **Dr. Susan Stuart** 46 Wells Street Westerly, RI 02891 Phone: 401-596-0174

Thundermist Health Center 450 Clinton Street Woonsocket, RI 02895 Phone: 401-767-4100

Toll Gate Pediatrics

176 Toll Gate Road Suite 101 Warwick, RI 02886 Phone: 401-737-9240

Transition Consultation Clinic

245 Chapman Street, Suite 100 Providence, RI 02905 Phone: 401-444-6118 Fax: 401-444-7938

Wood River Health Services 823 Main Street

Hope Valley, RI 02832 Phone: 401-539-0228 Fax: 401-539-2663

PERSPECTIVES CORPORATION

Perspectives Corporation is a home-based program designed to provide intensive, therapeutic support services for deaf or hard-of-hearing children with additional emotional or behavioral health needs.

1130 Ten Rod Road, Building C, Suite 101, North Kingston, RI 02852 Phone: 401-294-3990 Fax: 401-294-9879 Video: 401-354-7799 Website: www.perspectivescorporation.com

RHODE ISLAND ASSOCIATION OF THE DEAF (RIAD)

The mission of the Rhode Island Association of the Deaf is to advocate for and improve the quality of life for members of Rhode Island's Deaf community. RIAD works to improve awareness, conditions, and opportunities for its members in all aspects of life.

PO Box 40853, Providence, RI 02940-0853 Website: www.riadeaf.org/index.htm

RHODE ISLAND COMMISSION ON THE DEAF AND HARD OF HEARING (RICDHH)

The Rhode Island Commission on the Deaf and Hard of Hearing provides information and referrals in response to questions about deafness and hearing loss. The Commission helps deaf and hard-of-hearing people find interpreters and advocates for equal accessibility to services. The Commission has a lending library of periodicals and videotapes. The Commission also offers sensitivity training on deafness, such as how to use TTY, cultural differences, emotional challenges, federal and state laws, and more.

1 Capitol Hill, Ground Level, Providence, RI 02908-5850 Phone: 401-222-1204 TTY: 401-222-1205 Fax: 401-222-5736 Website: www.cdhh.ri.gov

RHODE ISLAND DEPARTMENT OF CHILDREN, YOUTH, AND FAMILIES

The Rhode Island Department of Children, Youth, and Families' Special Needs Adoption Program provides permanent families to children who have experienced significant losses and trauma in their lives. These children may qualify for Adoption Subsidy and Medicaid.

101 Friendship Street, Providence, RI 02903 Phone: 401-528-3502 Website: www.dcyf.ri.gov

RHODE ISLAND DEPARTMENT OF EDUCATION (RIDE) OFFICE OF STUDENT, COMMUNITY, AND ACADEMIC SUPPORTS

The Office of Student, Community and Academic Supports provides assistance and support to schools and parents in meeting the special education needs of children in Rhode Island.

Shepard Building 255 Westminster Street, Providence, RI 02903 Phone: 401-222-4600 Fax: 401-222-6030 Website: www.ride.ri.gov; IEP Website: www.ritap.org/IEP

RHODE ISLAND DEPARTMENT OF HUMAN SERVICES (DHS)

In Rhode Island, the Department of Human Services manages programs and services for children (including children with special needs), adults, and families. Programs and services for children with special needs include CEDARR, Early intervention, and Medical Assistance.

Center for Child and Family Health 600 New London Avenue, Cranston, RI 02920 Phone: 401-462-5300, 800-244-8700, Spanish: 401-462-1500 TTY: 401-462-3363 Website: www.dhs.ri.gov

RHODE ISLAND DEVELOPMENTAL DISABILITIES COUNCIL

The Rhode Island Developmental Disabilities Council promotes creative ways for men, women, and children with disabilities to live more independent, fulfilling lives.

400 Bald Hill Road, Suite 515, Warwick, RI 02886 Phone: 401-737-1238 TTY: 401-737-1238 Fax: 401-737-3395 Website: www.riddc.org

RHODE ISLAND DISABILITY LAW CENTER

The mission of the Rhode Island Disability Law Center is to assist people with differing abilities in their efforts to achieve full inclusion in society and to exercise their civil and human rights.

275 Westminster Street, Suite 401, Providence, RI 02903-3434 Phone: 401-831-3150, 800-733-5332 TTY: 401-831-5335 Fax: 401-274-5568 Website: www.ridlc.org

RHODE ISLAND EXECUTIVE OFFICE OF HEALTH AND HUMAN SERVICES

Center for Child and Family Health 600 New London Avenue, Cranston, RI 02920 Phone: 401-462-5300 (English and Spanish) TTY: 401-462-3363 / RI Relay: 7-1-1 Website: www.eohhs.ri.gov

RHODE ISLAND HEARING ASSESSMENT PROGRAM (RIHAP)

RIHAP coordinates and provides hearing screening for all newborn infants in Rhode Island. If there are concerns about a baby's hearing, referrals to appropriate medical and audiological services are provided to the family.

Women and Infants Hospital 134 Thurbers Avenue, Suite 215, Providence, RI 02905 Phone: 401-277-3700 TTY: 401-277-3701 Email: rihap@wihri.org Website www.womenandinfants.org/Services/Hearing-Assessment.cfm

RHODE ISLAND HOSPITAL

AUDIOLOGY & SPEECH LANGUAGE PATHOLOGY SERVICES

Rhode Island Hospital offers many audiology and speech language pathology services, including hearing tests, hearing aids, and comprehensive speech, language, and communication assessments.

115 Georgia Avenue, Providence, RI 02903 Phone: 401-444-5845 Website: www.rhodeislandhospital.org/rehabilitation/audiology

RHODE ISLAND OFFICE OF REHABILITATION SERVICES

The Rhode Island Office of Rehabilitation Services may be able to provide vocational counseling and guidance; vocational evaluation to determine skills, abilities, and potential to work; vocational training; purchase of hearing aids and appropriate communications devices; interpreter services for purpose of obtaining and maintaining employment; job placement assistance; and rehabilitation technology services.

40 Fountain Street, Providence, RI 02903 Phone: 401-421-7005, 401-462-7791 (Spanish speakers) TDD: 401-421-7016 (TDD) Webiste: www.ors.state.ri.us

RHODE ISLAND PARENT INFORMATION NETWORK (RIPIN)

RIPIN is a non-profit organization formed by parents and professionals. The goal of this organization is to give parents of children with disabilities information, training, referrals, personalized support, and parent-to-parent networking. RIPIN has a toll-free number to call for information and resources for parents of disabled children.

1210 Pontiac Avenue, Cranston, RI 02920 Phone: 401-270-0101 Fax: 401-270-7049 Toll-Free: 800-464-3399 Website: www.ripin.org RIHAP Parent Resource Specialist Phone: 401-277-3690 Email: ElBrown@Wihri.org

RHODE ISLAND RELAY SERVICE PROVIDED BY HAMILTON RELAY

Rhode Island Relay Service enables communications between people using TTY devices and people using regular telephones. Because of the Americans with Disabilities Act, deaf, hard-of-hearing, and speech-disabled people are able to use standard telephones to communicate with friends, businesses, and family with the help of text telephones.

Phone: 800-745-6575 or 711 TTY: 800-745-5555

RHODE ISLAND SCHOOL FOR THE DEAF (RISD)

The Rhode Island School for the Deaf offers a wide range of educational programs to deaf and hard-of-hearing children (and their families) from birth through high school. RISD's mission is to ensure that every child who is deaf or hard of hearing will become an independent, contributing citizen. The school aims to provide fully accessible and appropriate environments to meet the unique educational, social, linguistic, and communication needs of every child.

1 Corliss Park, Providence, RI 02908-1795 Phone: 401-222-3525 Fax: 401-243-1024 Website: www.rideaf.net

SARGENT REHABILITATION CENTER

The Sargent Rehabilitation Center provides outpatient rehabilitation services to people of all ages with functional disabilities caused by accidents, illnesses, or developmental disabilities. The Center provides evaluation and treatment in audiology, speech language pathology, special education, occupational and physical therapy, psychology, social services, and vocational training. The Center also features an assistive listening device center, provides non-commercial advice on hearing aids and other communication systems, and has a mobile unit used toprovide hearing screening.

800 Quaker Lane, East Greenwich, RI 02818 Phone: 401-886-6600 Fax: 401-886-6632 Website: http://www.sargentcenter.org/ProgramsandServices/RegionalResourceCenter

SHRINERS OF RHODE ISLAND CHARITIES TRUST

The Shriners Program provides financial support for the purchase of hearing aids and earmolds for children who are deaf or hard of hearing. Children from birth through 18 years of age who are treated at the Rhode Island Hospital Hearing and Speech Center have access to this program.

Co-op Bldg, 1st Floor, Rm 170.34 2 Dudley Street, Providence, RI 02905 Phone: 401-444-4757 Website: www.rishriners.org

SOCIAL SECURITY ADMINISTRATION

The Social Security Administration manages the Supplemental Security Income (SSI) program, which provides monthly cash benefits to eligible children from birth to age 18 with disabilities. If a child is eligible for SSI because of a disability, then that child is also eligible to receive Medicaid.

380 Westminister Street, Room 318, Providence, RI 02903 Phone: 877-402-0808, 800-772-1213 Fax: 401-528-4698 Website: www.ssa.gov

STATE OF RHODE ISLAND HEARING CENTER

The Rhode Island Hearing Center at Rhode Island School for the Deaf provides comprehensive audiological evaluations and outreach services for Rhode Island children in preschool through college, free of charge. In addition, the Hearing Center carries out the public mandate to screen the hearing of children in preschool through grade three throughout Rhode Island.

1 Corliss Park, Providence, RI 02908-1795 Phone: 401-222-3525 TTY: 401-222-3888 Fax: 401-222-6998

SUPPLEMENTAL SECURITY INCOME (SSI)

Supplemental Security Income is a federal program that provides benefits to adults and children with disabilities who have limited income and resources. The Social Security Administration can provide more information on SSI benefits and eligibility.

Social Security Office 380 Westminster Street, Room 318, Providence, RI 02903 Phone: 401-528-4535 or 800-772-1213 Fax: 401-528- 4698 Website: www.ssa.gov

TECHACCESS OF RHODE ISLAND

TechACCESS of Rhode Island is a private, non-profit resource center that serves people with disabilities who are interested in assistive technology. Information and referral services regarding assistive technology products, funding, and services are provided at no charge. TechACCESS also provides referrals to service providers, vendors, and advocacy services.

110 Jefferson Boulevard, Suite I, Warwick, RI 02888-3854 Phone: 401-273-1990, 401-463-0202, 800-916-8324 TTY: 401-273-1990, 401-463-0202 Fax: 401-463-3433 Website: www.techaccess-ri.org

VSA ARTS OF RHODE ISLAND

VSA Arts of Rhode Island is a statewide non-profit organization providing high-quality programs and opportunities for people with disabilities to actively participate in the visual, literary, and performing arts.

500 Prospect Street, Pawtucket, RI 02860 Phone: 401-725-0247 TTY: 401-725-0247 Fax: 401-725-0397 Website: www.vsartsri.org

WOMEN AND INFANTS HOSPITAL AUDIOLOGY CLINIC

The audiology clinic at Women and Infants Hospital provides audiology testing and services for infants older than two months. The clinic works closely with community pediatricians and other physicians, as well as Rhode Island Early Intervention, to coordinate and provide audiological testing for infants and children of all ages. The clinic also offers Educational Audiology services and works with local school districts.

134 Thurbers Avenue, Suite 215, Providence, Rhode Island 02905 Phone: 401-453-7751 Website: http://www.womenandinfants.org/newbornhealth/pediatric-audiology.cfm



Resources by Topic

These resources are organized according to the order of questions in the Frequently Asked Questions section of this guide.

PARENT SUPPORT

AVAILABLE IN RHODE ISLAND:

Early Intervention Program Northern RI Collaborative Auditory Oral Program Rhode Island Commission on the Deaf and Hard of Hearing Rhode Island School for the Deaf Rhode Island Parent Information Network

AVAILABLE THROUGH THE INTERNET:

Alexander Graham Bell Association for the Deaf, Inc. American Society for Deaf Children Clarke Schools for Hearing and Speech Laurent Clerc Center, Gallaudet University National Cued Speech Association

PAYING FOR EARLY INTERVENTION

Early Intervention Program Clarke Schools for Hearing and Speech Northern RI Collaborative Auditory Oral Program Parent Infant Partners, Rhode Island School for the Deaf Rhode Island Department of Human Services

LANGUAGE AND SOCIAL DEVELOPMENT

AVAILABLE IN RHODE ISLAND:

Early Intervention Program Northern RI Collaborative Auditory Oral Program Parent Infant Partners, Rhode Island School for the Deaf

AVAILABLE THROUGH THE INTERNET:

Alexander Graham Bell Association for the Deaf, Inc. American Society for Deaf Children Clarke Schools for Hearing and Speech

UNDERSTANDING COMMUNICATION

AVAILABLE IN RHODE ISLAND:

Early Intervention Program Northern RI Collaborative Auditory Oral Program Parent Infant Partners, Rhode Island School for the Deaf Rhode Island Parent Information Network

AVAILABLE THROUGH THE INTERNET:

Alexander Graham Bell Association for the Deaf, Inc. Auditory -Verbal International Clarke Schools for Hearing and Speech Helen Beebe Speech and Hearing Center Science of Learning Center on Visual Language and Visual Learning, Gallaudet University

SPEECH AND LANGUAGE

AVAILABLE IN RHODE ISLAND:

Early Intervention Program Northern RI Collaborative Auditory Oral Program Parent Infant Partners, Rhode Island School for the Deaf

AVAILABLE THROUGH THE INTERNET:

Alexander Graham Bell Association for the Deaf, Inc. Auditory- Verbal International Clarke Schools for Hearing and Speech Helen Beebe Speech and Hearing Center

LEARNING ABOUT AMERICAN SIGN LANGUAGE

AVAILABLE IN RHODE ISLAND:

Parent Infant Partners, Rhode Island School for the Deaf Rhode Island Association of the Deaf Rhode Island Commission on the Deaf and Hard of Hearing

AVAILABLE THROUGH THE INTERNET:

American Society for Deaf Children Science of Learning Center on Visual Language and Visual Learning, Gallaudet University

LEARNING AMERICAN SIGN LANGUAGE

AVAILABLE IN RHODE ISLAND:

ASL Academy Brown University Community College of Rhode Island Family Sign Language, Northeast Regional Center of Gallaudet University Parent Infant Partners, Rhode Island School for the Deaf Perspectives Corporation Rhode Island Commission on the Deaf and Hard of Hearing

AVAILABLE IN OTHER STATES:

Bridgemark Bristol Community College Boston University Northeastern University Holy Cross College

HEARING TESTING

PEDIATRIC AUDIOLOGY SERVICES

For the most up-to-date listing of pediatric audiology services visit

www.health.ri.gov/find/audiology

SEDATED AUDITORY BRAINSTEM RESPONSE (ABR)

Memorial Hospital, 111 Brewster Street, Pawtucket, RI 401-729-2022

Rhode Island Hospital Audiology/Speech Hasbro Children's Hospital, 593 Dudley Street, Providence, RI 401-444-5485

UNSEDATED ABR FOR INFANTS AND TODDLERS

Alliance Hearing and Balance Center 845 North Main Street, Suite 2, Providence, RI 401-861-7293

Charlton Memorial Hospital Audiology

- » 283 Pleasant Street, Fall River, MA, 508-324-3203
- » 49 State Rd, N. Dartmouth, MA, 508-910-3478

Lawrence & Memorial Hospital Speech & Audiology Services, New London, CT 860-271-4848 Memorial Hospital 111 Brewster Street, Pawtucket, RI 401-729-2022

Rhode Island Hospital Audiology/Speech 115 Georgia Avenue, Providence, RI 401-444-5485

Women & Infants Hospital Audiology Department 134 Thurbers Avenue, Suite 215, Providence, RI 401-453-7751

VISUAL REINFORCEMENT AUDIOMETRY (VRA) FOR INFANTS, TODDLERS, AND CHILDREN OF ALL AGES

Alliance Hearing and Balance Center 845 North Main Street, Suite 2 Providence, RI 401-861-7293

Aquidneck Hearing Center 850 Aquidneck Avenue Unit B-9, Middletown, RI 401-849-4448

Aquidneck Hearing Center 567 Metacom Avenue, Unit 6, Bristol, RI 401-254-4327

Charlton Memorial Hospital Audiology » 283 Pleasant Street, Fall River, MA, 508-324-3203 » 49 State Rd, N. Dartmouth, MA, 508-910-3478

ENT Associates of Westerly 17 Wells Street, Suite 201, Westerly, RI 401-596-2033

Hear For You Hearing & Balance Center 6 Blackstone Valley Place, Bldg 3, Suite 307, Lincoln, RI 401-475-6116

Hearing Health Care Connection 10 Smith Avenue, Smithfield (Greenville), RI 401-949-1100

Lawrence & Memorial Hospital, Speech & Audiology Services 365 Montauk Avenue, New London, CT 06320 860-271-4848

Meeting Street (ages 7–36 months, must be enrolled at Meeting Street to receive services) 1000 Eddy Street, Providence, RI 401-533-9104

Memorial Hospital 111 Brewster Street, Pawtucket, RI 401-729-2022

New England Center for Hearing Rehabilitation 354 Hartford Turnpike (Rte 6), Hampton, CT 860-455-1404

Rhode Island Hearing Center, RI School for the Deaf 1 Corliss Park, Providence, RI 401-222-3525

Rhode Island Hospital Audiology/Speech 115 Georgia Avenue, Providence, RI 401-444-5485

University of Rhode Island, Department of Communicative Disorders 3071 Kingstown Road, Kingston, RI 401-874-4742

University Otolaryngology

- » 1351 South County Trail, Suite 303, East Greenwich, RI, 401-885-8484
- » 130 Waterman Street, Providence, RI, 401-274-3277
- » 118 Dudley Street, Providence, RI, 401-274-2300
- » 116 Main Street, South Kingstown (Wakefield), RI, 401-782-4400

Women & Infants Hospital Audiology Department 134 Thurbers Avenue, Suite 215, Providence, RI 401-453-7751

VISUAL REINFORCEMENT AUDIOMETRY (VRA) OR OTHER SERVICES FOR CHILDREN OLDER THAN AGE THREE

Atlantic Hearing Center (ages 3+)

- » 1150 Reservoir Avenue, Suite 305B, Cranston, RI, 401-942-8080
- » 24 Salt Pond Road, Bldg H-2, Wakefield, 401-942-8080

Audiology Rehabilitation Services (ages 6+) 200 Tollgate Road, Suite 203, Warwick RI 401-461-3965 Eye Health Vision Centers (ages 4+) 73 Valley Road, Middletown, RI 401-849-4448

Hear Care Rhode Island (ages 6+) 200 Tollgate Road, Suite 203, Warwick, RI 401-737-1760

Rhode Island Audiology (ages 5+)

- » 1395 Atwood Avenue, Suite 104, Johnston, RI, 401-946-4660
- » 727 East Avenue, Pawtucket, RI, 401-946-4660
- » 148 Social Street, Woonsocket, RI, 401-946-4660

Rhode Island Ear Nose and Throat (ages 2+) 333 School Street, Suite 302, Pawtucket, RI 401-728-0140

HEARING AIDS

AVAILABLE IN RHODE ISLAND:

Early Intervention Program Parent Infant Partners, Rhode Island School for the Deaf Rhode Island Commission on the Deaf and Hard of Hearing Rhode Island Department of Human Services Rhode Island Hearing Center, Rhode Island School for the Deaf Rhode Island Parent Information Network Shriners of Rhode Island Charities Trust

AVAILABLE THROUGH THE INTERNET:

Alexander Graham Bell Association for the Deaf, Inc. American Society for Deaf Children Hear Now Miracle Ear Children's Foundation

COCHLEAR IMPLANTS

AVAILABLE IN RHODE ISLAND:

Early Intervention Program Hasbro Children's Hospital Cochlear Implant Program Memorial Hospital of Rhode Island, Audiology Department Parent Infant Partners, Rhode Island School for the Deaf Rhode Island Hearing Assessment Program Rhode Island Hospital, Audiology and Speech Pathology Department Women and Infants' Audiology Department

AVAILABLE IN OTHER STATES:

Boston Children's Hospital Cochlear Implant Awareness Foundation New England Center for Hearing Rehabilitation

DEAF ADULTS

AVAILABLE IN RHODE ISLAND:

Rhode Island Association of the Deaf Rhode Island Commission on the Deaf and Hard of Hearing

ASSISTIVE DEVICES

AVAILABLE IN RHODE ISLAND:

Early Intervention Program Hearing Loss Association of Rhode Island Parent Infant Partners, Rhode Island School for the Deaf Rhode Island Commission on the Deaf and Hard of Hearing Sargent Rehabilitation Center TechACCESS of Rhode Island

CAPTIONED MOVIES

AVAILABLE IN RHODE ISLAND:

Rhode Island Commission on the Deaf and Hard of Hearing

AVAILABLE THROUGH THE INTERNET:

Captioned Media Program

FINDING EMPLOYMENT

AVAILABLE IN RHODE ISLAND:

Rhode Island Office of Rehabilitation Services netWORKri

AVAILABLE THROUGH THE INTERNET:

O*NET Online United States Department of Labor America's Career InfoNet

SPECIAL ACCOMMODATIONS FOR DRIVER'S TEST

AVAILABLE IN RHODE ISLAND:

Rhode Island Commission on the Deaf and Hard of Hearing Rhode Island Parent Information Network

SUMMER CAMP

Aspen Camp Camp Mark Seven Camp Isola Bella Clarke School for Hearing and Speech Gallaudet University Rochester Institute of Technology



National Resources

ALEXANDER GRAHAM BELL ASSOCIATION FOR THE DEAF, INC. (AG BELL)

AG Bell is a national organization interested in improving educational, professional, and vocational opportunities for people who are deaf or hard of hearing. AG Bell promotes better public understanding of hearing loss in children and adults. Members receive the following publications: Volta Review, Newsounds, and Our Kids Magazine

3417 Volta Place, NW, Washington, DC 20007-2778 Phone: 800-432-7543, 202-337-5220 TTY: 800-432-7543, 202-337-5221 Fax: 202-337-8314 Website: www.agbell.org

AMERICAN ACADEMY OF AUDIOLOGY (AAA)

The AAA is a professional organization of individuals dedicated to providing high-quality hearing care to the public.

11730 Plaza America Drive, Suite 300, Reston, VA 20190 Phone: 800-222-2336, 703-790-8466 TTY: 703-610-9022 Fax: 703-790-8631 Website: www.audiology.org

AMERICAN SOCIETY FOR DEAF CHILDREN (ASDC)

ASDC is a non-profit organization that provides current information, support, and encouragement to parents and families with children who are deaf or hard of hearing. ASDC promotes parent's rights regarding communication choices for their children and promotes quality education to improve children's lives. It provides a positive attitude toward signing and Deaf Culture and publishes a newsletter called The Endeavor.

PO Box 3355, Gettysburg, PA 17325 Phone: 800-942-2732 TTY: 717-334-7922 Fax: 717-334-8808 Website: www.deafchildren.org

AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION (ASHA)

ASHA is the national professional, scientific, and credentialing association for audiologists, speech language pathologists, and speech, language, and hearing scientists.

10801 Rockville Pike, Rockville, MD 20852 Phone: 800-638-8255 TTY: 800-498-2071 Website: www.asha.org

BEGINNINGS FOR PARENTS OF CHILDREN WHO ARE DEAF OR HARD OF HEARING, INC.

Beginnings is a non-profit organization that produces materials and videos to help families make choices about communication methods.

PO Box 17646, Raleigh, NC 27619 Phone: 919-850-2746 TTY: 919-850-2746 Website: www.ncbegin.org

BOYS TOWN NATIONAL RESEARCH HOSPITAL FOR CHILDHOOD DEAFNESS

Boys Town National Research Hospital is a licensed hospital that researches hearing loss and communication disabilities. This institute accepts children from around the world, without regard to race, creed, or financial means, for evaluation, diagnosis, treatment, and remediation of hearing impairment, speech and language disorders, learning disabilities, and related problems in communication. The hospital also operates a summer program for children who are gifted and deaf.

555 North 30th Street, Omaha, NE 68131 Phone: 402-498-6540, National Hotline 800-448-3000 TTY: 800-320-1171, National Hotline 800-448-1833 Fax: 402-498-6562 Website: www.boystownhospital.org or http://babyhearing.org

CAPTIONED MEDIA PROGRAM (CMP)

The National Association for the Deaf provides free loans of educational and entertainment open-captioned CD-ROMS and videos for deaf and hard-of-hearing people. Parents and teachers may also borrow captioned videos and CD-ROMS free of charge. Funds for the CMP are provided by the US Department of Education.

1447 East Main Street, Spartanburg, SC 29307 Phone: 800-237-6213 TTY: 800-237-6819 Fax: 800-538-5636 Website: www.cfv.org

COCHLEAR IMPLANT AWARENESS FOUNDATION

CIAF's mission is to provide information, resources, and support to prospective cochlear implant recipients and their families.

3109 Beaver Creek Lane, Springfield, Illinois 62712 Phone: 800-795-0824 Website: www.ciafonline.org

DEAFPRIDE

Deafpride is an organization that advocates for the rights of deaf people and their families.

1350 Potomac Avenue, SE, Washington, DC 20003 Phone: 202-675-6700

FAMILIES FOR HANDS AND VOICES

Families for Hands and Voices is a national, parent-driven organization dedicated to nonbiased support of families who have children who are deaf or hard of hearing. Activities include outreach events, educational seminars, advocacy and lobbying efforts, a parent-toparent support network, and a newsletter.

P.O. Box 371926, Denver, CO 80237 Phone: 866-422-0422 Website: www.handsandvoices.org

GALLAUDET UNIVERSITY, LAURENT CLERC NATIONAL DEAF EDUCATION CENTER

Gallaudet University's Laurent Clerc National Deaf Education Center shares the concerns of parents and professionals about the achievement of deaf and hard-of-hearing students in different learning environments across the country. The Clerc Center has been mandated by Congress to develop, evaluate, and disseminate innovative curricula, instructional techniques and strategies, and materials. The aim of the Clerc Center is to improve the quality of education for deaf and hard-of-hearing children and youth from birth through age 21.

800 Florida Avenue, NE, Washington, DC 20002 Phone: 202-651-5031 TTY: 202-651-5031 Fax: 202-651-5636 Website: http://clerccenter.gallaudet.edu

HEAR NOW

This program provides hearing aids to people with limited financial resources through the non-profit Starkey Hearing Foundation. Hear Now accepts hearing aid donations from all over the country. Hear Now is also involved in increasing public awareness of the need for affordable technology for people with hearing loss.

9745 East Hampton Avenue, Suite 300, Denver, CO 80231-4923 Phone: 303-695-7797, 800-648-4327 TTY: 800-648-4327 Fax: 303-695-7789 Website: www.starkeyhearingfoundation.org/programs/hear-now

THE HEARING EXCHANGE

The Hearing Exchange is an online community where ideas, information, support, and stories related to hearing loss are shared. It contains stories by children with hearing loss and their parents.

PO Box 689, Jericho, NY 11753 Phone: 516-938-5475 Website: www.hearingexchange.com

HELEN BEEBE SPEECH AND HEARING CENTER

The Helen Beebe Speech and Hearing Center promotes the auditory-verbal philosophy of training children with hearing loss. The Center's facilities and expertise help people pursue auditory-verbal training and provide services to those in need of speech, language, and hearing therapy.

PO Box 969, 220 Commerce Drive, Suite 320, Fort Washington, PA 19034 Phone: 215-619-9083 Fax: 215-619-9087 Website: www.helenbeebe.org

HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

The national center and its ten regional offices provide diagnostic evaluation, comprehensive vocational and personal adjustment training, and job preparation and placement for people who are deaf-blind.

111 Middle Neck Road, Sands Point, NY 11050 Phone: 516-944-8900 TTY: 516-944-8637 Website: www.hknc.org

JOHN TRACY CLINIC

The John Tracy Clinic is an educational facility offering direct instruction and correspondence courses free of charge to families of children who are deaf (from birth through age six) and who live anywhere in the US or the world.

806 West Adam Boulevard, Los Angeles, CA 90007-2505 Phone: 800-522-4582, 213-748-5481 TTY: 213-474-2924 Fax: 213-749-1651 Website: www.jtc.org

MARION DOWNS NATIONAL CENTER FOR INFANT HEARING

The Marion Downs National Center for Infant Hearing provides information on universal newborn hearing screening, assessment, diagnosis, and early intervention.

University of Colorado at Boulder Campus Box 409, Boulder, CO 80309 Phone: 303-492-6283 TTY: 303-492-4124 Website: www.colorado.edu/slhs/mdnc

MIRACLE-EAR CHILDREN'S FOUNDATION

Miracle-Ear Children's Foundation provides free hearing aids and services to children 16 years old or younger from low-income families.

Miracle-Ear, Inc. 5000 Cheshire Lane North, Minneapolis, MN 55446 Phone: 877-268-4264 Miracle-Ear Children's Foundation Phone: 800-234-5422

Website: www.miracle-ear.com/resources/children_request.asp

NATIONAL ASSOCIATION OF THE DEAF (NAD)

The National Association of the Deaf is a non-profit consumer organization safeguarding the accessibility and civil rights of people who are deaf or hard of hearing in education, employment, healthcare, and telecommunications. NAD provides grassroots advocacy and empowerment, deafness related information and publications, legal assistance, policy development, public awareness, and youth leadership development.

814 Thayer Avenue, Silver Springs, MD 20910-4500 Phone: 301-587-1788 TTY: 301-587-1789 Fax: 301-587-1791 Website: www.nad.org

NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT (NCHAM)

The goal of NCHAM is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

Utah State University 2880 Old Main Hill, Logan, UT 84322 Phone: 435-797-3584 Website: www.infanthearing.org

NATIONAL CUED SPEECH ASSOCIATION (NCSA)

NCSA is a non-profit organization that promotes and supports the effective use of cued speech for communication, language acquisition, and literacy. NCSA raises awareness of cued speech and its applications, provides educational services, assists local affiliate chapters, establishes standards for cued speech, and certifies cued speech instructors and transliterators.

23970 Hermitage Road, Cleveland, OH 44122 Phone: 800-459-3529 Website: www.cuedspeech.org

SCIENCE OF LEARNING CENTER ON VISUAL LANGUAGE AND VISUAL LEARNING (VL2) AT GALLAUDET UNIVERSITY

VL2 is one of six Science of Learning Centers funded by the National Science Foundation and is hosted by Gallaudet University.

Website: vl2.gallaudet.edu

SELF HELP FOR HARD OF HEARING PEOPLE, INC. (SHHH)

SHHH exists to open the world of communication for people with hearing loss through information, education, advocacy, and support.

7910 Woodmont Avenue, Suite 1200, Bethesda, MD 20814 Phone: 301-657-2248 TTY: 301-657-2249 Fax: 301-913-9413 Website: www.shhh.org

US DEPARTMENT OF EDUCATION

The US Department of Education's Information Resource Center can provide information on the Department's programs and agenda, registration for satellite events, directory assistance for the Department, referrals to Department specialists or other experts, and answers to frequently asked questions. Spanish speakers are available.

Washington, DC 20202 Phone: 800-872-5327 (USA-LEARN), 202-401-2000 TTY: 800-437-0833 Website: www.ed.gov

Acknowledgements

The Rhode Island Resource Guide for Families of Children who are Deaf or Hard of Hearing was made possible by the efforts of many dedicated professionals and parents. The Rhode Island Department of Health would like to thank the following organizations and individuals for their compassion and efforts toward this project.

Rhode Island Commission on the Deaf and Hard of Hearing Providence, RI

Rhode Island Department of Education (RIDE), Office of Student, Community and Academic Supports Providence, RI

Rhode Island Hearing Assessment Program Women and Infants Hospital Providence, RI

Rhode Island Parent Information Network Cranston, RI

Rhode Island School for the Deaf Providence, RI

Drawings by: Nicole Katzman, MAT, MA Rhode Island Parent Information Network Cranston, RI

Pamela Zellner Rhode Island Commission on the Deaf and Hard of Hearing Providence, RI

Some information was adapted from the State of Alaska's Hearing Resource Guide, Boys Town National Research Hospital, Colorado Resource Guide www.raisingdeafkids.org, www.babyhearing.org, and www.hdhearing.com