HAWAII STATE DEPARTMENT OF HEALTH

Hawaiʻi State Resource Guide for Families of Children with Hearing Loss

Hawai‘i State Department of Health

Questions or Comments?
For more information, please contact the
Newborn Hearing Screening Program

Phone (808) 733-9054

**www.health.hawaii.gov/
genetics/programs/nhsp**

Table of Contents Page

HAWAII STATE DEPARTMENT OF HEALTH

A variety of terms are used when talking about people with differing hearing levels. Throughout this document we use the term **Deaf or Hard of Hearing (D/HH)** to convey audiological information as it aligns with guidelines from *The Joint Committee on Infant Hearing* (JCIH, 2019); you may also see the terms hearing differences, hearing loss, or hearing status.

This resource guide does not include detailed information about ‘Deaf Identity’; however, we acknowledge it is a complex and personal experience that refers to how individuals identify themselves culturally and linguistically.

Aloha mai kākou!

(Welcome)

Congratulations on the beautiful addition to your family.

A whole new world is opening up to you and as you navigate this new world, we want to provide you with some ideas to consider. You may be receiving information and opinions from different doctors, online resources, and family members/friends.
It can be a lot. You know your child best.

Here are a few things to think about:

1. We see you;
2. You are not alone;
3. Your child will be successful;
4. You, your child(ren), your family, all have choices;
5. Love is powerful.

This resource guide is filled with information and resources to support you on your learning journey. When considering the information, it is important to allow yourself time to review, research, and ask questions.

There is no such thing as a bad question.

Early identification and intervention can help children reach their fullest potential, but family involvement is the most important part in helping them to grow and thrive.

We look forward to meeting you and your ʻohana along your journey. Whatever you are feeling and experiencing is okay. We, the greater community of families with children who are deaf or hard of hearing in Hawai'i, are your cheering squad.

Holomua Kākou!

Sincerely,

A Fellow Parent of a Deaf Child
Oʻahu, Hawaiʻi

Parent Support

1

> *"I can't imagine my life without my Deaf son, Caleb. He makes us whole, complete, and perfect. Instead of living in a world I knew, he opened the doors to a universe I didn't know. I never want to stop walking through all the doors he's creating for us."*
>
> *Nikki Kepoʻo*

When your child was diagnosed with a hearing difference, it may have been a surprise to you.

You may not have other family members with hearing loss. You may not have thought much about hearing difference before your baby was born. Depending on the age of your child, without realizing what it was, you may have noticed signs such as delayed speech and language development or not responding to sounds in their environment.

The diagnosis of hearing difference in your child may cause you to have new feelings. Some parents might feel surprise, shock, grief, worry, anger, or sadness. All these feelings are normal. You may have many different feelings at the same time, you may go back and forth between feelings or feel stuck in one feeling. It may be challenging and stressful; this process is a normal part of the grieving cycle families may experience when receiving a new diagnosis.

As time passes and you adjust to the new diagnosis, new feelings and more questions may arise. Allowing yourself to feel all your feelings is an important step forward on your journey to a "new normal."

Some of the feelings you might feel during the adjustment process include:

Extreme Sadness – You may feel hopeless and may lose interest in things that you used to enjoy. These feelings can result from sadness about losing certain hopes and dreams you had for your child.

Disbelief – You may want to dismiss or refuse to believe that your child has a diagnosed hearing difference. This reaction can give your mind time to work through the early surprise of a diagnosis. However, significant delay in following up or taking action to meet your child's needs may be harmful to their progress.

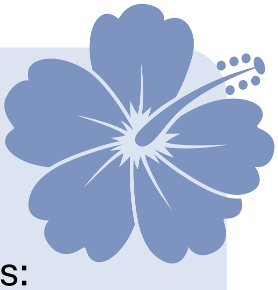
Fear or Anxiety or Worry – You may be afraid of the diagnosis and/or worry about what it means for your child. You may have unanswered questions about your child's future and worry about challenges your child may face. You may feel out of control of the situation.

Anger – You may feel angry when you hear the diagnosis. You may wonder why this happened to your child. You may be angry at the experts who were involved in identifying and diagnosing the hearing difference. You may feel angry when you talk to other family members or healthcare providers about the diagnosis.

Guilt – You might wonder what caused your child's hearing difference and feel guilty about things you did or did not do. You may feel guilty about not being able to "protect" your child from a difference. There is nothing you could have done differently. There is nothing you did to "cause" the hearing difference.

Acceptance – At some point, after you have cycled through the emotions countless times, you may accept your child's diagnosis of hearing loss. Acceptance does not have to mean that you like it, rather that you recognize it as a reality. At various milestones in their life, you may cycle back through the feelings; that is normal. In time, their hearing status will be just one small part of what makes them wonderful.

Joy – While grief can be painful, joy can also be experienced during this time. Make room for joy. Focusing on special moments that bring joy helps families put aside concerns and focus on their natural and loving parent-child connections. This may involve engaging in activities that bring joy and fulfillment, finding beauty in life, or intentionally seeking out moments of happiness.



Tips for you as you go through the adjustment process:

- Remember that your feelings are normal. The adjustment process takes time. There are people in the community who are willing to help and walk with you on your journey when you are ready.
- Be open with your feelings.
- Learn all you can about your child's hearing levels/abilities. The more you learn and are involved in your child's development, medical care, therapies, and education, the better.
- Take care of yourself, both mind and body.
- Ask for help. Seek out other parents of children who are deaf or hard of hearing, as well as pediatric experts in hearing loss, who can help answer your questions and share their experiences. Resources are available to you.
- Your child will thrive in a home full of love and patience.

"Fostering Joy D/HH" is a movement to celebrate the magic of raising children who are deaf/hard of hearing. Check the project out for more ideas and resources:

https://handsandvoices.org/resources/fostering-joy.htm

Newborn Hearing Screening

2

Roughly three to four in every 1,000 children born in Hawai‘i have hearing loss, which is the highest rate in the nation. There are more than 60 infants born annually in Hawai‘i with permanent hearing loss.

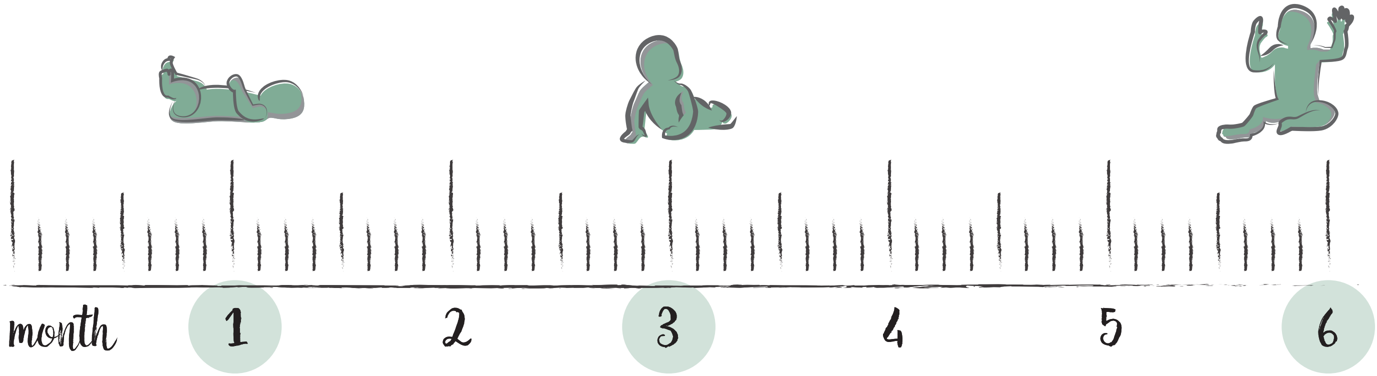
Most babies have their hearing checked before they leave the hospital or within a few days of birth. This is called ‘newborn hearing screening.’

The Newborn Hearing Screening Program (NHSP) is situated within the Early Hearing Detection and Intervention (EHDI) program under the State of Hawai‘i Department of Health. The goal of EHDI is to identify children with hearing loss and begin intervention services as early as possible.

Keep in mind

- Even if a baby passes their newborn hearing screening, children can lose their hearing abilities after birth.
- Listen to your gut. If you feel your child is showing signs of diminished hearing, ask your child’s pediatrician for a referral to see a pediatric audiologist.

The Early Hearing Detection and Intervention (EHDI) program recommends the "1-3-6 Plan"



	1 Month	3 Months	6 Months
When?	By 1 month of age	By 3 months of age	By 6 months of age
What?	All infants will have newborn hearing screening	All infants who do not pass newborn hearing screening should have additional tests (diagnostic audiological evaluation)	All infants with hearing loss should receive early intervention services
Details	• The purpose of screening is to find out if the baby needs more testing. • Infants have newborn hearing screening in the hospital after birth. • Infants born at home can find out where to get hearing screening through their midwife or doctor. • Screening is done with an otoacoustic emissions (OAE) test and/or an automatic auditory brainstem response (AABR) test.	• A complete evaluation will find out the infant's hearing status. • Sometimes the baby needs to be tested several times to identify hearing status. • If the baby has hearing loss, the evaluation aims to identify the type and degree of hearing loss, plus treatment options. • The tests are done by an audiologist. • Test results may lead to referrals to specialists (i.e., eye doctor, ear nose and throat doctor, genetics doctor).	• Early intervention services are available to children 0-3 years of age. • Early intervention services help children with any level of hearing loss learn language and other important skills. • Professionals can give in-home support that is specific to a child's hearing and communication needs. • Research shows that early intervention services are very important to a child's development of language and communication skills.

Questions about EHDI?

Refer to the National Center for
Hearing Assessment and Management

www.infanthearing.org

Checklist

☑ We obtained and read through the Parent Resource Guide.

☐ We find ways to connect with our child and ‘Foster Joy’ in our ‘ohana.

☐ Know how the ear works, what my child’s hearing levels are in each ear, and what type of hearing loss he/she has.

☐ Connected with other parents who have children who are deaf or hard of hearing.

☐ Know how to care for and troubleshoot, my child’s listening technology.

☐ Explored communication/modality opportunities.

☐ Know strategies to support my child’s language acquisition and use them daily.

☐ Am aware of resources locally and nationally, to support my child and our family.

☐ Read to my child every day.

☐ Know our legal rights as parents of a child who is deaf or hard of hearing.

Hawai‘i State Department of Health
Newborn Hearing Screening Program

Phone (808) 733-9054

www.health.Hawaii.gov/genetics/programs/nhsp

Milestones for Language Development

Children go through developmental stages and reach milestones as they develop speech and language.

The following table outlines typical language milestones at different ages. While these milestones are age aligned, it is important to remember that the point at which language is accessed full time would be the starting point for your child. Hearing age or age when full time use of hearing assistive technology (hearing aids or cochlear implant) would be a starting date for a child utilizing hearing technology. This can be calculated at the start of the use of sign language full time as well.

0-3 Months	• Startles or cries at unexpected sounds; wakens at loud noises. • Stills in response to new sounds. • Turns to people, especially caregivers, when they speak. • Stops activity and pays attention to a new voice. • Quiets or smiles when spoken to. • Makes pleasure sounds (cooing). • Cries differently for different needs.
3-12 Months	• Watches your face when you speak or your hands when you sign. • Points to people, objects, and places, but not at self. • Responds to their name being said or signed. • Follows simple instructions such as “no” or “stop.” • Imitates facial expressions and mouth movements. • Can say/sign 1-3 words with meaning.
12-24 Months	• Has a vocabulary of 50-100 words. • Vocabulary is mainly nouns, such as people, places, animals, or things. • Tries to imitate easy words (signed or spoken). • Points to and names simple objects and body parts. • Begins saying two to three word phrases such as “more milk.” • Understands and answers simple sentences such as “show me your eyes (nose, mouth, hair)” or “Where is dad?”
24-36 Months	• Uses three to four word sentences. • Speech is more accurate and they can be understood by familiar adults. • Uses pronouns “I,” “you,” and “me” correctly. • Knows a couple of colors when named/signed. • Asks and answers questions beginning with “what,” “where,” and “when.” • Knows around three prepositions such as “in,” “on,” or “under.” • Uses some plurals such as “socks” or “shoes.”

Strategies to Support Language Development

Language development strategies and techniques support a parent in their ability to teach their child who is deaf or hard of hearing to attend to language to support the child's use of language. The following are a few strategies to get you started.

*Please note that while this list of strategies targets the development of spoken language as written these strategies can support the use of signed language as well.

Be a Director

As a new listener, your child doesn't know what sound is yet or what's important to listen to.

"Be a Director" means you intentionally direct your child to listen (or watch for signed language). They need to learn and understand all those sounds (and references) around them so their brain can start making meaning of them.

When you use this strategy, you're developing your child's auditory attention. This allows your child the opportunity to detect and pay attention to the sounds and speech around them and learn which ones are important.

- Get your child's attention when there's a sound or person you want them to notice, watch and listen to. Also do this before you begin talking to them.
- Point to your ear to alert them.
  Say *"Listen! (pause) I hear that. (pause)"*
  Or before talking with them, call their name and say *"(Child's name), Listen! (pause)"* then start talking to them.
- Pause and notice if your child alerts to the sound. If they do, help them listen and pay attention.
  "Yes, I hear the (name of the object or person)."
- If you're telling them something, wait until they respond to your request to *"Listen!"* before you begin talking.

Be a Bird Dog

Always point out sounds (and visual objects) and name them.

After you use “Be a Director” to direct your child to listen (and watch), you’ll go a step further.

Name the sound, imitate it, and pause to see how your baby reacts. Then label the sound and talk more about it. You’re connecting the sound with a name and language describing it. When you use this strategy, you’re focusing on auditory attention and promoting knowledge of spoken language.

- Direct your baby
  “Listen! (pause) I hear that, (pause) I hear an airplane!”
- Pause and point toward the object.
- If your child is younger, imitate the sound.
  “Ahhhhh!”
- Add a comment, use a simple sentence.
  “The airplane is flying. It’s flying high! The airplane is flying fast.”

Play-By-Play

Much like a sports announcer gives a play-by-play of the action, you can use the “Play-By-Play” strategy to describe what your child experiences. This is also called self-talk since you’re talking aloud to yourself. This provides your child with the opportunity to hear lots of words and get you closer to the goal of 40 million words by age 4.

As you talk aloud about your thoughts and feelings, your child will learn that others may think and feel differently than they do. When you use this strategy, you’re promoting your child’s knowledge of language by surrounding them with spoken words during the meaningful interactions they have with you and other caregivers all day.

- Narrate or describe out loud what you’re thinking, feeling, and doing.
  “You are so thirsty. Let’s get a drink from the fridge.”

  “Let’s open the door.” (Using “Hear it Before They See it,” then open the door.)
- After you open the door, you could say
  “Brr, it’s cold in the fridge. What would you like to drink? I see orange juice, milk, apple juice. What do you want?”
- Pause and wait
  “Oh, you want milk. Milk is yummy. Let’s take the milk out of the fridge and find a clean cup. I am pouring the milk in the cup. Here you go, here’s your milk. Oh, you were very thirsty. You’re drinking your milk.”
- Use familiar phrases and commands so you can support your child’s understanding of language during daily routines. Build their language by adding new words or phrases.
- Speak at a normal rate with pauses and emphasis on the key words in your sentences. This gives your child time to respond and join in the conversation.

Help Me But Don’t Tell Me

Sometimes the best way to learn is by doing. “Help Me But Don’t Tell Me” means you’ll provide clues to give your child the opportunity to think and use their reasoning to grow their listening and language skills. Instead of telling them all the answers, give them clues to help them think and problem solve to discover the answer on their own.

The goal is to promote your child’s listening and thinking skills to help them connect pieces of information they know, which expands and enhances their knowledge of language. When you use this strategy, you’re building your child’s confidence in their listening and language skills and stimulating independent thinking.

- Provide different kinds of clues or information: Label the category / Provide a rhyming word / Suggest an opposite / Use a describing word
- Label by category, provide information, and ask for an answer.
  “This is an animal that lives on the farm. It gives us milk. And it has horns. Do you know what it is?”
- If your child doesn’t guess correctly, try again and use a different clue based on what they know.
  “It says moooooo.”
- Use rhyming words or opposites to help your child guess.
  “Oh, this is a little animal that rhymes with house and starts with an /m/. Do you know what it is?”
- Give examples from the same category.
  “Listen, apple, banana, orange. What group do they belong to?”
- If they can’t guess, help them by providing choices.
  “Are they animals or fruits?”

For more strategies please visit HearingFirst.org’s web page titled LSL Strategies and Techniques

www.hearingfirst.org/m/resources/176

?

Questions you could ask

- How can I get connected with a deaf or hard of hearing mentor?
- Who can support me in learning more about my options for communication modalities for my child?
- Who will teach me a signed language so that I may support my child?
- Who can support me in learning how to utilize language development strategies with my child?
- Can these be taught through goals supported by my Early Intervention Professional?

Consider the strengths and hearing access of your child

- Who is in your village and will need to learn these options and language strategies with you to best support your child?

Search and watch videos of thousands of words and phrases in American Sign Language (ASL).

www.signasl.org

mommy

daddy

play

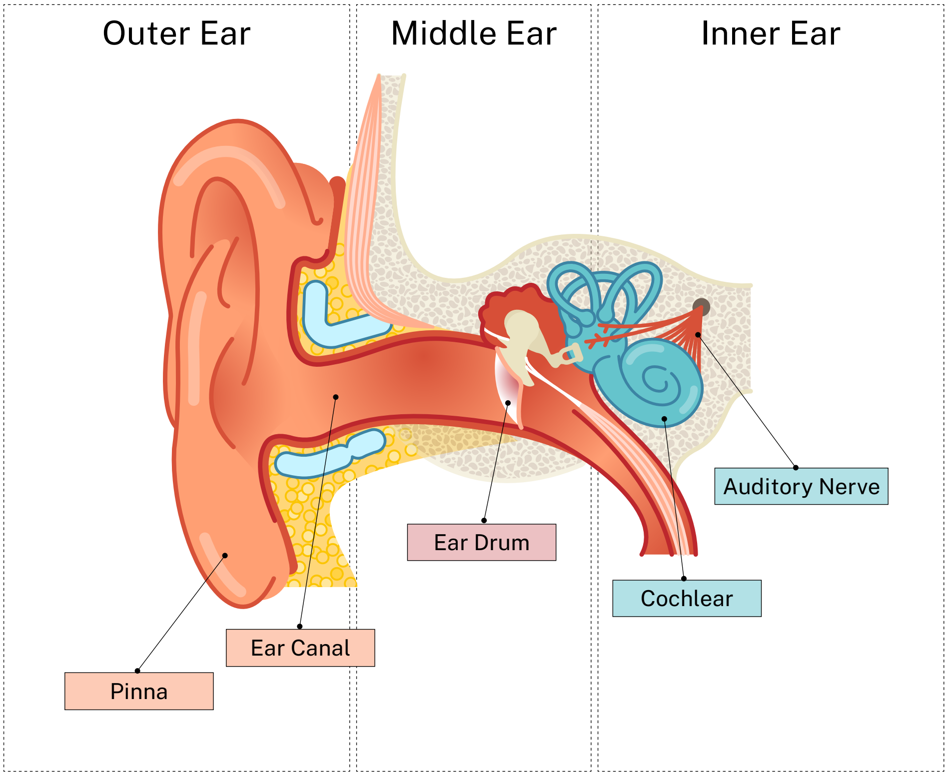
bed

please

eat

milk

4 How Do We Hear?



Outer ear

Includes the outer ear (pinna), canal, and the eardrum (tympanic membrane). The pinna collects sound waves, they travel through the ear canal, hit the eardrum, and it vibrates.

Middle ear

Is an air-filled space between the eardrum and the inner ear. It contains three tiny bones called the ossicles (malleus, incus, stapes) and three semi-circular loops. Sound waves hit the eardrum, travel through the ossicles, and cause the fluid in the inner ear to move. The semi-circular canals are part of the inner ear. The inner ear includes the cochlear and the vestibular system.

Inner ear

Inside of the cochlea, a snail-shell shaped organ, there are thousands of tiny sensors called hair cells. Sound waves travel through the outer and middle ear, then through the cochlea. The hair cells send electrical impulses to the brain via the auditory nerve.

Cochlear nerve

The hearing nerve, also known as the 8th cranial nerve, carries sound information from the ear to the brain.

Brain

The brain receives electrical impulses, processes that sound information, and attaches meaning to it.

Hearing Tests for Young Children

Otoacoustic Emissions (OAE)

This test checks the inner ear's response to sound.
During the test, the child must be calm and quiet, or asleep.

Auditory Brainstem Response (ABR)

This test checks the brain's response to sound.
The child must be asleep (sedated or unsedated) for this test.

Pediatric Audiological Evaluation (PAE)

This evaluation is used for children who are seven months of age or older. The audiologist will measure the child's hearing levels based on their responses to sound. The child must be awake and alert for this test.

Questions you may want to ask about testing for hearing loss

- How do I prepare my child for the test?
- Can you please explain which hearing tests will be done and which area of the ear you are testing?

Who Does the Testing?

Audiologist

A hearing professional with a Masters or Doctoral degree in Audiology. An audiologist is a hearing specialist who manages and treats patients with hearing loss, balance issues, or other ear-related concerns.

Pediatric Audiologist

An audiologist who specializes in testing and treating infants and children.

Otolaryngologist

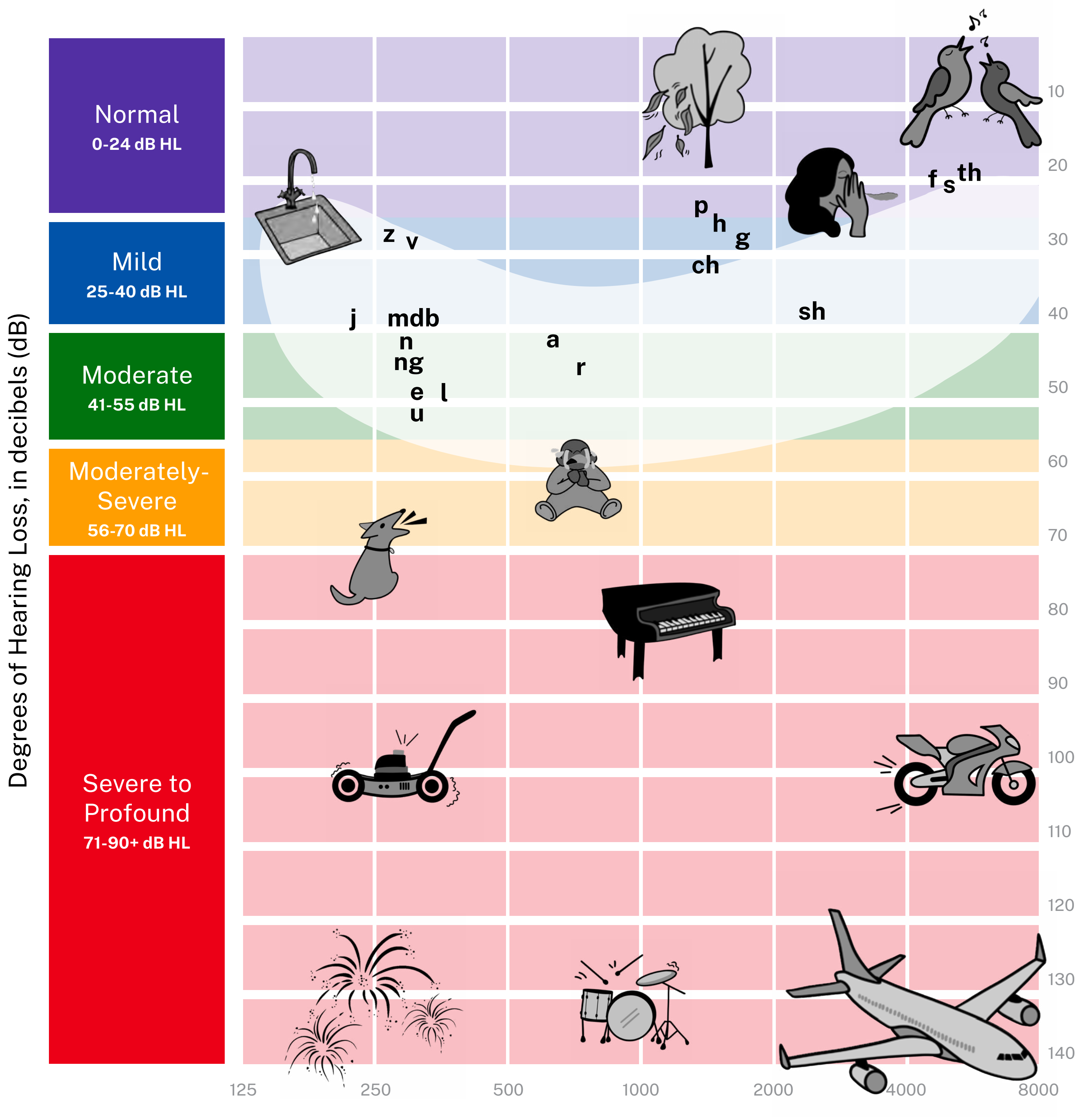
A medical doctor who specializes in diagnosing, managing, and treating patients with hearing loss and/or diseases and disorders of the structures of the head and neck. They are also called ear, nose, and throat (ENT) doctors.

Questions you may want to ask your audiologist

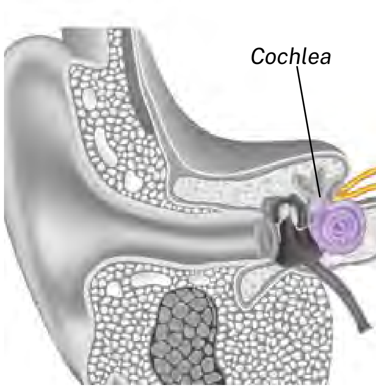
- Can you please show me a chart of what my child can and cannot hear without hearing aids?
- Can you please show me how my child's access to sound changes when they are wearing hearing aids?
- How often do my child's hearing levels need to be tested?

Degrees of Hearing Loss

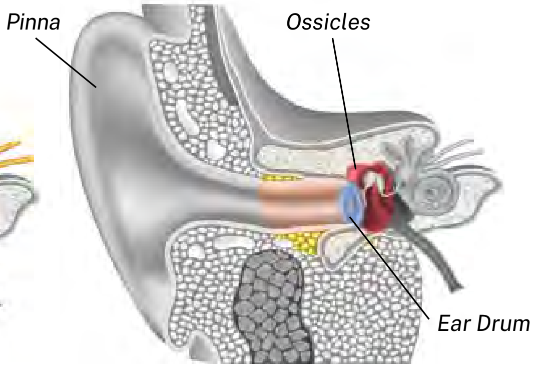
Hearing loss can range from minimal to profound. The amount of sound information a child's brain can access is dependent upon their type and degree of hearing loss.



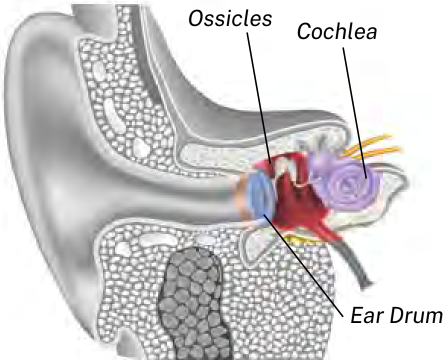
DEGREE OF HEARING LOSS	POTENTIAL IMPACT ON SPEECH AND LANGUAGE	POTENTIAL IMPACT ON EDUCATION	POTENTIAL IMPACT ON PSYCHOSOCIAL
Mild (25-40 dB)	Child can "hear" but misses fragments of speech leading to misunderstanding. At 30dB can miss 25-40% of speech signal. Especially in noisy environments, they are unable to perceive all high pitch speech sounds sufficiently. If unaided, they will miss out on incidental learning opportunities.	Without amplification, child may miss 50% of class discussions. Child is more fatigued than classmates due to effort to suppress background noise. Preferential/strategic seating and hearing assistive technology (such as FM systems) are recommended along with full time hearing aid use.	Behavior may be confused for immaturity or inattention. Missing auditory information may negatively impact self-esteem. People may say, "selective hearing" or "not paying attention."
Moderate **(41-55 dB)**	Hearing aids and intervention services is needed to support a child develop listening and spoken language skills. Without amplification, 50-75% of speech signal can be missed at 40dB and 80-100% with 50dB loss. Without amplification, he/she understands conversation at a distance of 3-5 feet, if sentence structure and vocabulary are known.	Without full time use of hearing aids and FM system, child may be judged as a less competent learner. Listening fatigue!	Socialization with peers can be difficult, especially in noisy settings such as cooperative learning situations, lunch, or recess.
Moderately-Severe (56-70 dB)	Even with hearing aids, child will typically be aware of people talking around him/her, but will miss parts of words.	With hearing aids alone, ability to understand in the classroom is greatly reduced by distance and noise. Listening fatigue!	Tendency for poorer self-concept and social immaturity may contribute to a sense of rejection.
Severe to Profound (71-90+ dB)	Without amplification, child may only hear loud noises at a 1ft (arm's length) distance. Children with severe-profound hearing loss will miss 100% of speech without amplification. In order to develop age appropriate listening and spoken language skills, child must use amplification (hearing aids or a cochlear implant) for all waking hours along with intensive aural training. In order to communicate and learn, a child with severe to profound hearing loss must use sign language if unaided.	Children in general education classrooms may develop greater dependence on adults due to difficulty perceiving or comprehending oral communication.	Children may be more comfortable interacting with peers who are deaf or Hard of Hearing due to ease of communication and great understanding of one's personal experience.



Sensorineural
Hearing Loss (SNHL)



Conductive
Hearing Loss



Mixed
Hearing Loss

Types of Hearing Loss

Sensorineural Hearing Loss (SNHL)

SNHL is the most common type of permanent hearing loss. SNHL occurs when there is damage to the inner ear (cochlea) or the nerve from the cochlea to the brain. Children with SNHL, in one ear (unilateral) or both ears (bilateral), will likely need hearing aids to develop age-appropriate spoken language skills. Cochlear implants may be an option for children whose hearing levels are in the severe to profound range.

Conductive Hearing Loss

Conductive hearing loss occurs when sound waves are unable to move normally through the outer ear and/or middle ear. It can be permanent or temporary in nature.

Permanent conductive hearing loss:

Permanent conductive hearing loss (microtia or atresia) is due to a malformed portion of the outer ear or middle ear. Children with microtia or atresia typically have hearing levels in the moderately-severe range.

- Microtia is a malformation of the outer ear (pinna). The pinna may be smaller than usual, misshapen or misplaced. Microtia can occur on one or both sides. Beyond the eardrum, the middle and inner ear (cochlea) may not be affected. Inner ear testing is required to rule out additional types of hearing loss.
- Atresia refers to a small/narrowed or non-existent ear canal.

Temporary conductive hearing loss:

Types of Hearing Loss (continued)

- Ear infections (otitis media) are very common in young children. Ear infections (fluid in the middle ear) cause temporary hearing difficulties. Your child may or may not feel pain or have a fever. If you suspect your child may have an ear infection, make an appointment with a doctor. Early treatment is important.
- Earwax can cause temporary hearing loss if it is not removed. Children with small ear canals or special medical needs are more likely to have extra earwax. If your child has a lot of wax, take him/her to the doctor to clean it out. Your child may need to see the doctor often if the wax keeps building up.
- Foreign object in the ear: If you suspect your child has something stuck in his/her ear canal, your child should see a doctor. Never attempt to remove an object on your own because this can push the object further into the ear canal or cause damage.
- Punctured eardrum (tympanic membrane): A punctured (or perforated) eardrum is a small hole in the eardrum. This can be caused by middle ear fluid or an injury to the eardrum. Symptoms may include pain, fever and/or bleeding. Take your child to the doctor as soon as possible for treatment.

Mixed Hearing Loss

Refers to a child that has coexisting (at the same time) conductive and sensorineural hearing loss. If your child has an ear infection, go to your pediatrician right away for treatment. Ear infections will worsen your child’s hearing levels/access to sound. Signs of ear infection may include irritability, soreness, redness, drainage, pulling on ears, etc. However, some children may be asymptomatic (they show no outward signs of distress).

Auditory Neuropathy Spectrum

Disorder (ANSD)

Is a condition that affects the quality of auditory information received by the brain. The outer ear collects sound normally, the inner ear receives sound normally, but it becomes disorganized or lost by the time it reaches the brain. Sometimes the sounds received by the brain are described as “choppy” or “muffled;” there is a range in severity. Little is known about the cause of ANSD. There is currently no known cure. Children with ANSD tend to have normal otoacoustic emission (OAE) results and abnormal or absent auditory brainstem response (ABR) results.

Binaural Hearing

If your child has hearing difference in both ears, he/she will be fitted with a hearing aid that matches their hearing levels in each ear. This is called a binaural hearing aid fitting. Reasons why binaural hearing is helpful:

1. Finding the sound (localization) - To figure out where a sound is coming from, it is best if sound can be accessed in both ears. The brain identifies where the sound is coming from by the loudness of the sound waves in each ear, the timing of when the sound waves arrive in each ear, and how the pitch varies at each ear.
2. Hearing better in noise - The auditory system has an easier time blocking out background noise and picking up the main signal (the person speaking) if sounds are heard in both ears.

Unilateral Hearing Loss

Children with a unilateral hearing loss (diminished hearing in just one ear) are able to access sound normally in one ear; however, they will face challenges. They may:

- Have difficulty detecting and localizing (figuring out where sound is coming from) sound especially in group discussions and loud environments.
- Be more fatigued in school due to greater effort needed to listen.
- Encounter social or behavioral problems in noisy cooperative learning environments or recess situations.
- Misconstrue peer conversations, feel rejected or ridiculed, and have increased misunderstandings while socializing.
- Be accused of selective hearing due to discrepancies in speech understanding in quiet versus noisy environments.
- May appear inattentive, distractible, or frustrated in learning situations.

Research shows that children with diminished hearing in one ear struggle more than their peers with typical hearing in both ears. The more severe the hearing loss, the more difficulties the child may experience. However, if your child gets the specialized support they need, they may stay on par with their peers.

Tips for optimizing auditory access for children with unilateral hearing loss:

- Reducing environmental/background noise.
- Your child will hear better in quiet environments.
- Allowing “listening breaks” and opportunities to rest without expectations of listening and attending.
- They will be more tired than their hearing peers because they have to listen twice as hard. This is called ‘listening fatigue.’
- Closing the gap.
- When communicating, be within arm’s distance. This will maximize auditory and visual cues.
- Gaining your child’s attention before speaking.
- Facing your child so he/she sees you when you talk.
- Using gestures, visual supports, and keeping your lips visible as much as possible.
- Positioning your child with their ‘hearing ear’ towards the person speaking/middle of the classroom.
- Identifying/pointing out environmental sounds (phones ringing, cars, airplanes) for/with them to help them learn where sounds are coming from.

?

Questions you can ask your audiologist

- Is a CROS hearing aid or bone-anchored sound processor appropriate for my child with unilateral hearing loss? CROS hearing aids send sound information from the ear that has diminished hearing to the ear that hears well.
- Would my child benefit from a hearing aid or a cochlear implant?
- How can we maintain the health of our child’s “hearing ear” from loud noises and infections?
- How often should we have the levels in our child’s “hearing ear” tested?

Types of Hearing Loss (continued)

Late or Delayed-Onset Hearing Loss

Late or Delayed-Onset Hearing Loss is when a baby has normal hearing levels at birth and loses their ability to hear as they grow older. A medical history and physical exam can help to find risk factors in babies who may have late onset hearing loss.

Risk factors for delayed onset hearing loss can include the following:

- Family history of genetic hearing loss
- Rubella or other non-bacterial infection when the mother was pregnant
- Structural changes of the ear, nose, or throat
- Birth weight less than 1500 grams
- Ototoxic medications (antibiotics that can damage the ear or auditory nerve) used for more than five days
- Bacterial meningitis
- Hyperbilirubinemia or jaundice that required a blood transfusion
- Head injury
- Prolonged stay in the neonatal intensive care unit
- Recurrent or persistent ear infections

Causes of Hearing Differences

You may be wondering...

"What caused my child's hearing difference?" Or "Does my child also have other medical issues/health concerns to worry about?"

A genetic counselor or genetics doctor can help to figure out if your child's hearing loss is due to a genetic cause and if there are other health concerns to be aware of. About half of all cases of childhood hearing loss are due to a genetic component, also known as a hereditary cause. In the other half of cases, possible causes may include illnesses and infections, certain medications, prematurity, trauma, birth defects, or an unknown anomaly.

The appointment with the geneticist will include a physical exam and review of your child's medical background. They will also ask about your family's medical history. They may share information about the chances of any future children also having a hearing difference. Your family may be offered genetic testing, which could involve a blood sample or saliva mouth swab. Some, but not all, families choose to do genetic testing to gain a full and complete understanding of their child's status.

For your audiologist

Your child's hearing on DATE:

Right ear	TYPE:	DEGREE:
Left ear	TYPE:	DEGREE:

Room for your notes....

After the Diagnosis

You may be wondering...
"Who has specialized knowledge about raising a child with hearing differences?"

Caregivers should seek advice from families with children who are deaf or hard of hearing. Additionally, families can gather information from a variety of experts in the field

- Pediatricians
- Audiologists
- Ear, nose, and throat (ENT) doctors
- Educators/teachers of the Deaf and Hard of Hearing
- Speech language pathologists
- Members of the Deaf community
- Persons who use American Sign Language

Different specialists may have differing opinions about treatment and management.

Ultimately, the treatment and management of your child's hearing differences should be tailored to his/her specific listening, communication, and learning needs. Only you can decide what works best for your family.

You may be wondering... ”How do we connect with other families with children who are deaf or hard of hearing?”

When there is a new diagnosis, some parents find it very helpful to connect with other families, locally and/or nationally, who also have children who are deaf or hard of hearing. Your audiologist, doctors, early interventionist, deaf mentor, or community partners can help to connect you with other families with children who are deaf or hard of hearing.

Questions you could ask other families with children who are deaf or hard of hearing.

- What worked for your family?
- How did you go about making decisions about communication modalities and assistive technologies?
- What was most helpful to you during the different stages of grief?
- How do you talk with your friends and extended family members about your child’s hearing difference/ability and communication needs?
- What does your family do to ensure your deaf or hard of hearing child has full access to language?
- How do you keep your child’s hearing aids on full-time?

“Fostering Joy D/HH” is a movement to celebrate the magic of raising children who are deaf/hard of hearing. Find the Fostering Joy Journal and other resources here:

https://handsandvoices.org/resources/fostering-joy.htm

> *“Fostering development and noticing the achievements of young children comes easily to most parents and other family members.*
>
> *The Fostering Joy journal gives families the opportunity to celebrate special moments when their children make them smile, make them proud, and bring them happiness.*
>
> *This journal is a precious gift to families with deaf and hard of hearing children helping them commemorate the wonder and beauty children who are deaf or hard of hearing bring to all of our lives.”*
>
> *Marilyn Sass-Lehrer, Ph.D.,*
> *Professor Emerita, Gallaudet University*

Amplification

5

As soon as a child is diagnosed with a hearing difference, he/she can be fitted with hearing aids. Parents should talk to an audiologist about which listening technology (i.e., hearing aid or cochlear implant) will work the best for their child. An audiologist will do multiple tests, make ear specific recommendations, and program the aids to match your child's hearing levels in each ear. One thing to note, hearing aids cannot be fitted until your child sees an otolaryngologist (ear, nose, throat doctor, or ENT) and receives "medical clearance." The ENT ensures it is physically safe for your child to wear hearing aids.

The audiologist will help you understand how hearing aids work, how to operate them, and how to care for them. Consistent use of working hearing aids will help your child hear to the best of his/her ability and develop speech and language skills. The loudness levels in your child's hearing aids will be locked so they cannot accidently turn up the volume.

As your child grows, so will his/her ears and ability to engage in the testing process, participate in more sophisticated hearing tests, and care for their own listening technology. As your child grows, the hearing levels in their listening technology will be adjusted as they become more reliable reporters. For the earmolds to fit properly, they should be remade on a regular basis. This will happen more often when children are very young. It will happen less often as children get older and their ears grow more slowly.

Types of Hearing Aids

There are many types of hearing aids. Your audiologist will make the best choice based on your child's age, type of hearing loss, and degree of hearing loss.

Behind-the-Ear Hearing Aids (BTE)

Most babies and young children will be fitted with a behind-the-ear hearing aid because they are easier to operate. They can also be connected to a Hearing Assistive Technology (HAT) device to be used at school. BTE hearing aids can be used for all degrees of hearing loss. Your audiologist will program the hearing aid based on your child's hearing levels.

Sound enters the hearing aid microphone

sound travels through the earhook

then into the tubing

through the earmold and then through the ear

Parts of the BTE Hearing Aid

Earmold – The earmold is specifically molded to shape to your child's ear. Soft tubing connects the earmold to the hearing aid. When sound is amplified in the hearing aid, it is sent through the tubing in the earmold, then to the ear canal. Since earmolds are custom-fit to your child's ear, they will need to be remade every 3-6 months as your child's ear grows. A snug earmold fit will help to control feedback. At the end of each day, earmolds should be cleaned to ensure wax is not clogging the earmold. A wax pick and brush found in your cleaning kit can be used to remove any wax.

Battery – Hearing aids can be powered by rechargeable or disposable batteries. Often the family will be given the choice for which they prefer. Hearing aids that are rechargeable will come with a charging case, and will need to be charged every night. Hearing aids that use disposable batteries can expect to get a few days to two weeks of use from each battery. The battery should be placed inside the hearing aid with the (+) and (-) signs facing the correct way. Your audiologist will show you how.

Hearing aids with disposable batteries for young children usually come with a tamper-proof battery door. You need a special tool to open it. Your child will not be able to open the battery door on his/her own. Batteries should be kept away from children and pets since they are small enough to be swallowed. If your child swallows a battery, you should immediately take him/her to the emergency room.

Microphone – The microphone picks up sound.

Earhook – The earhook is a hard plastic piece that curves over the top of the ear. It protects the microphone and receiver. It also directs the sound from the hearing aid into the earmold. The earhook may contain a filter to change how a sound is heard by your child. The filter can look like rubbish. Do not remove any object from the earhook without first checking with your audiologist.

How Can You Help Your Child Adjust to Hearing Aids?

Your child should wear his/her hearing aids for all waking hours. If your child will not keep the hearing aids on, check if they are causing soreness (redness or other signs that the hearing aids do not fit properly). Also, watch your child's response to loud sounds. Contact your audiologist if you think the hearing aids are too loud or hurting your child in any way.

If your child will not keep their hearing aids on, talk with your audiologist and Early Intervention Deaf and Hard of Hearing Specialist for ideas. You can try different strategies for keeping the hearing aids on. One example is to pair time spent wearing hearing aids with things that your child likes, like reading stories or playing with a special toy. Then, slowly work up to longer wearing times. Wearing times should be controlled by you and not by your child. The goal is for your child to wear his/her hearing aids for all waking hours. Be matter-of-fact and not apologetic when putting hearing aids into your child's ears. Think of putting the hearing aids on as you would eyeglasses.

You should tell your audiologist about your child's response to sound. This is helpful because you see your child the most. Write things down so that you don't forget to discuss your concerns or what you have seen. Adjustments to the hearing aids can be made based on test results and on your reports about how your child responds to sound while wearing the hearing aids. When changes are made, you may find that it takes time for your child to adjust to the latest sound from the hearing aids.

Ideas for Keeping Hearing Aids on the Ears

It can be difficult to keep an infant or toddler from pulling hearing aids out of his/her ears or to keep the hearing aid from flopping around on the ear. There are some ways to deal with these problems.

Pilot Caps are specifically designed to accommodate hearing aids and can be helpful for infants and toddlers who have a tendency to pull them off. The pilot cap covers your child's head and has special mesh fabric on the side to allow sound to get to the microphone on the hearing aid. This cap will help your child not be able to pull their hearing aids off as quickly, and allow you more time to redirect them. Hearing aid pilot caps can be purchased online through Etsy.com and other retailers.

Headbands can also be used. They go around the forehead and over the outer ears and hearing aids. You need to make sure the headband does not cover the microphone. Check out Ear Suspenders™ for behind the ear hearing aids or BAHA Bowtique™ for softbands.

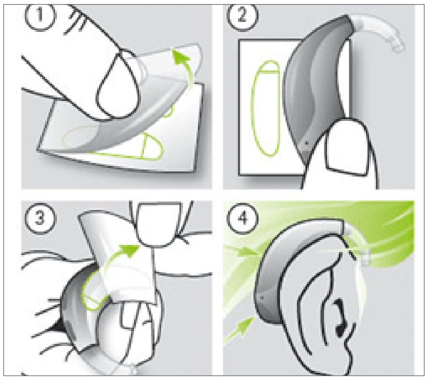
Retainer Clips (Ear Gear™ and Critter Clips™ are name brands) can be clipped to the back of the shirt with a cord that attaches to the hearing aid. If the hearing aid is pulled off or falls off, it will dangle from the clip at the back of the child's shirt. The hearing aid will not be dropped or thrown and is less likely to be chewed on.

Double-sided Tape that is used for wigs and toupees can also help keep the hearing aid from flopping around the ear.

Pilot Caps

Headbands

Retainer Clips



Double-sided Tape

Images 1 and 2 courtesy of www.babyhearing.org

Image 3 courtesy of www.ndcs.org.uk
Image 4 courtesy of www.phonak.com

Questions you can ask your audiologist

- Can you please show me a chart of what my child can and cannot hear?
- On a chart, can you please show me how my child's access to sound changes when their hearing aids are being worn vs. when they are not being worn?
- How often do my child's hearing levels need to be tested?
- How should I clean my child's hearing aids?
- How do I check that the hearing aids are fully functioning?
- How often should I check that the hearing aids are working?
- What do I do if the hearing aids break?
- How will I know when my child needs new hearing aid molds?

Limitations of Hearing Aids

Distance

The amount of distance between a sound and the hearing aid microphone can impact how well your child is able to hear it. In other words, the further away your child is from a person who is speaking, the softer the speech is when it reaches your child's ear and hearing aid microphone.

Background Noise

Background noise can interfere with your child's understanding of the sounds they hear. Hearing aids amplify all sounds, including background noise. A person with normal hearing is better able to ignore background noises than a child who uses hearing aids. For a person with hearing loss, it is harder to pick out the important sounds from the background noise. Reducing background noise and creating a quiet listening environment will help your child be able to hear better. There are things you can do in your home to reduce background noise and create a better listening environment. You can place rugs on the floors, rubber or felt pieces on the legs of chairs and tables, turn off the television, close the windows, and put soft matting under the tablecloth to reduce the sounds of dishes and silverware on the table.

Hearing Aid Acoustic Feedback

Feedback from a hearing aid sounds like a loud high-pitched whistle. It occurs when sound escapes out of the gap between the child's ear (pinna) and the earmold. Feedback can be annoying to the people nearby, but it does not hurt your child. Feedback can occur when a child covers their hearing aid with a hand/hat or presses his/her head against a surface. When holding your baby or young child, if the child's ear rests against you, feedback may occur and the hearing aid may whistle. Snuggle time is critically important for bonding, so just move your child's head slightly to stop the noise. Another possible cause of feedback is an earmold that does not fit tightly enough or there is a crack in the tubing. If your child experiences constant feedback, there is a visible crack, or the mold falls out too easily, contact your audiologist. It takes many months to replace molds and/or repair listening technology. Do not delay in calling!

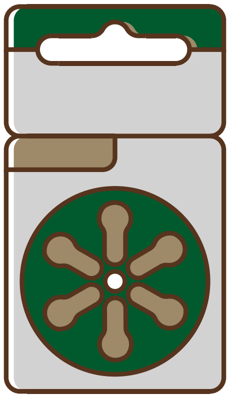
Hearing Aid Care and Maintenance

When your child is fitted with hearing aids, the audiologist will explain how they work and the different parts/functions. You will also be given a "Hearing Aid Care Kit." It should include a wax pick/brush, earmold blower, listening tube, and dehumidifier. You will learn how to put the hearing aid on your child safely, change the batteries or charge the device, check the tubing and earmold, and check the sound coming from the hearing aid with the listening tube. If you did not receive a tutorial from your audiologist, you can ask at your next appointment or reference the manual in the hearing aid kit.

When your child is in school, the school staff should check the hearing aids and hearing assistive technology (i.e., HAT/FM system) daily for proper function during school hours. If they attend a Department of Education preschool, include "daily listening checks with logs" on their individualized education plan (IEP). As your child gets older, he/she can be responsible for some of their own hearing aid maintenance.

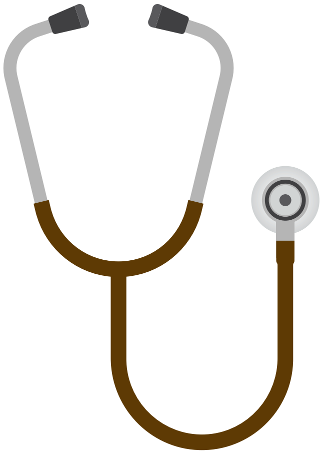
Dehumidifier

At the end of each day, or whenever the hearing aid is not in use, place it in the dehumidifier to dry it out. You can purchase a UV dehumidifier machine or use the container and capsules provided by your audiologist.



Batteries

If you have rechargeable hearing aids, it is important to make sure they are charged every night to ensure they will have enough battery life for the next day. Hearing aids with disposable batteries need to be checked daily to ensure the amount of battery life that is remaining. It is a good idea to carry spare batteries, or send them with your child, in case they run out unexpectedly. Most hearing aids have a battery life light which indicates the charge level of the hearing aid. A blinking green light typically means there is a sufficient charge. An orange or red blinking light will indicate that the charge level is low, and no blinking light will indicate that the batteries have been depleted.



Listening Tube

Before putting the hearing aids in, ensure they are working properly. Check them daily with a listening tube. You cannot check the functionality of the hearing aids by simply putting the aids up to your ear.

Step 1) put the listening tube in your ear and the opening over the hearing aid mold; Step 2) talk into the hearing aid microphone; Step 3) listen for static, distortion, and broken or no sound.

If there is a problem, contact your audiologist for advice or to request an appointment for a hearing aid check. For young children who are not able to tell you that their hearing aid is not working, you should listen to the hearing aid each day to make sure it is working.

Troubleshooting the BTE Hearing Aid

Problem:
No sound or distorted sound

- Replace the battery or charge the device.
- Check for corrosion on the battery contacts inside the hearing aid. This can be cleaned off with a small brush provided in the hearing aid cleaning kit.
- Clean wax from the earmold.
- Clear moisture from the earmold and tubing.

Problem:
Whistling or feedback

- Check that the earmold is correctly in the ear and snug.
- Clean wax from the earmold.
- Clear moisture from the earmold and tubing using the blower in your care kit. Make sure to put in the dehumidifier each night.
- Check the tubing to see if it is cracked or loose from the earmold. If so, make an appointment to see your audiologist.
- Wax may be blocking the ear canal. Make an appointment to see your pediatrician or ENT.

Reminder:
Daily Checks and Maintenance

Visual check

- Check the tubing, earmolds, battery.
- Check the battery compartment for “rust.” If found, use the brush in your clearing kit. If problems persist, call your audiologist.

Listening check

- Listen for static, distortions, or unclear sound. If found, call your audiologist.
- Use these sounds (oo-ee-ah-mm-sh-ss-jj-nn-hh-zz) to check the technology and to monitor what your child is hearing vs. what they are missing. Speech perception and production need to be monitored regularly.

Room for your notes....

Cochlear Implants (CI)

Not all children will benefit from cochlear implants. Speak to your child's audiologist and implanting ENT to get more information and find out if your child is a good candidate.

Cochlear Implants (CI) are surgically implanted hearing devices. CI's provide direct electrical stimulation to the hair cells in the inner ear (cochlea).

There are two parts to a cochlear implant system: the internal implant and the external processor. The processor, which looks like a behind-the-ear hearing aid, can be worn behind the ear or attached to the child's clothing. The processor is held in place by magnets on the implant, which is under the skin. The cochlear implant does not "restore" or "cure" hearing. It does allow a person to identify the sensation of sound.

You may be wondering...

"What is the criteria for cochlear implant candidacy in children?"

The child must:

- Have a severe to profound sensorineural loss in one or both ears.
- Demonstrate limited benefit from hearing aids.
- Be free of any medical conditions that would cause the surgery to risk their general health/lives.

The family must:

- Be willing and able to provide the child with necessary supports following surgery.
- Have realistic expectations for cochlear implant and understand that full-time use following activation is essential.
- Understand that "success" of the cochlear implants depends on intensive follow-up therapies to teach the child how to use the implant, development of auditory skills, and learn how to listen.
- Be willing to be actively involved in their child's follow-up therapies and services.
- Have a plan for how they will support their child's educational needs once they enter school.

"What happens after my child gets a cochlear implant?"

If your child does get a cochlear implant, he/she will receive services from a team of professionals. Doctors, audiologists, speech-language pathologists, teachers, and counselors will work with your child as he/she gets the implant, receives follow-up care, learns to listen, improves speech, uses speech reading, and handles communication. It is important to learn how to support your child, how to monitor their progress, and what red flags to look for while they are acquiring new skills.

For more information on cochlear implant technology and what follow-up therapy entails, ask your child's audiologist or surgeon/Otolaryngologist (ENT doctor). These professionals can work with families to decide if a child would benefit from an implant, determine eligibility, perform the surgery, and provide follow-up care.

Other Devices


Image courtesy of www.cochlear.com

Bone-Anchored Sound Processor

A bone-anchored sound processor may be used for children with either a conductive or unilateral profound sensorineural hearing loss. A Conductive loss can include a blocked or damaged middle ear, such as having no ear canal or no ossicles (small bones in the middle ear). It uses bone conduction to send sound directly to the cochlea, which is working well. The sound bypasses the blocked or damaged middle ear system. Bone-anchored sound processors can also be used by children who have a unilateral profound sensorineural hearing loss (in only one ear.) The bone conduction hearing aid would be placed on the side of the hearing loss to access sound on that side. The sound would be transferred to the other cochlea to be processed and heard. When children are young, a bone-anchored hearing aid will be worn on a soft-band, and can later be implanted. You can ask your audiologist if the bone-anchored sound processor is right for your child.

Hearing Assistive Technology (HAT)/ FM systems

Children who are deaf or hard of hearing have a difficult time hearing in noisy environments such as cars or classrooms. In these settings, hearing aids may not be enough. Hearing Assistive Technology/FM systems can help your child hear better in these difficult listening environments.

How do HAT/FM Systems Support Listening Devices?

Hearing aids and cochlear implants have many benefits for a child. However, those technologies are limited by the distance from the speaker, background noise, and sounds in the environment.

The further the child is from a speaker, the softer the sound is by the time it reaches the microphone on the child's hearing aid or cochlear implant. In noisy environments, it is difficult to tell a speaker's voice apart from background noise. A deaf or hard of hearing child can become confused by all of the sounds they are hearing. An HAT/FM system has a microphone that sends a speaker's voice straight to the child's hearing aid or cochlear implant. This cuts down background noise and reverberation. The speaker wears a wireless microphone that sends his/her voice directly to the child's hearing aid or cochlear implant and is not limited by distance or positioning in the classroom/home. Even with a HAT/FM system, it is still best to have children with differences seated close to the person speaking in order to take full advantage of visual cues plus sound input. In a circle-group setting, it's best to have the child seated at the speaker's "10 and 2," not beside them, so they can see the speaker's face.

Early Intervention Services

6

The Hawaiʻi State Department of Health (DOH) Early Intervention Section (EIS) is a federal-and state-mandated program that provides services to support the development of infant and toddlers from birth to three years of age. Information and support are provided to parents to increase their knowledge and ability to support their child's development. EIS is responsible for the implementation of Part C of the federal mandate called Individuals with Disabilities Education Act (IDEA). EIS makes sure that Hawaiʻi meets the requirements and regulations of Part C of IDEA.

For information about Part C, IDEA, please go to U.S. Department of Education's Individuals with Disabilities Education Act (IDEA) website

https://sites.ed.gov/idea/early-learning-early-childhood

Early Intervention Referrals

Parents, family members, healthcare providers, or caregivers who are concerned about the development or special health care needs of a child, birth-3 years of age, can make a referral to Early Intervention (EI). After a referral is made, the EI program nearest to the child's home will meet with the family and begin the process of completing a full developmental evaluation.

Make a referral to
Early Intervention (EI) by calling

Oahu: **(808) 594-0066**
Neighbor: **1-800-235-5477** (toll-free)

Evaluation

Children with confirmed hearing loss automatically qualify for Early Intervention Services under the 'biological risk' category. However, an evaluation will be completed, using a 'five domain assessment tool,' to gain a more well-rounded understanding of the child's overall strengths and needs. Evaluations help EI staff to identify a child's strengths and areas of need.

A 'five domain assessment tool' is used to evaluate a child's developmental progress in five different developmental areas: cognitive, social, emotional, physical, and language. An examiner interacts with a child using toys/objects to observe their ability to follow instructions, problem solve, and perform tasks.

A parent interview is also used to gather helpful information that does not come up on the evaluation. The child's performance is scored based on standard criteria. The results show a child's development compared to other children of the same age, and also whether or not there are developmental delays.

If the results of the initial evaluation show 'no areas of concern,' that does not necessarily mean there are no areas of concern for the future. Families may misinterpret the initial evaluation results as, "My child is doing fine; therefore, we do not need Early Intervention." However, the reason deaf and hard of hearing children automatically qualify for services is that as children grow, areas of concern may arise over time and worsen with age.

Deaf and hard of hearing children who receive Early Intervention Services from an early age, have better outcomes because it minimizes potential delays in the areas of language, cognition, social-emotional, etc. If deaf children miss their important developmental milestones in Early Intervention, they will not enter kindergarten ready to learn.

Individualized Family Support Plan (IFSP)

An Individualized Family Service Plan (IFSP) is a family-focused document that outlines the child/family's needs and concerns with goals and objectives, and services to address those needs. Parents, Early Intervention (EI) service providers, specialists, and doctors can be included as members of the IFSP team. The IFSP document is a plan that guides the services for the child and his/her family. The family will be assigned a care coordinator who will help to navigate the family through the IFSP process. A periodic review of the IFSP must be held at least every six months to determine if progress is being made toward achieving the outcomes.

Child/Family Outcomes

The IFSP recognizes that families are crucial to the child's overall development. Families are involved in designing every section of the IFSP. Outcomes are primarily geared towards language and communication as well as promoting social, emotional, physical, self-help, and cognitive development. In the "Child/Family Outcomes" section you can share the priorities/concerns you have for your child's development, as well as your family's growth. You will be asked questions such as:

- What do you want to see happen for your child/family?
- What is happening now with your child/family?
- What strategies and resources will be used to achieve this outcome?
- How will you know if progress is being made?
- What is your criteria for success?

If you do not know how to answer these questions, it is ok to ask for help/guidance. There are countless free resources available that can guide your family in designing an IFSP that feels right for you.

Check out 'Language Milestones for Children Who are Deaf or Hard of Hearing: birth to five years of age.'

https://www.cde.ca.gov/sp/ss/dh/sb210langmilestones.asp

Check out 'Help Me Grow: Developmental Milestones.'

https://helpmegrowmn.org/HMG/DevelopMilestone/index.html

Ideas for 'Child/Family Outcomes' could include:

- Parents would like to learn the structure of the ear, how it works, and where their child's hearing loss is.
- Parents would like to learn how to read an audiogram, and what their child is able to hear both with and without their amplification.
- Parents would like to learn about their child's amplification, and how to care for it.
- Parents would like to learn about the different communication modalities (ASL, Total Communication, Listening and Spoken Language).
- Parents would like to learn how to communicate with their child in ASL throughout the day during daily routines.
- Parents would like to learn communication strategies that they can use in their home to encourage listening and language development.

Outcomes/Goals can also be developed to address concerns in your child's development as it relates to their hearing loss. For deaf or hard of hearing children, outcomes/goals are typically developed in three areas;

- Auditory skills
- Receptive language skills
- Expressive communication skills

Creating outcomes/goals in these areas is important to be able to monitor your child's listening and language development as these are the areas that are typically impacted by hearing loss. Listening and language goals can be tailored to fit your family's communication modality choice.

Below are a few examples of goals that you can ask your Early Interventionist to focus on. The objectives can be tailored to your child's listening and language level.

Ideas for 'Auditory Outcomes' could include:

Outcome/Goal: My child will continue to work on increasing their auditory skills.

Objectives: Given parent education opportunities with the DHH or EI during home visits, the child will develop the following skills:

- My child will wear amplification for all waking hours.
- My child will be able to localize to the sound source.
- My child will be able to discriminate between familiar songs by performing the associated finger-plays.
- My child will show awareness to Ling-Madel-Hewitt sounds through play audiometry.

Ideas for 'Receptive Outcomes' could include:

Outcome/Goal: My child will increase their understanding of spoken words/signs.

Objectives: Given parent education opportunities with the DHH or EI during home visits, the child will develop the following skills:

- Will respond to their name when called/signed.
- Will show their understanding of familiar people and look at them when named.
- Will respond to simple commands by performing the action ("come here," "sit down," "clap your hands").
- Will show their understanding of 20 words.
- Will point to 3-5 body parts.
- Will follow one and two step directions.

Ideas for 'Expressive Outcomes' could include:

Outcome/Goal: My child will be able to expressively communicate with others using spoken words or ASL.

Objective: Given parent education opportunities with the DHH or EI during home visits, the child will develop the following skills:

- Will use a variety of sounds in babble (b/p/m/n/d).
- Will imitate pitch and duration.
- Will use 10-20 spoken/sign word approximations.
- Will use rising intonation to indicate a question.
- Will combine words/signs (more milk).
- Will use simple question forms (where/what/who?).

Room for your notes....

“Parents are considered equal partners...”

The Individual with Disabilities Education Act (IDEA) state the following:

2004 IDEA Reauthorization: Sections 300.343(c)(iii) and 300.346(a)(1) and (b) ***“Parents are considered equal partners with school personnel in making these decisions, and the IEP team must consider the parents’ concerns and the information that they provide about their child in developing and implementing the IEP.”***

2004 IDEA Reauthorization: Sec. 614 (3) Development of IEP; (B) Consideration of Special Factors. The IEP team shall: ***“(iv) Consider the communication needs of the child, and in the case of the child who is deaf or hard of hearing, consider the child’s language and communication needs, opportunities for direct communications with peers and professional personnel in the child’s language and communication mode, academic level, and full range of needs, including opportunities for direct instruction in the child’s language and communication mode; and (v) Consider whether the child requires assistive technology devices and services.”***

Transition Out of IDEA Part C Early Intervention Services

Children who are deaf or hard of hearing can receive Early Intervention (EI) services until the day before their third birthday. At three years of age, children may transition to the Department of Education (DOE), a private or public preschool, Head Start, or other programs in their community.

Families are supported through the transition by their child's care coordinator and the IFSP team. A family may have their child evaluated by the DOE for eligibility for a special education program. There may be a series of 3-4 meetings to determine if the child qualifies for Part B services under the Individuals with Disability Education Act.

Transition Conference

These conferences are run by the Early Intervention (Department of Health) program, can be held at a variety of locations, and can include the Department of Education in addition to private and community programs.

- Typically occur six months before the child's third birthday.
- An opportunity to ask questions about the transition process and the DOE system as a whole.
- Families can gather information from different programs, such as DOE, Head Start, or community preschools. These programs may be options for their child's placement at age three.

School Team Meeting

(a.k.a. Student Focus Group (SFT)/ Student Services Team (SST) Meeting)

This meeting is conducted by the Department of Education (DOE) at the school closest to the child's home (referred to as "the home school").

- DOE will use the information parents provide to decide if there is a suspicion of a disability.
- If 'yes,' the DOE will ask for written informed parental consent to engage in the evaluation process. The evaluation process might include: parent interviews, observations, and/or assessments.
- If the family consents, the team will review any data/assessments/reports provided by early intervention, data/assessments/reports conducted through an outside agency, and/or medical data/assessments/reports.

Eligibility Meeting

- Parents can be provided with copies of assessments and/or summary reports prior to the eligibility meeting. A request can be made through the Student Services Coordinator (SSC).
- The DOE will present the results from their assessments. Data from the assessments, and input of the family and the EI representatives, will be considered.
- Parents may ask questions and share insights.

Questions you might want to ask

- Who will be doing the assessments/observations on my child?
- What makes the assessor uniquely qualified to conduct the assessments on my child?
- Which assessments will be conducted on my child? Are they designed for children who are deaf or hard of hearing?
- Can you please provide us with a digital copy of our child's observations/assessments at least one week prior to the eligibility meeting?

- The home school team will determine if the child is eligible for special education services based on the criteria in 1 of 14 categories such as: deaf, hard of hearing, deaf-blind, multiple disabilities, other health impairment, etc.

Individualized Education Plan (IEP) Meeting

- If a child is found eligible for special education services through the DOE under the Individuals with Disabilities Education Act (IDEA), the IEP team will develop an IEP based on the unique needs of the child.
- The IEP team must include the child's caregivers in the creation of the IEP. Other team members can include one general education teacher, one special education teacher, one administrator, and a Teacher of the Deaf (TOD). *TOD's are special education teachers who specialize in the education of, and accommodations for, students who are deaf or hard of hearing. Additional IEP team members may include specialists such as speech language pathologists, psychologists, physical or occupational therapists, EI representatives, or other persons invited by the parents or the DOE.
- The IEP is done at least once a year. The annual IEP will include educational goals, objectives, special education services, and supplemental aids and related services.

IEP Placement Meeting

- Following the completion of the IEP, parents will be given a "reasonable amount of time" to look over the IEP.
- Based on the IEP, the team decides where the IEP can be implemented. If the IEP cannot be implemented at the home school, the team should discuss alternative placement options that can best meet the child's needs. Meaning, if the child's specialized instruction needs are greater than the resources available at their home school, the child may be eligible for an alternative programmatic placement.
- If parents consent to the IEP, they are consenting to the initial provision of special education services as they are laid out in the IEP.
- If parents do not consent, child will not receive the special education and related services outlined in the IEP. Parents have the right to refuse consent for an IEP and can still advocate for their child's needs through other avenues, such as requesting an independent evaluation or seeking mediation. The school district cannot use due process procedures or other dispute resolution options to force the parents to consent.

Questions you could ask during the eligibility meeting

- Was enough data collected to fully understand my child's strengths and areas of need?
- How does this eligibility category impact provision of services when my child attends school?

Questions you could ask during the IEP meeting

- How will progress on these goals and objectives be measured?
- Who is responsible for monitoring progress on these goals and objectives?
- How often will data be collected and shared on these goals and objectives?
- Who is responsible for working on these goals and objectives?
- What supports and services will be in place to help my child achieve these goals and objectives?
- What supplemental aids will be used to support my child and who will ensure their functionality daily?

Questions you could ask about IEP placement

- Can this school/district implement the IEP as it is written?
- How will the school meet my child's needs?

Rights of Students Who Are Deaf, Hard of Hearing, or Deaf-Blind

Hawaiʻi Board of Education
Policy 900-5

The Board of Education is committed to providing quality educational opportunities for all students with disabilities, including those who are deaf, hard of hearing, and deaf-blind. This commitment includes ensuring instructional programming that safeguards the following rights for students who are deaf or hard of hearing, and deaf-blind:

1. The right to qualified teachers, interpreters, support services staff, and resource personnel who can communicate effectively with the child using the child's own mode of communication, be it (a) a signed system based on English Code; (b) American Sign Language; (c) an oral system; or (d) a simultaneous communication system as determined with appropriate diagnostic information, consideration of the student's learning style, and collaboration with the student's educational planning team, including parents and guardians;
2. The right to associate with peers, including age, cognitive, and language appropriate peers;
3. The right to exposure to adult role models who are deaf, hard of hearing, or deaf-blind;
4. The right to have American Sign Language as one of the academic subjects in their educational curriculum when the child's identified primary language is considered to be American Sign Language;
5. The right to appropriate screening and assessment of hearing and vision capabilities and communication and language needs at the earliest possible age, and to continuing screening services throughout the child's educational experience;
6. The right to early intervention to facilitate the acquisition of a solid language base or bases to be developed at the earliest possible age;
7. The right to their parents' or guardians' full, informed participation in their educational planning;
8. The right to individual consideration for free and appropriate public education across a full spectrum of educational programs;
9. The right to placement that is best suited to the child's individual needs including but not limited to social, emotional, cultural needs, age, hearing loss, visual acuity, academic level, mode of communication, style of learning, and motivational and family support;
10. The right to equal access to all academic programs in their educational settings and supplemented with necessary and appropriate support services; and
11. The right to equal access to all school-supported non-academic extracurricular and athletic programs supplemented with necessary and appropriate support services.

https://boe.hawaii.gov/wp-content/uploads/2024/07/900-5-05-19-2015.pdf

[Approved: 05/19/2015 (as Board Policy 900.5); amended: 06/21/2016 (renumbered as Board Policy 900-5)] Former policy 2205 history: 01/22/1998

We hope that this resource guide is useful for you and your ʻohana. We encourage you to seek out more resources, as listed in the Appendices of this guide.

Finally, we wish you and your child the very best as you grow and learn together on your journey.

Your Team of Professionals

From now until your baby turns 3, you'll be working with different professionals to help support you and your baby. Use this space to keep track of everyone who is part of your team.

Pediatric Audiologist

NAME:
CONTACT INFORMATION:
ADDRESS OF OFFICE:

Ear, Nose, and Throat doctor (ENT)

NAME:
CONTACT INFORMATION:
ADDRESS OF OFFICE:

Early Intervention Care Coordinator

NAME:
CONTACT INFORMATION:
ADDRESS OF OFFICE:

Early Intervention Primary Service Provider

NAME:
CONTACT INFORMATION:
ADDRESS OF OFFICE:

Deaf and Hard of Hearing Specialists

NAME:
ROLE:
CONTACT INFORMATION:

NAME:
ROLE:
CONTACT INFORMATION:

NAME:
ROLE:
CONTACT INFORMATION:

Your Appointment Planner

DATE:
TIME:
WHO:
WHERE:
REASON FOR VISIT:
OUTCOME:

DATE:
TIME:
WHO:
WHERE:
REASON FOR VISIT:
OUTCOME:

DATE:
TIME:
WHO:
WHERE:
REASON FOR VISIT:
OUTCOME:

DATE:
TIME:
WHO:
WHERE:
REASON FOR VISIT:
OUTCOME:

Appendix A

Hawaiʻi Organizations and Associations

Comprehensive Service Center (CSC)

Phone: 808-369-0499
Web: **www.csc-hawaii.org**

The CSC supports D/HH individuals of all ages, birth to elders, and their families, across all of the Hawaiian Islands. As a comprehensive resource center, they offer 1-to-1 parent education opportunities, Parent Guides and Deaf Mentors, ASL classes, a lending library, fun family events in the community, and much more.

Assistive Technology Resource Centers of Hawaiʻi (ATRC) and Career Explorations of Hawaiʻi

414 Kuwili Street, Suite 104
Honolulu, HI 96817

Phone: 808-532-7110 (Oahu)
1-800-645-3007 (Neighbor Islands, toll-free)
Fax: 808-532-7120
Email: atrc@atrc.org
Web: **www.atrc.org**

A non-profit organization providing information, training, outreach, and policy development on assistive technology for persons with any type of disability. Operates assistive technology equipment loan banks on four islands. Provides low interest financial loans to purchase assistive technology devices and service.

Department of Education (DOE):
Hawaiʻi School for the Deaf and the Blind (HSDB)

3440 Le'ahi Avenue
Honolulu, HI 96815

Phone: 808-733-4999 (TTY/Voice)
Library Phone: 808-733-4831
Fax: 808-733-4824
Web: **https://www.hsdb.k12.hi.us**

The Hawaiʻi School for the Deaf and Blind is a public education facility that provides services to the islands' deaf, blind, and deaf-blind students. One of the main functions of HSDB is providing an ASL immersion program that follows the tenets of a bi-cultural, bi-lingual philosophy.

Department of Health (DOH):
Children and Youth with Special Health Needs Program

741 Sunset Avenue
Honolulu, HI 96816

Phone: 808-733-9055 (TTY/Voice)
Fax: 808-733-9068

Provides care coordination, social work, nutrition services, financial assistance, outreach and advocacy for hearing impaired children ages 0 to 21 years who meet financial and medical eligibility requirements. Services may include ENT and audiologist visits and hearing aid purchase and related services. To see if you qualify for financial assistance for hearing aids, look for the blue "Apply Now" button to fill out the 'CYSHNP Online Referral Form': https://health.hawaii.gov/cshcn/home/communitypage/

Department of Health (DOH):
Early Intervention Section

1350 South King Street, Suite 200
Honolulu, HI 96815

Phone: 808-594-0000 (Voice)
Fax: 808-594-0015

Hawaiʻi's lead agency for Part C of I.D.E.A. (Individuals with Disabilities Education Act), the Early Intervention Section support families of infants or toddlers, from birth to age three, who are developmentally delayed, biologically at risk, or environmentally at risk and the many public and private agencies that provide prevention *and intervention services that serve them. Infants and toddlers may receive evaluation services, care coordination, and an Individualized Family Support Plan (IFSP) which identifies the service and support needs of both the child and family. These services are available at no cost to families. Through care coordination, the family is linked to programs that can meet these needs. The Early Intervention Section also operates the Hawaiʻi Keiki Information Service System (H-KISS), a free information and referral service that provides a vital link to services for families with children ages 0-5.*

Disability and Communication Access Board (DCAB)

919 Ala Moana Boulevard, Room 101
Honolulu, HI 96814

Phone: 808-586-8121 (TTY/Voice)
Fax: 808-586-8129
Web: **https://health.hawaii.gov/dcab**

A state agency that serves as a central clearinghouse of information on resources and services to people with disabilities and makes policy recommendations on their behalf. Publishes Haʻilono Kina quarterly newsletter. Establish guidelines and recommended fee schedules for sign language interpreters and other communication assistants utilizing state services. Coordinates the Hawaiʻi Quality Assurance Screening and credentials sign language interpreters who do not possess national certification. Neighbor island offices in Lihue and Kahului.

Hands & Voices, Hawaiʻi

Phone: 808-223-9229
Email: HV.Hawaii@gmail.com

Hands & Voices Hawaiʻi is dedicated to supporting families with children who are deaf or hard of hearing, without bias towards communication modes or methodology. This is a local chapter of the parent-driven, non-profit organization which provides families with the resources, networks, and information they need to improve communication access and educational outcomes for their children.

Hawaiʻi Pacific Deaf-Blind Project

Pacific Outreach Initiative, University of Hawaiʻi at Manoa
1776 University Avenue, UA 4-6
Honolulu, HI 96822

Phone: 808-956-5861
Fax: 808-956-7878
Web: **https://www.csc-hawaii.org/hpdbp**

The Hawaiʻi Deaf-Blind Project provides technical assistance to children and youth who are deaf-blind, birth through 21 years of age, and to their families and service providers. This may include in-home consultation, school consultation, family support, networking, in-service, biannual statewide trainings, referrals to other agencies, and resources.

Leadership in Disabilities & Achievement of Hawaiʻi

245 N. Kukui Street, Suite 205
Honolulu, HI 96817

Phone: 808-536-9684
Outer Islands toll-free: 1-800-533-9684
Fax: 808-537-6780
Web: **https://ldahawaii.org**

Hawaiʻi Organizations and Associations (continued)

Leadership in Disabilities & Achievement of Hawaiʻi (LDAH) is a non-profit organization founded in 1968 by parents of children with disabilities. The Parent Training & Information Center (PTI) for Hawai'i's mission is to enhance education, work, and life opportunities for children and youth with disabilities by empowering them and their families through information, training and mentoring, and by public outreach and advocacy. LDAH supports parents of children with any disability and the professionals who serve them in the following ways: information/ referral, education and training, mentoring and advocacy, small grant awards to benefit children with disabilities, School Readiness Project, and Sharing the Commitment (STC)--Poʻokela Project

Special Parent Information Network (SPIN)

919 Ala Moana Blvd. Room 101
Honolulu, HI 96814

Oahu: 808-586-8126 Voice/TTY, Fax: 808-586-8129
Kauai: 808-274-3141, ext. 6-8126
Hawai'i: 808-974-4000, ext. 6-8126
Maui: 808-984-2400, ext. 6-8126
Molokai & Lanai: 1-800-468-4644, ext. 6-8126

Email: spin@doh.Hawaii.gov
Web: **https://spinhawaii.org**

A parent to parent organization in Hawaiʻi that provides information, support, and referral to parents of children and young adults with disabilities, and the professionals who serve them.

University of Hawaiʻi School of Medicine Speech and Hearing Clinic (UHSHC)

677 Ala Moana Blvd. Suite 625
Honolulu, HI 96813

Phone: 808-692-1580
Fax: 808-566-6292
Web: **https://uhphawaii.org/index.php/csd**

The UHSHC serves as a teaching facility for speech pathology graduate students enrolled in the Department of Communication Sciences and Disorders. Graduate students work directly with patients under the close supervision of an instructor. The UHSHC provides speech, language, and hearing services to the Hawaiʻi community. The clinic provides multi-disciplinary diagnostic evaluations and therapeutic services to children and adults on an outpatient basis.

Appendix B

Internet Resources

“Just in Time”

A tool to help families with children who are deaf or hard of hearing (D/HH) connect to family-to-family supports. This resource contains essential resources from families and professionals to address hearing-related needs.

https://www.infanthearing.org/just-in-time

“Off to a Great Start!” from Hands & Voices

A virtual, family-friendly resource from Hands & Voices Family Leadership in Language and Learning (FL3) Center. This is an interactive webpage for parents to explore resources to support the early intervention journey and is designed for families of children who are deaf or hard of hearing, including a fun guide with family support activities.

https://handsandvoices.org/great-start

Alexander Graham Bell Association for the Deaf and Hard of Hearing

A national organization providing support, information, and resources to guide people who are deaf or hard of hearing learning to hear and speak.

https://agbell.org

American Society for Deaf Children

The American Society for Deaf Children (ASDC) is committed to empowering all families with deaf and hard of hearing children and youth by embracing full language and communication access in inclusive environments through mentoring, advocacy, resources, and collaborative networks.

https://deafchildren.org

EHDI-PALS

A web-based, searchable national directory connecting families, healthcare professionals, and state public health organizations with pediatric audiology expertise for children ages birth to five years old.

https://ehdi-pals.org

FL3 “Parent Tip Sheets”

Parent Tip Sheets were created for parents and caretakers of children who are deaf or hard of hearing (D/HH) to use with the support of an Early Intervention provider with experience working with children who are D/HH. Each Tip Sheet briefly describes the developmental process of infants and toddlers post-identified hearing condition for cognitive, social, emotional, language (semantics, syntax-morphology, pragmatics, phonology–auditory and visual), pre-literacy and literacy development. These Tip Sheets provide suggestions for parents and caretakers, for fun, everyday activities to enhance their baby’s development in these aspects! Hang these up on your refrigerator and pick an activity or two to include in your baby’s daily routine or when you are out and about exploring the world.

www.handsandvoices.org/fl3/topics/tipsheets.html

Internet Resources (continued)

Hands & Voices

A parent-led, professionally collaborative organization dedicated to serving families with children who are deaf or hard of hearing without bias around communication modes or methodology.

handsandvoices.org

"Fostering Joy D/HH" is a Hands & Voices project to celebrate the magic of raising children who are deaf or hard of hearing. https://handsandvoices.org/resources/fostering-joy/journal.html

Hearing First

Hearing First supports families and professionals to help children with hearing loss access sound, benefit from technology, and access early learning opportunities.

HearingFirst.org

John Tracy Center

John Tracy Center provides, worldwide and without charge, parent-centered services to young children with hearing loss, offering families hope, guidance, and encouragement.

jtc.org

Laurent Clerc National Deaf Education Center

National educational center that develops and disseminates innovative curricula, instructional techniques, and products for deaf and hard of hearing children throughout the United States. The Clerc Center, located on Gallaudet's campus in Washington DC, provides information, training, and technical assistance for parents and professionals to meet the needs of deaf and hard of hearing students birth to age 21.

clerccenter.gallaudet.edu/ndec/families

Mama Hu Hears

Mama Hu Hears was created by Dr. Michelle Hu, a pediatric audiologist who is also profoundly deaf in both ears. Mama Hu Hears is a place of support, education, and guidance for deaf or hard of hearing children and their families.

www.mamahuhears.com

National Association of the Deaf

A national civil rights organization for and by people who are deaf and hard of hearing, the NAD advocates for the rights of deaf people across the lifespan including early intervention, education, employment, health care, technology, telecommunications, youth leadership, and more.

nad.org/resources/early-intervention-for-infants-and-toddlers/information-for-parents/

National Center on Deafblindness

The National Center on Deafblindness works with state deaf-blind projects and other partners to improve educational outcomes and quality of life for children who are deaf-blind and their families.

https://www.nationaldb.org

National Cued Speech Association

The National Cued Speech Association champions effective communication, language development, and literacy through the use of Cued Speech.

cuedspeech.org

SigningTime

Children friendly programming that features American Sign Language shows and music.

www.signingtime.com

Sign It ASL: American Sign Language Classes Online

Sign It ASL has free ASL classes for families with children ages 0-36 months.

www.signitasl.com

Supporting Success for Children with Hearing Loss

Through advocacy and education, Supporting Success for Children with Hearing Loss empowers families and communities with evidence-based tools and practical information.

www.successforkidswithhearingloss.com

Facebook Groups

- Hawaii Parents of Deaf and Hard of Hearing Children
- Fostering Joy-Families of Deaf and Hard of Hearing Children
- Hands & Voices Deaf and Hard of Hearing Plus

Appendix C

Smartphone Apps

Advanced Bionics BabyBeats™ App

Stimulates your baby's senses through musical activities. It can be beneficial for children with a range of hearing devices. Try using the app with a vibrating speaker for profoundly deaf children.

ASL Bloom App

Free app for learning American Sign Language

ASL Sign Language Dictionary

View thousands of words and phrases in the Sign ASL Android App. Download for free

Signed Stories App

Offers animated children's stories in American Sign Language

VL2 Storybook App

Offers animated children's stories in American Sign Language

Hawaiʻi State Department of Health

Questions or Comments?
For more information, please contact the
Newborn Hearing Screening Program

Phone (808) 733-9054

**www.health.Hawaii.gov/
genetics/programs/nhsp**

Checklist

- ☑ We obtained and read through the Parent Resource Guide.
- ☐ We find ways to connect with our child and 'Foster Joy' in our 'ohana.
- ☐ Know how the ear works, what my child's hearing levels are in each ear, and what type of hearing loss he/she has.
- ☐ Connected with other parents who have children who are deaf or hard of hearing.
- ☐ Know how to care for and troubleshoot, my child's listening technology.
- ☐ Explored communication/modality opportunities.
- ☐ Know strategies to support my child's language acquisition and use them daily.
- ☐ Am aware of resources locally and nationally, to support my child and our family.
- ☐ Read to my child every day.
- ☐ Know our legal rights as parents of a child who is deaf or hard of hearing.

Hawai'i State Department of Health
Newborn Hearing Screening Program

Phone (808) 733-9054

www.health.Hawaii.gov/genetics/programs/nhsp