

Parent Resource Guide

FOR FAMILIES WITH YOUNG CHILDREN WHO ARE DEAF OR HARD OF HEARING (DHH)

A resource provided by the DC Early Hearing Detection and Intervention (EHDI) program

PREPARED BY: Community Health Administration



Early Hearing Detection and Intervention



COVERNMENT OF THE DISTRICT OF COLUMBIA

Early Hearing Detection and Intervention

*There are different words used when talking about people with various hearing levels, with different meaning based on one's cultural perspective. Throughout this document we use the term *deaf or hard of hearing*, or *DHH*, as an inclusive term of the entire spectrum of people, representing varied hearing levels. The term hearing loss is maintained to clearly convey audiological information. This approach aligns with guidelines from The Joint Committee on Infant Hearing (JCIH, 2019).

This document would not be possible without the input and expertise from DC EHDI Partners including dedicated professionals, parents with deaf children, and deaf adults. Special thanks to:

Dr. Claire Buxton Annette Forseter Shenita-Ann Grymes Lindsay Handelsman Katie Huray Nicole Hutchinson Dr. Judie Lomax Dr. James Mahshie Dr. Elizabeth Marcinkus

Emily Small Karen Quinones Nikki West Emily Wolski

and many others who contributed time, ideas, and feedback on the development of this resource.

Contact DC EHDI at dcehdi@dc.gov or 1-800 MOM BABY (1-800-666-2229).

December 2024

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Welcome to Holland

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

When you're going to have a baby, it's like planning a fabulous vacation trip —to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David.

The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills.... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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Love Your Baby

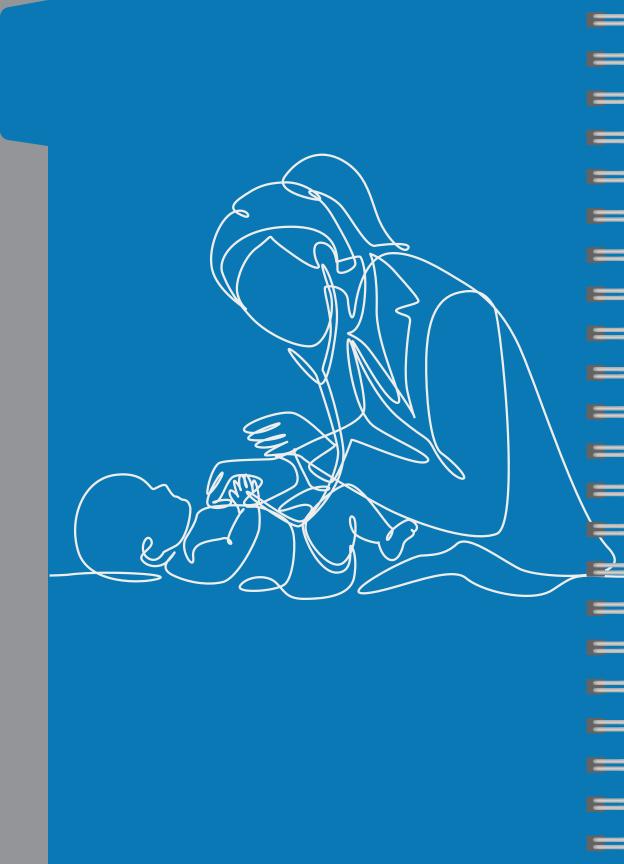
Families make all the difference.

Every parent wants what is best for their child. There is no one "right" way to raise a child who is deaf or hard of hearing (DHH), but instead many ways. Family values, resources, opinions, and experiences vary from family to family. What works for one family may not work for another, and that's okay. You know your child best and ultimately decide what is best for your family. The involvement of parents and family has a strong positive impact on your DHH child's language development. A loving family is invaluable when it comes to a child's social, emotional, and physical development, and a child with hearing loss is no different.

The most important thing to remember is to *love your baby*. Your child is unique and wonderful exactly as they are, and you are fully equipped to be the parent they need. Continue to talk to your baby. Get to know other parents of deaf or hard of hearing children. Learn about your options and the different language modalities. Ask for resources in your area that can support your family in this hearing loss journey. But know that you are not alone. Just love your baby and know that they're going to be okay.



-Janelle Bess, DC parent of a deaf child



Contact Information

PROFESSIONALS

From now until your baby turns 3, you'll be working with different professionals to help your baby. Use this space to keep track of everyone who is part of your team. If you need help in any area, contact your baby's doctor, early intervention service coordinator, or the DC EHDI program for more recommendations.

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	ar, Nose, and Throat doctor (ENT) ame:
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	ddress of office:
	arly Intervention (Strong Start) Service Coordinator ame:
C	ontact information:
	arly Intervention (Strong Start) Primary Service Provider ame:
С	ontact information:

Pediatric Audiologist Name:
Contact information:
Address of office:
Provider Name:
Role:
Contact information:
Provider Name:
Role:
Contact information:
Provider Name:
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Contact information:

DC EARLY HEARING DETECTION AND INTERVENTION (DC EHDI) PROGRAM



Early Hearing Detection and Intervention

DC EHDI Program's goal is to ensure that children who are deaf or hard of hearing (DHH) are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate intervention to optimize language, literacy, cognitive, social, and emotional development.

If you have any questions and aren't sure who to reach, please contact DC EHDI at <u>dcehdi@dc.gov</u> or 1-800 MOM BABY (1-800-666-2229).

ADDITIONAL SUPPORTS

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You may connect with other people who are valuable resources for your family. This may include Deaf professionals or adults, parents of other children who are DHH, specialized teachers, community members, and more. Note their contact information here.

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Raising a DHH Child

Section 3

Raising a Child Who is Deaf

Finding out that your child is deaf or hard of hearing (DHH) can feel very overwhelming and scary. You might be surprised or even relieved to understand why your child wasn't responding to your voice. It's important to work through those feelings. Your child is learning who they are and how to understand the world from you.

Raising a deaf child can come with extra challenges, like learning a new language, going to more medical and therapy appointments, using hearing aids or cochlear implants, participating in early intervention appointments, and more. It's important to ask questions until you feel you understand enough to make informed decisions for your child and your family. There are many ways to raise a deaf child, and only you can decide what will work best for your family. You are your child's best advocate and supporter. Learn what your child needs and help them get it.

Here are some key points to remember:

- Access to language is really important. Language helps your baby's brain grow and learn. See Section 6: Language and Communication for more information and next steps.
- Get connected with the Strong Start early intervention program to help your child develop age-appropriate language skills. Check **Section 5: Early Intervention Services** for more information.
- It might help to meet other parents and caregivers with children who are deaf or hard of hearing. They can offer support and share their experiences. Your audiologist, early intervention provider, or **Section 9: Resources** can help you connect with other families.
- Meeting adults who are deaf or hard of hearing can also be useful to understand what their lives are like. Your audiologist, early intervention provider, or **Section 9: Resources** can help you find ways to meet replace with deaf adults and deaf professionals.

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• Your friends and family might have questions about your child's hearing. It's okay if you don't have all the answers right now. You can share what you know from the audiologist and early intervention team with them or show them this resource guide. If you are comfortable, you can also invite them to appointments. Ask them to be patient as you learn more about your baby's hearing and language needs.

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• Remember, you don't have to make decisions that will last forever. Your child's needs might change, so be flexible and adjust things as needed. Pay attention to what works best for your child.



How We Hear

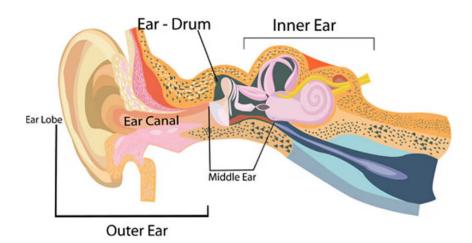
Section 4

How We Hear

Hearing loss can happen if any part of the ear or hearing system isn't working properly. Your baby has been identified as deaf or hard of hearing. Your baby's audiologist can help explain what kind and how much hearing loss your baby has.

PARTS OF THE EAR

- **Outer Ear:** This is the part we see on the sides of our heads (called the pinna) and the ear canal.
- **Middle Ear:** This includes the eardrum and three tiny bones (ossicles) that help send sounds from the eardrum to the inner ear.
- Inner Ear: This has the cochlea (the spiral-shaped organ for hearing), semicircular canals (for balance), and nerves that send sound messages to the brain.
- Auditory System: This is how sound moves from the outer ear to the brain, which helps us hear.



TYPES OF HEARING LOSS

- Sensorineural Hearing Loss: This happens when the inner ear doesn't send sound properly. It is typically permanent, usually doesn't get better over time, and might be caused by genetics, infections, or other health issues.
- **Conductive Hearing Loss:** This happens when sound has trouble traveling through the outer or middle ear. Sometimes, it can be fixed with medical treatment. It might be caused by ear infections, ear wax blocking the ear canal, syndromes, or other ear problems.
- Mixed Hearing Loss: This is when someone has both sensorineural and conductive hearing loss in the same ear.
- Auditory Neuropathy Spectrum Disorder (ANSD): This is a type of hearing loss where the auditory nerve or brain doesn't process sounds normally.

Depending on your baby's hearing loss, there might be technology that can help them hear better. See **Section 7: Technology Opportunities** for more information.

FOR AUDIOLOGISTS:

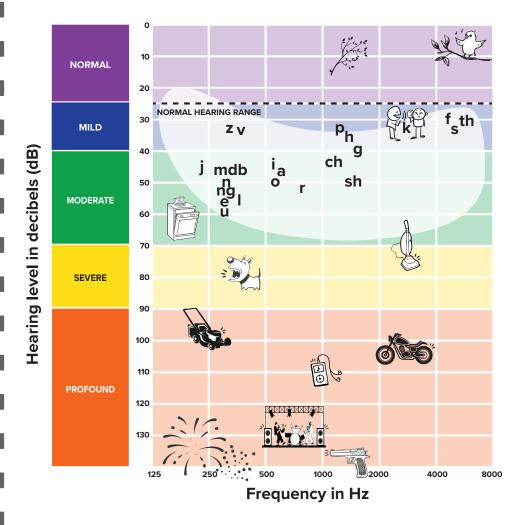
Your child's hearing on _____ (date).

Degree.	Right Ear:	Туре	:	Degree:	
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Left Ear: Type: _____ Degree: _____

DEGREE OF HEARING LOSS

Hearing loss can be described from normal to profound. Your baby might hear the same in both ears or differently in each ear. Hearing loss in one ear is called **unilateral**, and hearing loss in both ears is called **bilateral**. An **audiogram** is a graph that shows how well your baby hears different pitches (high and low sounds).



It is important for your child to have language access no matter what their hearing level is. Language happens in the brain, and it is primarily accessed through hearing or vision (see **Section 6: Language and Communication**).

HEARING TESTS

Your baby's audiologist will suggest which tests your baby should have and how often. These tests help find out what your baby hears and how they might respond to hearing aids or other devices.

- Auditory Brainstem Response (ABR): This test checks how the hearing nerve and brain process sound without being invasive.
- Otoacoustic Emissions (OAE): This test checks the inner ear by placing an earplug in your baby's ear and measuring how the ear reacts to sounds.
- Visual Reinforcement Audiometry (VRA): This test plays sounds through speakers or headphones to see the quietest sound your baby can hear. Light-up toys or screens encourage your baby to turn toward the sound when they hear it. This test is usually done when your baby can hold their head up and sit on their own, around 6 to 12 months old.

Remember, hearing could change at any time. If you have concerns about your child's hearing, ask to get retested as soon as possible.



Early Intervention Services

"Parenting a deaf or hard of hearing child can be overwhelming at first. Early intervention is a support system that can teach you how to communicate and take care of your baby. If you're concerned about your child's future, Early intervention provides your child with a strong start by helping you learn your child and their strengths and needs."

-DC parent of a deaf child

WHAT IS EARLY INTERVENTION (EI)?

Early Intervention is a free program for families with babies and toddlers (from birth to age three) who may have developmental delays, including language delays. In DC, the early intervention program is called Strong Start. Strong Start services happen in places where your child usually spends time, like at home or daycare. You will work with a primary service provider who will help you with strategies to support your child's development. The provider will have training in different areas like physical therapy, speech therapy, or hearing services, but they are all experts in working with very young children.

HOW TO GET REFERRED TO STRONG START

If you or someone else, like a doctor, notices that a child isn't developing as expected, you should contact Strong Start. You can call them at (202) 727-3665 or make a referral online at <u>eip.osse.dc.gov</u>.

HOW DOES A CHILD QUALIFY FOR SERVICES?

Your child can qualify for Strong Start in two ways:

- If they have a known condition like hearing loss.
- If they are behind in at least one area of development, such as social skills, communication, thinking, movement, or self-care.

WHAT HAPPENS AFTER YOU'RE REFERRED TO STRONG START?

Strong Start must follow certain steps and timelines. Within 45 days of your referral, these things will happen:

• A service coordinator will contact you and set up an initial assessment.

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- You will meet with the coordinator to assess your child's and family's needs.
- You and the early intervention team will create a plan called an **Individualized Family Services Plan (IFSP)** with goals and chosen providers.

After creating the IFSP, services should start within 30 days. Ask your service coordinator to find a provider with experience working with young children who are DHH. Your family is eligible for early intervention until your child's 3rd birthday.



Language and Communication

Your baby learns about the world through their senses: seeing, smelling, touching, tasting, and hearing. Talking and interacting with your baby is very important for their language development. Language helps your baby's brain grow and learn.

There isn't one way to communicate with every baby. Children who are deaf or hard of hearing (DHH) might use different languages, communication tools, and technologies. It's very important to give your baby regular and complete access to any language they use, whether it's signed, spoken, or a mix of both.

HOW YOUR BABY CAN LEARN LANGUAGE

There are many ways for your baby to develop language skills. With help from trusted professionals, you'll find what works best for your baby (see **Resources** for organizations that can help). The key is to help your baby start communicating as early as possible. Many people can help you decide what's best, like a **speech-language pathologist** who has experience with young children who are DHH or any deaf professional in the field.

ACCESS TO LANGUAGE

Your baby's brain needs to have access to language to learn it. They might use hearing aids or cochlear implants to hear spoken language or your family's language. They might also use a visual language, like **American Sign Language (ASL)**, to communicate. Your baby must get a lot of language input, whether it's through hearing, seeing, or both. Your baby can learn more than one language.

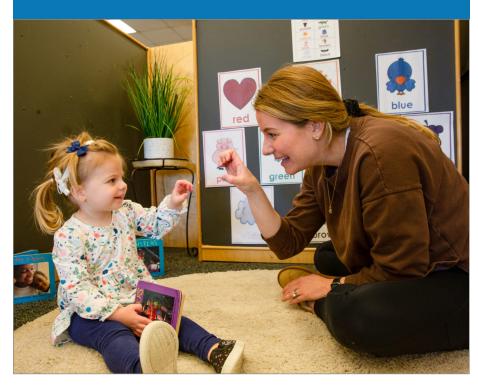
QUESTIONS TO THINK ABOUT:

- How can I help my baby communicate with everyone in my family about different topics?
- What languages can my baby use?
- Will my baby have good language models to learn from?
- What resources do I need to support my baby's communication?
- Who can I contact for help?

DEFINITIONS:

• Language: A system used by a group of people to communicate. This can be English, Spanish, American Sign Language, or other languages.

• **Communication:** Any way of sharing or sending information. This can include body language, facial expressions, gestures, signs, reading, writing, and more.



SPEECH AND LANGUAGE DEVELOPMENT GUIDE

Development generally happens in a certain order, but there is variation in the exact age and order babies can show different skills. Below are general expectations for when babies will begin to do certain things relating to language and communication. Language development looks similar for babies who use visual languages (like American Sign Language) and spoken languages (like English or Spanish). Babies who are profoundly deaf without hearing technology may still vocalize and babble early in their development. If you have any concerns about your baby not doing things at these times, contact your baby's doctor or early intervention primary service provider.

*notes specific skills for babies with auditory access (hearing aids, cochlear implants)

Birth to 3 months

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- Quiets or smiles when you talk
- Makes sounds back and forth with you
- Makes sounds that differ depending on whether they are happy or upset
- Coos, makes sounds like oooooo, aahh, and mmmmmmm
- Alerts to sound*

4 to 6 months

- Giggles and laughs
- Responds to facial expressions
- Looks at objects of interest and follows objects with their eyes
- Vocalizes during play or with objects in mouth
- Begins to babble with hands and/or voice. May use babbling to get your attention
- Blows "raspberries"
- Vocalizes different vowel sounds sometimes combined with a consonant, like uuuuuummmm, aaaaaaagooo or daaaaaaaaaaa*
- Reacts to toys that make sounds, like those with bells or music*



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7 to 9 months

- Looks at you when you call their name
- Stops for a moment when you say or sign, "no"
- Looks for loved ones when upset
- Raises arms to be picked up
- Recognizes the names of some people and objects as spoken words or signs
- Pushes away unwanted objects
- Babbles long strings of sounds like mamamama, dadadada, or babababa*

10 to 12 months

- By age 10 months, reaches for objects
- Points, waves, and shows or gives objects
- Imitates and initiates gestures for engaging in social interactions and playing games, like blowing kisses or playing peek-a-boo
- Enjoys dancing
- Responds to simple words or signs like "go bye-bye" and "look at mommy"
- Says or signs one or two words like mama, dada, hi, and bye
- Tries to copy sounds that you make*

12 to 18 months

- Follows simple directions "give me the ball" "come here"
- Points to make requests, comment, or get information
- Shakes head for "no" and nods head for "yes"
- Understands and uses words for common objects, actions, and people
- Identifies one or more body part
- Uses gesture when excited, like clapping or giving a high five

The brain does not discriminate between spoken and signed languages... people do!"

-Dr. Laura Ann Petitto



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19 to 24 months

- Uses and understands at least 50 words for food, toys, animals, and body parts. Speech may not be clear.
- Puts two or more words together like "more water" or "go outside"
- Uses words to ask for help

ASHA (2024). Communication milestones: Birth to 1 year. Retrieved May 30, 2024, from asha.org/public/developmental-milestones/communication-milestones-birth-to-1-year/

HandSpeak (2024). Language development milestones in sign language from age 0 to 5. Retrieved August 21, 2024, from handspeak.com/learn/416/

Technology Opportunities

Hearing technology may help your child hear better. Since every child's hearing loss is different, it's important to find the right technology for your child. An **audiologist** who works with young children can recommend the best hearing devices for your child. You might also be able to get insurance coverage for these devices. Check with your audiologist about possible funding options. For more help, see **Section 9: Resources** for places in DC that specialize in pediatric audiology.

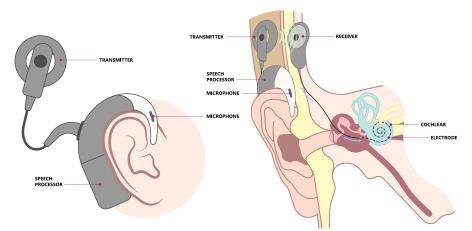
HEARING AIDS

Hearing aids make sounds louder. They can be used by people of all ages, even babies. If your baby uses hearing aids, they might hear spoken language and other sounds more clearly. There are different styles of hearing aids, but behind-the-ear models are often best for young children because they fit well with growing ears.



COCHLEAR IMPLANTS

A cochlear implant (CI) is a surgically implanted device for children with severe to profound hearing loss who don't benefit from hearing aids. It has an internal part that helps the inner ear and an external part that sits behind the ear and sends sound from the external microphone to the internal component through a magnet. Children can get cochlear implants as young as 9 months, or sometimes earlier, based on an evaluation by a specialized team.



BONE CONDUCTION HEARING DEVICES

Bone conduction hearing devices (BCHD) are used for children with conductive hearing loss. These devices send vibrations through the bones in the skull to the inner ear. For young children, these devices can be worn on a headband or with an adhesive adapter behind the ear. As your child grows, they might be able to use an implanted bone-conduction device.



Every child's needs are unique. Your audiologist will help you choose the best device and keep track of your child's progress. Remember, hearing technology affects each child differently, so it's important to work with your audiologist and other professionals to find the best fit for your child and family.

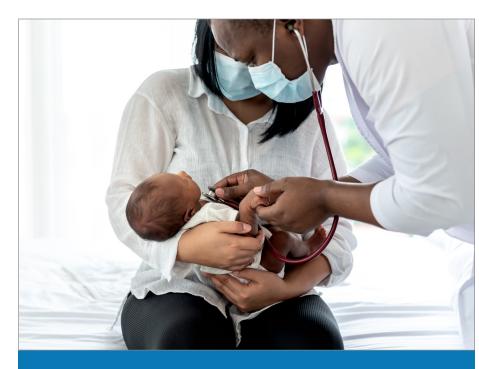
Children Who Are Deaf with Additional Disabilities

About 40% of children who are deaf or hard of hearing (DHH) also have other disabilities, like a syndrome, intellectual disability, or vision problems and may be called deaf disabled. Hearing loss can be related to many other conditions, but only your baby's doctor can help understand the reasons behind it. If your baby has another disability, your doctor should explain how it affects their overall development and what support your family might need.

It can be helpful to work with other experts who have special knowledge to support your baby's growth. Your baby's doctor, early intervention service coordinator, and primary service provider can help make sure your family gets the right support. Parent and caregiver support groups might also be available, depending on your baby's needs.

If you have concerns about your baby's development, talk to your baby's doctor and early intervention team about any tests or assessments that could provide more information.





CYTOMEGALOVIRUS (CMV)

CMV is a common virus that usually doesn't harm healthy people. However, if a baby gets CMV before they are born (called congenital CMV), it can lead to serious health problems later on. This can include hearing or vision loss and learning difficulties. CMV is the most common cause of hearing loss in babies who aren't deaf from genetics. Babies with congenital CMV might be born deaf or hard of hearing, or they may start to lose their hearing as they grow. Changes in hearing can make it harder for children to learn to talk and communicate with others.

Find out more about CMV at: cdc.gov/cytomegalovirus/congenital-infection/hearing-loss.html

Resources

LOCAL RESOURCES

- 😻 indicates a resource by parents of children who are DHH
- indicates a resource by adults who are DHH
- indicates a resource by professionals with experience working with children who are DHH

DC Early Hearing Detection and Intervention (EHDI) at DC Health 🛦

The DC EHDI Program's goal is to ensure that children who are deaf or hard of hearing (DHH) are identified through newborn, infant, and early childhood hearing screening and receive diagnosis and appropriate intervention to optimize language, literacy, cognitive, social, and emotional development.

PHONE: 1-800-666-2229 (1-800 MOM BABY) EMAIL: <u>dcehdi@dc.gov</u> WEB: <u>dchealth.dc.gov/service/newborn-screening</u>

Strong Start, DC Early Intervention Program 🛦

Strong Start provides services and supports for children birth to 3 who are deaf or hard of hearing, have developmental delays, or disabilities, and their families. Early intervention services are provided in a child's natural environment, such as their home, child development facility or a community setting such as the library. If you have questions or developmental concerns about a child who is younger than the age of 3, contact Strong Start to submit a referral.

PHONE: (202) 727-3665 **WEB:** eip.osse.dc.gov

Advocates for Justice and Education 🛦

Advocates for Justice and Education seeks to empower families, youth, and the community to be effective advocates to ensure that children and youth, particularly those who have special needs, receive access to appropriate education and health services through one-on-one assistance, training, and advocacy. **PHONE:** (888) 237-8060 **WEB:** <u>aje-dc.org</u>

Children's National Hospital Hearing and Speech Center 🛦

Children's National Hospital audiologists are trained to evaluate hearing from birth to young adulthood. We use both objective and subjective measures to assess auditory status. We utilize different techniques, based on a child's age and understanding. We provide hearing aid fitting and verification, cochlear implant candidacy testing, and cochlear implant programming follow up at a variety of specialty care centers throughout the Washington, DC metropolitan area.

PHONE: (202) 476-5600 **WEBSITE:** childrensnational.org/get-care/departments/hearing-and-speech

Gallaudet Allied Health Services 🔨 🛕

Gallaudet Allied Health Services provides audiology, speech-language, and psychology services to individuals within the Washington DC metropolitan area.

- The Hearing and Speech Center provides hearing, balance, and speech and language services using client-centered and evidencebased care for clients of all ages. Our clinicians are joined by our Doctor of Audiology (AuD) and Speech-Language Pathology (SLP) graduate students to provide rich clinical practices and care. To meet the communication needs of all of our clients, our clinicians provide services in spoken English, American Sign Language (ASL), and Spanish.
- The Gallaudet Psychology Clinic offers comprehensive neuropsychological and psychological assessment, consultation and psychotherapy services for deaf and hard of hearing children with a range of medical, neurological, developmental, attention, learning, emotional, and behavioral concerns. Clinicians provide outpatient evaluation and psychotherapy services to members of the deaf and hard of hearing community in the DC/Maryland/Virginia (DMV) area and beyond. We serve individuals ranging in age from infancy to young adulthood. We primarily focus on deaf and hard of hearing individuals as well as individuals who are part of deaf and hard of hearing families/communities including Children of Deaf Adults (CODAs).

PHONE: (202) 651-5328 (Voice/TTY); (202) 250-2199 (Video Phone) EMAIL: <u>GUHSC@gallaudet.edu</u>

WEB: gallaudet.edu/hearing-speech-center gallaudet.edu/psychology-clinic

Kendall Demonstration Elementary School 📀 🔼 🛦

Kendall Demonstration Elementary School (KDES) is located on Gallaudet University's campus in Washington, DC and offers a variety of programs for deaf and hard of hearing (DHH) children and their families.

The Parent Infant Program (PIP) at KDES is a free program for DHH infants and toddlers under three and their families. PIP uses a bilingual approach that emphasizes language acquisition in both American Sign Language (ASL) and English. While enrolled in PIP, families will develop their ASL skills to create a nurturing, language-accessible home for their DHH child.

PIP offers:

- Twice weekly center-based playgroup (infants and toddlers must be accompanied by a parent or caregiver)
- Community-based playgroups & events
- Home Visits
- Family Workshops and ASL Classes
- Partnering/collaboration with child's IFSP team and service providers

The Early Childhood Education (ECE) program at KDES also offers preschool and pre-kindergarten classes for DHH children who are 2 years old (by Sept. 30th) and older.

PHONE: (202) 250-2761

EMAIL: <u>KDESadmissions@gallaudet.edu</u>

WEB: kdes.gallaudet.edu/academics/early-childhood-education-program

Maryland/DC Hands & Voices, and DC Guide By Your Side 📀 🔼 🛦

"What works for your child is what makes the choice right." ™

A parent-driven organization that provides unbiased support, resources, and family events for families with children who are deaf or hard of hearing in Maryland and Washington, DC, without bias around communication modes or methodology.

DC Guide By Your Side (DC GBYS) offers unbiased information, one-on-one support and resources, and trained Parent Guides and/or Deaf Adult Guides to talk and meet with you.

PHONE: (240) 780-2280 EMAIL: <u>MDDCHandsandVoices@gmail.com</u> WEBSITE: mddchandsandvoices.org

Mayor's Office for Deaf, Deaf Blind and Hard of Hearing 🔼 🛦

The mission of the MODDHH is to address the concerns of Deaf, DeafBlind, Deaf Disabled, Hard of Hearing, and Late Deafened residents of DC through policy, advocacy, community engagement, and information sharing.

PHONE: (202) 727-5969 EMAIL: <u>moddhh@dc.gov</u> WEB: communityaffairs.dc.gov/moddhh

National Therapy Center 🛦

National Therapy Center (NTC) is a pediatric therapy practice that specializes in working with children with a range of speech, language, feeding, motor and cognitive disorders. The NTC Team consists of experienced professionals in the areas of speech/language therapy, occupational therapy and applied behavior analysis (ABA). NTC also has specialists within those areas, including SLPs, who sign and work on both spoken English and ASL skills. **PHONE:** (202) 470-4185

EMAIL: <u>contact@nationaltherapycenter.com</u> WEBSITE: <u>nationaltherapycenter.com</u>

Potomac River Clinic 🛦

Potomac River Clinic (PRC) is a non-profit organization designed to support families of children with hearing loss in the Washington, DC metro area. Intervention begins with diagnosis (including ABR testing), provision of hearing aids and referral for a cochlear implant candidacy if appropriate, auditory-verbal and speech-language therapy, and ongoing audiological services including hearing aid and cochlear implant programming.

PHONE: (202) 333-1403 EMAIL: <u>info@potomacriverclinic.org</u> WEB: potomacriverclinic.org

The River School and Potomac River Clinic's Parent-Infant Program 🔹 🛦

A free resource for families of children diagnosed with hearing loss, ages birth to three. Parents, along with their infants and toddlers, meet each week for an hour. Parents learn about issues relating to hearing loss and share experiences with other families in similar situations, while the children engage in fun, language-stimulating activities. Sessions run from September until early June.

PHONE: (202) 337-3554 EMAIL: parentinfant@riverschool.net

NATIONAL RESOURCES

3

"Just in Time" Resource for Families of Children who are Deaf or Hard of Hearing

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

WEB: infanthearing.org/just-in-time/index.html

"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/hard of hearing, including a fun guide with family support activities.

WEB: 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.

PHONE: (202) 337-5220 EMAIL: info@agbell.org WEB: agbell.org/Families

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.

PHONE: (800) 942-2732 EMAIL: <u>info@deafchildren.org</u> WEB: 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.

WEB: ehdi-pals.org

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.

PHONE: (303) 492-6283 WEB: handsandvoices.org

Hearing First

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

PHONE: (800) 522-4582 WEB: <u>HearingFirst.org</u>

John Tracy Clinic

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

PHONE: (213) 748-5481 WEB: 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.

PHONE: (202) 651-5051 EMAIL: <u>clerc.center@gallaudet.edu</u> WEB: <u>clerccenter.gallaudet.edu/ndec/families</u>

National Association of the Deaf

A national civil rights organization for and by deaf and hard of hearing people, 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.

PHONE: (301) 328-1443

WEB: <u>nad.org/resources/early-intervention-for-infants-</u> and-toddlers/information-for-parents/

National Center on Deafblindness

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

PHONE: (516) 366-0047 EMAIL: <u>support@nationaldb.org</u> WEB: nationaldb.org

National Cued Speech Association

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

PHONE: (800) 459-3529 EMAIL: <u>info@cuedspeech.org</u> WEB: <u>cuedspeech.org</u>



Glossary

American Sign Language (ASL): a complete, natural, visual language primarily used by signing deaf communities in the United States and much of Canada.

Audiologist: a specialized healthcare professional who evaluates, diagnoses, and manages hearing and balance needs.

Auditory neuropathy spectrum disorder (ANSD): a hearing disorder in which sound enters the inner ear normally, but the transmission of signals from the inner ear to the brain is impaired. Although people with auditory neuropathy may hear sounds, they struggle to understand speech clearly.

Auditory verbal therapy (AVT): a specialized intervention program that teaches deaf and hard of hearing children to listen and speak with the use of hearing technology.

Bilateral hearing loss: hearing loss impacting both ears.

Bone conduction hearing device (BCHD): a hearing device that uses vibrations through the bones in a person's skull to send sounds to their inner ear when someone has a conductive hearing loss.

Conductive hearing loss: a loss of sensitivity to sound, due to an abnormality or blockage of the outer ear or the middle ear.

Cochlear implant (CI): a surgically implanted device to provide a person with hearing levels in the moderate to profound level with sound perception.

Cued Speech: a method of communication combining simple hand cues with natural mouth movements of speech to make all sounds of a spoken language visually accessible. Any spoken language can be cued.

Congenital Cytomegalovirus (cCMV): Congenital CMV is a common infection that is harmless to most people but can cause birth defects if it is caught before a baby is born.

Deaf: a term used to describe a person with severe to profound hearing levels. When written with a capital "D," it may refer to a person who is part of the Deaf community or culture, often choosing to communicate through American Sign Language (ASL).

Ear, Nose, and Throat (ENT) Physician: A medical doctor who specializes in the diagnosis and treatment of diseases that affect the health of the ears, nose, and throat also known as an Otolaryngologist. Some ENTs specialize in providing care for young children.

Early intervention (EI): educational and family support program for infants and toddlers (age birth–3) with or at risk for developmental delays or disabilities.

Early intervention primary service provider: an early intervention professional with specific knowledge in an area of development and need for your child. Your primary service provider will work with you, providing support and strategies to encourage development.

Early intervention service coordinator: a primary point of contact for families with children receiving early intervention services, a service coordinator provides essential communication and case management through the EI process.

Hard of hearing: the term to describe those with mild to severe hearing levels and most often able to use hearing technology, such as hearing aids or cochlear implants.

Hearing aid: an electronic device used to amplify sound.

Individualized Family Services Plan (IFSP): an individualized plan created for a child enrolled in early intervention and their family. The IFSP includes developmental outcomes, strategies, and services needed to meet those outcomes.

Medical Home: The medical home builds partnerships and coordinates care between doctors, families, and community resources for families with children who are DHH.

Mixed hearing loss: a combination of both a sensorineural and conductive hearing loss in the same ear.

Pediatrician: a doctor who specializes in the health of children from infancy to early adulthood (0-18 years), with in-depth knowledge of the growth, development, and behavior of children. Your pediatrician should serve as a resource for your family to help connect you to other supportive services including referrals for other providers.

Pediatric audiologist: a specialized healthcare professional who evaluates, diagnoses, and manages hearing and balance needs for young children.

Sensorineural hearing loss: a type of hearing loss when the inner ear does not transmit sound typically. This type of hearing loss is typically permanent and does not resolve over time. It may be caused by genetics, infections, or medical complications.

Single-sided deafness (SSD): severe-to-profound hearing levels in one ear and typical or near-typical hearing in the other ear.

Speech language pathologist (SLP): also known as a speech therapist, an SLP is a professional who assesses and treats communication and swallowing disorders in people of all ages. They develop and implement treatment plans, monitor progress, and adjust plans as needed. They may also educate a patient's family on strategies for overcoming speech, language, and feeding difficulties. SLPs may specialize in certain areas such as articulation, stuttering, voice, or deaf and hard of hearing.

Unilateral hearing loss (UHL): hearing loss of any level impacting one ear.







Early Hearing Detection and Intervention



WEARE GOVERNMENT OF THE DISTRICT OF COLUMBIA CMURIEL BOWSER, MAYOR