



MISSOURI DEPARTMENT OF
HEALTH &
SENIOR SERVICES

Early Hearing Detection and Intervention (EHDI) Parent Resource Toolkit



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Parent Letter

Dear Parents,

Having a baby is one of the most exciting and intense experiences a family can have. With the birth of a baby, every family wonders what the future will hold. Sometimes babies and young children need extra help to grow and learn. By now, you have been told that your child has a hearing loss. You may have a lot of questions. You may be experiencing many different feelings. Parenting a child with hearing loss has its own set of challenges, but you will also find that it brings great rewards as you watch your child learn, grow, and develop.

Because the early years are such an important time for development, your child's clinical audiologist or doctor is required by law to notify the Missouri Department of Health and Senior Services' (DHSS) Missouri Newborn Hearing Screening Program (MNHSP), also known as Missouri's Early Hearing Detection and Intervention (EHDI) Program, of all young children who have hearing loss. After a diagnosis of hearing loss, the EHDI goal is to support you. The MNHSP refers families to three key resources soon after a child is identified with hearing loss. These resources are available to help you understand more about your child's hearing loss and find answers to your questions. If you do not wish to receive these resources, you have the right to decline when the service provider contacts you.

1) **The Family Partnership:** The DHSS Family Partnership provides parent-to-parent support to families that have children with special health care needs. The DHSS Family Partnership's Family Partners for families with children who are deaf or hard-of-hearing (Family Partner DHH) contacts families of infants diagnosed with permanent hearing loss, so you can connect with someone who understands what you are going through. For more information, contact the Family Partnership Program at (800) 451-0669.

2) **The MOHear Project:** MOHear is a collaboration between the DHSS MNHSP and Missouri State University (MSU). MOHears are audiologists, speech-language pathologists, or educators of the deaf or hard-of-hearing who can provide unbiased information to families with an infant newly diagnosed with hearing loss. MOHears help parents understand their baby's diagnosis and early intervention options. A parent may be connected to a MOHear through their audiologist, their First Steps intake coordinator, or the DHSS Family Partnership's Family Partner DHH. For more information, contact the MOHear Project at (417) 836-6677.

3) **Missouri First Steps:** First Steps is Missouri's Early Intervention system that provides services to families with children, birth to three years of age, with disabilities or developmental delays. The program is designed to meet the needs of families related to enhancing their child's development, learning, and participation in family and community life. All children with permanent hearing loss are eligible to receive early intervention and educational support services. For additional information about First Steps, please call toll-free at 1-866-583-2392.

Best wishes to you and your family.

Sincerely,

The Missouri Department of Health and Senior Services



Hearing Aids and Implants

Types of Hearing Aids and Cochlear Implants

Hearing aids can turn the volume of sound up to provide the best access to speech and language for your child. Hearing aids are all digital and programmed on the computer. This means the hearing aid is set for your child's specific hearing loss. The hearing aid will help your child hear the sounds they are missing but will not make loud sounds any louder. This allows your child to hear speech but not be uncomfortable in loud places. Your audiologist will discuss hearing aids they think are best for your child. Below are the different types of hearing aids.

Behind-the-Ear (BTE) – Behind-the-ear (BTE) devices are appropriate for people with a wide range of hearing loss, from mild to profound. This device fits neatly behind your ear. The body of the hearing aid attaches to a custom ear mold or thin tubing. Because this device has several parts, manual dexterity is necessary to ensure proper insertion and placement.

- *BTE hearing aids come in different sizes. The smaller models are for mild to severe hearing loss and the larger models are for severe to profound hearing loss.*
- *Most children wear the Behind-the-Ear (BTE) type because it can grow with your child.*



Bone Anchored Hearing Aid (BAHA) – Bone-anchored hearing aids (BAHA) are surgically implanted devices that may partially restore hearing for people with certain types of hearing loss. BAHA hearing aids use vibrations through the bones in your skull to send sounds to your inner ear.

- *This type of hearing aid can only be used if your child has at least one normal hearing inner ear (i.e., single-sided deafness or conductive hearing loss due to abnormal outer or middle ear).*
- *A BAHA is worn on a softband (i.e., headband) until age 5 years old. Once the skull has grown enough, an abutment or magnet is surgically implanted to use with the external processor.*



Cochlear Implants (CI) – A cochlear implant is a small, complex electronic device that can help to provide a sense of sound to a person who is profoundly deaf or severely hard-of-hearing. The implant consists of an external portion that sits behind the ear and a second portion that is surgically placed under the skin (see figure). An implant has the following parts:

- *A microphone, which picks up sound from the environment.*
- *A speech processor, which selects and arranges sounds picked up by the microphone.*
- *A transmitter and receiver/stimulator, which receives signals from the speech processor and converts them into electric impulses.*
- *An electrode array, which is a group of electrodes that collects the impulses from the stimulator and sends them to different regions of the auditory nerve.*
- *An implant does not restore normal hearing. Instead, it can give a deaf person a useful representation of sounds in the environment and help him or her to understand speech.*

A cochlear implant is very different from a hearing aid. Hearing aids amplify sounds so they may be detected by damaged ears. Cochlear implants bypass damaged portions of the ear and directly stimulate the auditory nerve. A cochlear implant is typically for children who have severe to profound hearing loss who are not benefiting from hearing aids.



Resources

- [Early Hearing Detection and Intervention \(EHDI\) A Roadmap for Families through Screening, Diagnosis and Intervention](#)
- [Type, Degree, and Configuration of Hearing Loss](#)
- [Auditory Neuropathy Spectrum Disorder \(ANSD\)](#)
- [Decision Guide to Communication Choices](#)
- [Making a Plan for Your Child](#)



Support Resources

Additional Resources for Families

Family Partnership

The [Special Health Care Needs Family Partnership Program](#) strives to enhance the lives of individuals and families impacted by special health care needs, providing resources and information to empower families to live a good life. The Program hosts regional and statewide events to benefit families through development of leadership skills, networking among peers, and staying current with trends and issues.

Family Partnership employs Family Partners, who are parents of individuals with special health care needs, including parents of children who are deaf or hard of hearing. They provide peer-to-peer support for families and have firsthand experience navigating options and solutions focused on the unique needs of individuals with complex medical conditions, from birth to age 21. In addition to supporting families, they also plan, schedule, and facilitate all Family Partnership events. Special Health Care Needs utilizes input and guidance from the Family Partners and the families served to enhance the quality of services and support for children and youth with special health care needs.

Missouri DeafBlind Project

The Missouri DeafBlind Project strives to improve services and results to youth who are DeafBlind and their families by strengthening collaborations among local, state and national teams, providing consultations and professional development. These efforts increase early identification and intervention, increase access to communication and the general education environments, facilitate family engagement, support successful transitions, and increase the number of highly qualified personnel. Technical assistance, training and resources are available for families and service providers of individuals with vision and hearing differences (birth through 21 years of age), contact:

Missouri DeafBlind Project
3815 Magnolia Avenue, Saint Louis, MO 63110
314-776-4320

Missouri Statewide Parent Involvement Network (MoSPIN)

The purpose of the Missouri Statewide Parent Involvement Network (MoSPIN) is to provide a no-cost homebased program for families of children, birth through five years of age, who are visually impaired, including those with multiple disabilities and combined vision and hearing challenges.

MoSPIN provides:

- Home visits by parent advisors... parents select one- or two-hour visits,
- Focus on parents as their child's first and most important teacher;
- Information to help parents understand their child's visual diagnosis and learning characteristics;
- Parent lessons on vision, communication, motor, hearing or cognition from the national INSITE curriculum;
- Ongoing support and provision of resources to families.

For additional information regarding the MoSPIN program or activities relating to families of children with combined vision and hearing loss, contact:

MoSPIN Coordinator and Lead Parent Advisor
Missouri School for the Blind
3815 Magnolia Avenue, St. Louis, Missouri 63110
314-633-1591

MOHear Project

The MOHear Project is a collaboration between the Missouri Department of Health and Senior Services' (DHSS) Missouri Newborn Hearing Screening Program and Missouri State University. MOHears are audiologists, speech-language pathologists, or educators of the deaf or hard-of-hearing who can provide unbiased information to families with an infant newly diagnosed with hearing loss.

MOHears help parents understand their baby's diagnosis and early intervention options. A parent may be connected to a MOHear through their audiologist, their First Steps intake coordinator, or the DHSS Family Partnership's Family Partner for families with children who are deaf or hard-of-hearing. For more information, contact the MOHear Project by phone at 417-836-6677.

Missouri Family to Family (MOF2F)

A [free statewide resource center](#) staffed by experts with lived experience that provides tools, resources, training, and peer support to people with disabilities, their families and supporters, contact:

MOF2F
5030 Cherry St. Kansas City, MO 64110
800-444-0821, mofamilytofamily@umkc.edu

Families First Program, Missouri School for the Deaf

The Families First Program provides home-based early intervention services throughout Missouri at no cost to families with children who are deaf or hard of hearing from birth through age 8. Eligibility for the Families First Program is based on a current Deaf or Hard of Hearing diagnosis by a licensed audiologist, including an audiogram and evaluation report within the past year. Contact [Families First Early Interventions](#) at 573-592-4000.

Missouri Assistive Technology

As Missouri's federally funded 21st Century Assistive Technology Act Program, the mission of [Missouri Assistive Technology](#) is to increase access to and acquisition of assistive technology and related services. At home, work, school or play, assistive technology provides choice, opportunity, and independence. Contact 816-655-6700.

Vocational Rehabilitation

VR helps students and youths with disabilities prepare for their future. We will work with you, your teachers, your parents, or other family members to plan for the next phase of your life. We want to help you achieve your employment goals and fulfill your dreams. Contact [Youth Services](#) at 877-222-8963.

Hearing Impairment/Deafness (Missouri Department of Elementary and Secondary Education)

Missouri Office of Special Education Compliance Standards & Indicators
900-ELIGIBILITY
Criteria: Hearing Impairment/Deafness.
573-751-3251
[Standards & Indicators](#)

Resource Guide for Missouri Families of Children from Birth to Age 12

[This online guide](#) is a navigation tool to help you find answers to the many questions you may have about the services and support available to you in Missouri.

Missouri Commission for the Deaf and Hard of Hearing

The [Missouri Commission for the Deaf and Hard of Hearing](#) works with individuals, service providers, businesses, organizations, and state agencies to improve the lives and opportunities of all Missourians with hearing loss. Contact 573-355-9320.

DEAF Inc

Founded in 2008, [DEAF](#), Inc. is a deaf-centric, community-based nonprofit organization located in St. Louis, Missouri. Dedicated to promoting communication access, DEAF, Inc. serves the deaf, hard of hearing, DeafBlind, and hearing community. We are committed to empowering individuals through a range of programs and services tailored to your needs. We believe in creating a supportive, accessible and inclusive environment for all. Whether you're seeking resources, support, or simply a sense of community, this is YOUR place.

DeafLead

[DeafLEAD](#) was founded to provide Deaf, Hard of Hearing, Late-Deafened, and DeafBlind individuals comprehensive, unified, and continuous support. We proudly serve individuals and their families with a trauma-informed approach as they navigate severe distress, disaster, or being the victim of a crime. Our staff and volunteers provide emotional support and access to resources to help people thrive.

The Whole Person

[The Whole Person](#) connects people with disabilities to the resources they need by supporting independent choice and advocating for positive change in the community. Our core values influence how we interact with each other, guide how we go about our work and fulfill our mission. Our core values are Respect, Integrity, Inclusiveness, Commitment, and Collaboration. The Whole Person provides services to people with disabilities and their families and strives to help them identify and implement resources appropriate to their situation. We serve the following counties in *Missouri: Cass, Clay, Jackson and Platte.



Resources for Intervention

Resources for Intervention

Missouri School for the Deaf

The mission of the Missouri School for the Deaf is to provide educational opportunities and outreach support for students to become successful life-long learners and productive citizens in a global society.

First Steps

First Steps is Missouri's Early Intervention system for infants and toddlers, birth to age three, who have developmental delays or diagnosed conditions associated with developmental disabilities. The federal law governing First Steps is Part C of the Individuals with Disabilities Education Act (IDEA). The Department of Elementary and Secondary Education (DESE) is the lead state agency responsible for implementing the First Steps program. First Steps is a voluntary program that provides families the tools they need to help their child be successful.

The MOOG Center for Deaf Education

The Moog Center for Deaf Education is unique in its approach to teaching children who are deaf or hard of hearing to talk. Our highly individualized instruction is tailored to each child's present level of achievement and learning style. Our innovative schedule allows children to be grouped according to their abilities in each subject area, including speech, language, auditory skills, and academics. Our teachers gear instruction to be appropriate for maximum challenge and maximum success. This is not only highly motivating for our children but results in their having high self-esteem.

Our children learn how to talk and understand when others talk to them. They also learn the same subjects as children with normal hearing in preschool and early elementary school. Our goal is to prepare our children to enter the general education setting once they have acquired the skills necessary to compete successfully, academically and socially, with their hearing-age peers.

Central Institute for the Deaf

CID's mission is to teach children who are deaf and hard of hearing to listen, talk, read and succeed. We empower families and professionals in St. Louis and worldwide to help children reach their fullest potential. We offer educational opportunities and resources for children and families, as well as professionals (deaf education and general education teachers, speech-language pathologists, auditory-verbal therapists, pediatric audiologists, program administrators and others).



Financial Resources

MPACT

Missouri Parents Act ([MPACT](#)) is a non-profit. We have been Missouri's federally funded Parent Training and Information Center since 1988. Our mission is simple: To empower families to advocate for themselves so that children with special education needs can reach their full potential in education and life – through support, training, and education.

How do we do it? Collaboration. We receive funding from the Missouri Department of Education and Secondary Education. We have amazing staff and incredible volunteers who are located throughout Missouri, working with agencies, parent groups and professional organizations toward one common goal: to assist parents in their effort to effectively advocate for their children's educational rights and services.

Denial of Insurance Coverage

If your insurance company denies coverage for your baby's first hearing aid, the following actions may help:

1. Initiate and follow your insurance company's appeal process.
2. Contact the Missouri Department of Commerce & Insurance to file a complaint. Call 800-726-7390 or [file your complaint online](#).
3. Work with your audiologist or physician to gather documentation showing the reasons for requesting the hearing aid. Enclose a copy of Section 376.1220, RSMo, (below) in correspondence to the insurance company.
4. Ask your audiologist about financial aid options provided through the clinic or hospital.
5. Ask your First Steps Provider about financial support for hearing devices provided through First Steps.

Statute for Insurance Coverage

376.1220. Insurance coverage for newborn hearing screenings mandated. —

1. Each policy issued by an entity offering individual and group health insurance which provides coverage on an expense-incurred basis, individual or group health service, or indemnity contracts issued by a nonprofit corporation, individual and group service contracts issued by a health maintenance organization, all self-insured group health arrangements to the extent not preempted by federal law, and all health care plans provided by managed health care delivery entities of any type or description that are delivered, issued for delivery, continued or renewed in this state shall provide coverage for newborn hearing screening, necessary rescreening, audiological assessment and follow-up, and initial amplification.
2. The health care service required by this section shall not be subject to any greater deductible or co-payment than other similar health care services provided by the policy, contract or plan.
3. This section shall not apply to a supplemental insurance policy, including a life care contract, accident-only policy, specified disease policy, hospital policy providing a fixed daily benefit only, Medicare supplement policy, long-term care policy, short-term major medical policies of six months or less duration, or any other supplemental policy as determined by the director of the department of commerce and insurance.
4. Coverage for newborn hearing screening and any necessary rescreening and audiological assessment shall be provided to newborns eligible for medical assistance pursuant to section 208.151, and the children's health program pursuant to sections 208.631 to 208.660, with payment for the newborn hearing screening required in section 191.925, and any necessary rescreening, audiological assessment and follow-up, and amplification as described in section 191.928.

376.1228. Hearing aids coverage for children required — amount of coverage — exclusions — additional state costs subject to appropriations.

1. For purposes of this section, the terms "health carrier" and "health benefit plan" shall have the same meanings given to the terms under section 376.1350, and the term "hearing aid" shall have the same meaning given to the term under section 345.015.
2. Each health carrier or health benefit plan that offers or issues health benefit plans that are delivered, issued for delivery, continued, or renewed in this state on or after January 1, 2022, shall, at a minimum, provide coverage to children under eighteen years of age for all hearing aids covered for children who receive MO HealthNet benefits under section 208.151.
3. The provisions of this section shall not apply to a supplemental insurance policy, including a life care contract, accident-only policy, specified disease policy, hospital policy providing a fixed daily benefit only, Medicare supplement policy, long-term care policy, short-term major medical policies of six months' or less duration, or any other supplemental policy as determined by the director of the department of commerce and insurance.
4. Any additional costs to the state created under the provisions of this section shall be subject to appropriation. If any agency of the federal government determines that this section violates 42 U.S.C. Section 18116 relating to nondiscrimination, the provisions of this section shall be null and void.

Financial Information Resources:

- [Children and Youth with Special Health Care Needs Program](#)
- [First Steps Eligibility Criteria](#)
- [First Steps – Individual Family Service Plan](#)
- [First Steps Teletherapy Guidelines for First Steps Services](#)
- [MO HealthNet](#)

For additional information, contact the Missouri Department of Health and Senior Services' (DHSS) Newborn Hearing Screening Program at 800-877-6246 or visit our website at health.mo.gov/newbornscreening.



MISSOURI DEPARTMENT OF
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An EO employer: Services provided on a nondiscriminatory basis. Individuals who are deaf, hard-of-hearing, or have a speech disability can dial 711 or 1-800-735-2966.