



Rural Living

Tips for Raising a Deaf/ Hard of Hearing Child in a Rural Community

2023

Developed by the Early
Hearing Detection &
Intervention Parent to
Parent Committee



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About this Guide

This 2023 Guide was developed by the Early Hearing Detection and Intervention (EHDI) Parent to Parent Committee, an interdisciplinary, interagency/inter-organizational and diverse parent/professional group.

This committee is open to anyone who is interested—professionals, parents, and DHH adults.

For more information, contact parentadvocate@handsandvoices.org.

**DHH and DHH Plus: Within this document, we use the abbreviation DHH to refer to all children who are deaf, hard of hearing, deaf/hard of hearing plus or deafblind.*

DHH Plus refers to children who experience any type of deafness and additional considerations adding complexities in support and services for the whole child. If your child has additional health or educational challenges there will be more to learn. Additional considerations may be medical, developmental, sensory, cognitive, physical and/or social-emotional. Other terms we want to acknowledge are Deaf Disabled, Deaf/hard of hearing Disabled, Deaf Plus, D/deaf with disabilities and deafblind.

Introduction:

This is a tool for rural families like yours, raising DHH* children far from large towns and cities. This includes families living in any area where services for DHH children are limited, or who have challenging commutes to providers. Professionals can also use this document to further their own understanding of the strengths and challenges families face living in rural settings. It was written by a national committee including professionals and families like yours to provide some resources and strategies.

You may live in a rural area due to your family, work, or financial circumstances. Some families choose to live in rural areas to enjoy the strong sense of community, a slower and less stressful pace of life, and easy access to nature. Whatever the reason, your Deaf, DeafBlind, hard of hearing, or DHH Plus child has the right to a free and appropriate public education (FAPE) in your community.

Frequent Challenges Experienced by Rural Families

Raising a healthy DHH child in a small town or in the country requires partnering with and educating your local professionals, family, and support networks, as well as relentlessly pursuing information and opportunities on behalf of your child. This takes research, determination, and creativity, but families who succeed are models for ALL parents of DHH children. Their efforts will not only benefit their child, but others to follow behind them.

This document provides guidance and resources for five common challenges, followed by tips for providers.

Although the law recognizes your right to identify the education, languages, and services that work best for your child, one common challenge is the lack of a match to your child's unique needs, specifically in rural areas. Availability of language access, therapies, and specialists may be hours away or across state lines. You may find yourself having to educate or even recruit therapists, teachers, and medical providers, travel out of state or off island to find the right professionals, or obtain services remotely via the Internet.

The rarity (low incidence) of childhood deafness also means that your child may not have easy access to DHH peers, educators, or role models in your community. Opportunities to socialize with friends are important and will require thinking outside the box. Consider finding camps and retreats, placing your child at a school for the Deaf, or finding social and educational opportunities online. You might also struggle to find social and mental health support for your child, yourself, or other members of your family.

Money can be another obstacle. Caring for any child may be expensive and limit your ability to work; this may be compounded when a child is DHH. If money is tight, you may need to prioritize housing or food. Although many DHH services are required to be offered at low or no cost, you might need assistance paying for hearing devices, transportation, Internet connections or other technology to help your child.

If your family speaks a language other than English, finding information and support in your home language can be even more challenging.

We live rural by choice. Throughout the states we have lived in, we value smaller class sizes and wide-open spaces. Yes, we have been advised to move. We accept the responsibility to take our deaf daughter to her pediatrician and specialists and we make it work.

Teri, Virginia parent

It is exhausting trying to educate everyone around us, drive hours away from home so our children can have qualified professionals, and then find creative ways to adequately support our children. Please acknowledge our efforts, just as we value those who come beside us to help our children succeed.

Kodi, Tennessee parent

Strategies:

- Ask your early interventionist or agency for resources and strategies to help your child.
- Connect with county and regional resources; ask about medical waivers for state health insurance plans.
- Advocate for information in your own language (print, video, connections).
- Find or create your own study group to learn and practice skills, whether in person or remote.
- Attend events whenever possible and make connections.
- Research and find low-cost internet plans (through county staff, Commission for the Deaf, etc.).

Resources:

- Language acquisition resources:
 - ▶ American Sign Language (ASL)
 - Gallaudet University/Laurent Clerc National Deaf Education Center:
 - Information about ASL for families: <https://clerccenter.gallaudet.edu/ndec/families/>
 - VL2: The Science of Learning Center on Visual Language and Visual Learning at Gallaudet: <https://vl2.gallaudet.edu>
 - ASL Connect (online courses for credit): <https://gallaudet.edu/asl-connect>
 - Sign On: American Society for Deaf Children (ASDC): <https://deafchildren.org>
 - SignIt: self-paced curriculum to learn ASL: <https://www.infantheating.org/signit/> Free for birth to 3 years; paid subscription available after that.
 - Handsland: Resources, workshops and consultation in ASL language development: <https://sites.google.com/handsland.com/handsland/home>
 - HandSpeak- ASL dictionary, deaf culture, videos: <https://handspeak.com>
 - Rocky Mountain Deaf School ASL Stories: <https://www.youtube.com/user/RMDSCO>
 - Online ASL curriculum- free and paid subscriptions: <https://www.startasl.com/>
 - DawnSignPress: ASL videos, Deaf culture video library and store: <https://dawnsign.com>
 - LifePrint: ASL University online curriculum and dictionary: <https://www.lifeprint.com>
 - ▶ Signing Exact English (SEE)
 - Northwest School for Deaf and Hard of Hearing Children
 - <https://www.northwestschool.com/resources/s-e-e-classes/>
 - ▶ Listening and Spoken Language Resources
 - Hearing First: Videos and materials for spoken language: <https://hearingfirst.org>
 - John Tracy Center: Online learning curriculum for new families: <https://jtc.org>
 - ▶ Cued Speech Resources
 - National Cued Speech Association (NCSA): Cued Language Resources; free membership for one year: <https://cuedspeech.org/learn/start-cueing/>
 - Described Captioned Media Project (DCMP): Lending libraries of resources: <https://dcmp.org/>
 - Research Brief: DHH In Rural Settings https://nationaldeafcenter.org/wp-content/uploads/2019/04/Research_Brief_DHH_in_rural_settings_v3.pdf
 - Low-cost Internet: Affordable Connectivity Program: <https://www.fcc.gov/acp>

Services Advocacy:

You may have heard that “you are your child’s best advocate.” Trusting your instincts, learning to speak up, asking questions, and sharing your insights are skills that take time to develop. In the end, you are

partnering with providers, educating others, and working with your community for your child's benefit. You are modeling advocacy for your child.

These are some typical issues you may experience:

- Impact of being “rare” in having a DHH child, and possibly having other unique qualities (different culture, live in a tribal community, use a different language, other specific health needs, and/or access needs, etc.).
- Lack of awareness of legal protections for your child in the community/classroom.
- Need for systems advocacy: it's not your job to serve your own child, including acting as an interpreter, transliterator, or classroom aid.
- Experience of “advocacy fatigue” for ongoing medical, school, social, recreational or workplace access.
- Difficulty in relaying new information from outside sources to local providers, such as “listening fatigue” or other unfamiliar concepts or research. For example, parents and professionals may be researching online resources instead of known, vetted materials.

Strategies:

- Advocate and explain your family's unique circumstances, including the need for support for your child to communicate in your family's home language and/or chosen communication methodology.
- Be assured you have the best understanding of your child's evolving needs and be assertive when your child's needs are not met by local services, especially regarding your child's need for communication access.
- Educate yourself by taking advantage of opportunities to attend conferences and workshops (in-person, virtual, local, regional, or national).
- Ask for information from your providers that is easily understood, culturally appropriate for your family, in your family's home language, and is specific to your child's current needs.
- You and your child's team should actively seek out and strongly consider your child's input and preferences in education, medical care, and community life. As your child grows, encourage them to advocate for themselves for their needs at school and in the community.
- Ask your child's school team to share concepts/strategies that you can use at home and in the community.
- Ask your child's team to consider a trial of strategies that your child has successfully used at home.
- Learn about laws that support your child's right to a free appropriate public education (FAPE) and communication access. Investigate relevant advocacy support organizations.
- Intentionally build relationships with your child's school, their education team, the school board, and with local political representatives. You may find a greater opportunity to be heard and have an impact in rural areas.
- Volunteer, whenever possible, to learn, build connections and become actively involved.
- Look for opportunities to represent rural lived experience on committees, panels, and projects to ensure the perspectives of diverse families are ‘at the table’ in systems improvements. Committees such as Early Hearing Detection and Intervention (EHDI) program, special education advisory committees, and community boards are good options.
- Know your right to appeal insurance decisions such as refusing out of network providers. (See Family Voices at <https://familyvoices.org> and the Colorado Hands & Voices Parent Funding Toolkit: <https://co-hv.org/colorado-parent->

As a parent of a Deafblind child with complex needs, I wear many hats. Because of the lack of resources or knowledge, I am a parent, one-on-one intervener, communicator, and advocate for my child.

I would like to be just Mom.

Karonica, Mississippi

[funding-toolkit](#))

- Seek out your district or state special education advisory committee. Being a member allows you the opportunity to work with professionals who make decisions about your child and education programs. Sharing information and advocating for your child (and hearing from others) can benefit all children.
- Join organizations such as a hospital family advisory group, municipality group, library support groups, clubs, or join local committees to educate others and learn about resources.
- Follow local social media and search for likeminded social groups in support of parenting your child.

Resources:

- Schools for the Deaf and early intervention programs are often mandated to serve families statewide.
- DHH Family Support Resources:
 - ▶ Hands & Voices (Parent support organization)
 - Find out if you have a local Chapter, or access support from Headquarters: <https://www.handsandvoices.org/chapters/starts.htm>
 - Hands & Voices ASTra (Educational Advocacy) Guidebook and Program Information (includes websites for Parent Training and Information (PTI) Centers, legal centers, educational law information: <https://handsandvoices.org/astra/index.html>
 - Military Project: Assistance for U.S. families with DHH kids: <https://www.handsandvoices.org/resources/military/index.html>
 - ▶ Find your closest Family-Based Organization serving families with hearing differences: <https://www.handsandvoices.org/fl3/topics/fam-fam-support/need-support.html>
- Center for Parent Information & Resources- State Parent Centers (non-disability specific): <https://www.parentcenterhub.org/the-parent-center-network/>
- Review your state Department of Education website.
- Deafblind Resources:
 - ▶ The National Center on Deaf-Blindness (NCDB): <https://www.nationaldb.org>
 - ▶ State Deafblind projects: <https://www.nationaldb.org/state-deaf-blind-projects/>
 - ▶ National Family Association for Deaf-Blind: <https://www.nfadb.org/>
 - ▶ Family to Family Communities: <https://www.nationaldb.org/for-families/>
- High School Transition: National Deaf Center: <https://nationaldeafcenter.org/resources/>
- State Developmental Disabilities Council: <https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities>
- State or territory Protection and Advocacy Organizations: <https://acl.gov/programs/pa-programs>
- Serving multicultural families in rural areas by a Teacher of the Deaf/Hard of hearing (TOD): <https://deafchildren.org/2020/01/multicultural-deaf-education-in-rural-communities/>
- National associations of state agencies of the Deaf and Hard of Hearing: <https://www.nad.org/resources/directories/state-agencies-of-deaf-hoh/>

Accessing Qualified Providers:

Finding providers with the specialized skills to help your child and your family can require some work and creativity.

- Lack of current expertise in deafness can be magnified by rural living.
- Lack of access to providers matching your child's language and/or cognitive abilities and skills, cultural experiences, and training needs.

- Providers may lack opportunities for specialized training and to practice skills.
- High turnover of staff and the impact of that loss on your child (especially if complex needs are present).
- Locating remote providers who match your child’s needs and are in your insurance network can be difficult.
- Lack of awareness of the need for specialized providers.

Strategies:

- Train local individuals to train others. Use this “train the trainer” model to build capacity for local providers who lack expertise in your child’s specific needs, including the need for full communication access. Share virtual, live, or recorded remote trainings, events or instructional videos with your child’s school or community.
- Ask for information about services out of state/area that can be accessed.
- Access virtual services or mobile clinic offerings when available to reduce commutes (e.g., audiology visits, “clinic evaluations”, mental health, Deaf mentors, sign, or cueing classes, etc.).
- Trust your intimate knowledge of your child and share what resources and strategies you have found online or remotely with your child’s current providers.
- Recruit motivated local individuals who could be specifically trained to fill needs.
- Request information from resource hubs that can be a referral source for other needs as they arise.
- Learn about insurance appeals for out of network providers when no appropriate in-network option is available.

Resources:

- [Family Guide to Audiology and Telehealth](#) within the Hands & Voices Virtual Waiting Room, designed to bring resources and connection online for families.
- National Center for Hearing Assessment and Management (NCHAM) teleaudiology resource page: <https://www.infantheating.org/teleaudiology/other.html>
- Hands & Voices Deaf Education Job Web Site: <https://deafed.net>
You could share this platform for posting open positions and resumes for deaf education with your school district.
- Success for Children with Hearing Loss: <https://successforkidswithhearingloss.com/> Provides educational resources for teachers and families.
- Language First: List of ASL-fluent professionals such as Speech therapists, Teachers of the Deaf and remote IEP support: <https://language1st.org/parent-resources>
- Clerc Online Community (Gallaudet University National Deaf Education Center) Resources for mainstreamed students. (Free to join but must create an account username/password): <https://clerccenter.gallaudet.edu/>
- DeafBlind webinars, remote services/evaluations: <https://www.perkins.org/>
- Family Connect (DeafBlind services): <https://aphconnectcenter.org/familyconnect/complex-needs/>
- NCDB Information Center: <https://www.nationaldb.org/info-center/>
- Exceptional Parent Magazine for the special needs community: <https://www.epmagazine.com/>

Distance/Transportation/Costs:

The cost, travel time, and time off work to get to appropriate in-person services can create barriers.

- Prohibitive commute: need to drive/fly long distances or large amounts of time to cross state lines, face extra costs (lodging/meals/loss of work time and/or wages). Weather may greatly impact travel. Some may feel compelled to move or relocate to be closer to services.

- Transportation: lack of a fully functional/reliable vehicle, public transportation, or need for medical transport.
- Other family members: need for childcare coverage for siblings and/or extended family care coverage when attending medical appointments or school meetings.
- Education: Your child may miss a significant amount of school or services due to the number of appointments involving extended travel per year.

Strategies:

- Inquire about Non-emergency medical transportation under Medicaid with your individual state.
- Inquire through your county or service provider about financial resources/programs available to cover care and transportation-related costs, including foundation grants, gift cards or stipends for required travel. Consider credit cards with travel and free lodging benefits to offset the cost of travel.
- Access remote services or mobile services; some providers periodically come to your area. Determine if your provider has a satellite office that is closer to you.
- Ask for scholarships to attend trainings specific to your child's needs through conferences, the county community center board or your school. (See Parent Counseling and Training in the IEP.)
- Some families, if possible, decide to move closer to services.

Resources:

- See your county for transportation funding such as Medicaid reimbursement. Your state may have Medicaid transportation providers.
- Look into Medicaid buy-in programs through your health department. These allow families to “buy into” Medicaid as a secondary insurance, reducing your costs for deductibles and copays.
- Explore Medicaid waivers for medically complex children through your county (e.g., the Katie Beckett waiver). See list by state/territories: <https://www.medicare.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>
- Find Medicaid non-emergency medical transportation: <https://www.cms.gov/medicare/medicaid-coordination/states/non-emergency-medical-transportation>
- Social workers in your county and at your child's hospital or clinic can assist with finding/coordinating transportation and understanding insurance and other financial resources available.
- Local chapters of national service organizations may assist with funding: (e.g., Lions Club, Easter Seals, Elks, Goodwill, Kiwanis, Shriners, and Sertoma).
- Family Voices: Parent Support Navigators are available regarding insurance, health care information and advocacy: <https://familyvoices.org/>
- Your state Deafblind Project, or local Hands & Voices Chapter may know specific resources in your area.

Social Isolation:

You and/or your child may face social isolation because deafness is rare.

- Your child may be the one child in a district who is DHH. Schools face barriers connecting kids across districts.
- Feeling isolated can affect your child's sense of well-being. A lack of peers who match a child's language abilities and skills or even understand a child's individual experience can be further isolating. This can be true for parents as well.
- Social opportunities for kids may be limited to DHH summer camps or online connections.
- You, your child, and family may have limited opportunities to connect with others who understand your culture, home language, or country of origin, including providers.

- Your community may lack Deaf/hard of hearing community members who can act as role models/mentors. Your child can miss out on seeing DHH people working in businesses, using interpreter agencies, teaching ASL classes, accessing community services, and working in group home or supported employment.

Strategies:

- Support your child's growth in their identity as a DHH individual with personal connections and full inclusion in family life and traditions. Also, consider exposure to books/movies, etc. with DHH characters.
- Ask your team about connecting with other local families with children who are DHH to find support for DHH child, siblings, parents and extended family, in-person or virtually. If served by a special education cooperative or regional office, ask about nearby districts.
- Make extended family and family friends aware of your child's needs as another source of advocacy and support.
- Ask your team about available DHH role model programs, Deaf mentors, or opportunities for your child to connect with other peers at school or elsewhere.
- Learn about the IDEA Special Considerations, your state's Deaf Child's Bill of Rights/Communication Plan or how the ADA (Americans with Disabilities Act) can increase or protect your child's access in school and the community. (IDEA is the federal Individuals with Disabilities Education Act, outlining special education services for students on IEPs or Individual Education Programs.)
- Find DHH adults and peers, including those from rural communities and diverse cultures to provide DHH adult role models to your child, their siblings, parents, and extended family. Look remotely if needed.
- Attend DHH child or family summer camps, as well as learning and transition programs for rural students, including those out of state. Pursue accommodations through the Americans with Disabilities Act.
- Consider combining distant family engagement events with a family vacation.

Our daughter's Teacher of the Deaf/Hard of hearing (TODHH) told us that the resources we were seeking weren't available in our community.

We set out to create our own through our state Hands & Voices Chapter.

Michael, Virginia

Resources:

- Parent organizations serving families with children who are DHH:
 - ▶ Hands & Voices: Find out if you have a local Chapter, or access support from Headquarters: <https://www.handsandvoices.org/chapters/starts.htm>
 - ▶ Find your closest Family-Based Organization serving families with hearing differences: <https://www.handsandvoices.org/fl3/topics/fam-fam-support/need-support.html>
 - ▶ American Society for Deaf Children (ASDC): <https://deafchildren.org/>
 - ▶ DeafBlind Projects: <https://www.nationaldb.org/state-deaf-blind-projects/>
- Organizations for DHH adults
 - ▶ National Association of the Deaf (NAD): <https://www.nad.org/>
 - ▶ AG Bell: <https://www.agbell.org/>
 - ▶ National Cued Speech Association (NCSA): <https://cuedspeech.org/>
 - ▶ CueSign: <https://www.cuesign.org/>
 - ▶ Association of Late-Deafened Adults (ALDA): <https://alda.org/>
 - ▶ Hearing Loss Association of America (HLAA): <https://www.hearingloss.org/>

- Deaf/HH Role Model Programs
 - ▶ NCHAM's list of programs: <https://www.infanthearing.org/dhhadultinvolvement/states/>
 - ▶ SKI-HI: <https://www.deaf-mentor.skihi.org/>
- Summer Camps through various national or state organizations, such as a School for the Deaf <https://www.ceasd.org/>. Also look at AG Bell, Hands & Voices, ASDC or the NAD websites and social media.
- Funding for summer camps: Service organizations listed above or the Hands & Voices Shine Bright scholarships: <https://www.handsandvoices.org/services/shine-bright.html>
- Conferences through ASDC (<https://deafchildren.org/>), Early Hearing Detection and Intervention (EHDI) <https://ehdiconference.org> and similar organizations may provide funding for parent attendance. Consider Disability or syndrome-related conferences such as CHARGE <https://www.chargesyndrome.org/for-families/conferences/> or Usher syndrome <https://www.usher-syndrome.org/events/ush-connections-conference-summaries.html>.

Technology/Remote Service Access:

Digital and remote services may be available but not accessible by rural families.

- Virtual access is not always available, reliable and/or has enough bandwidth in your rural area.
- Internet providers may not be able to accept more customers in certain areas.
- Remote access may not be affordable.
- Virtual access may not be a fit for the service your child needs. A virtual connection may not provide quality equitable interaction for medical services or when high-speed internet is needed for fluency of ASL, cue, etc.

Strategies:

- Pursue lower-cost internet services through local programs.
- Pursue free equipment such as video phones, captioned phones, and devices either through the captioned telephone or video relay provider or through a state/territory/island program. Training may also be available through state commissions, etc.
- Contact your child's clinical or educational audiologist for help.
- Continue to advocate for your family's needs when technology is inconsistent or in-person services are more beneficial.
- Join your local library and reserve a meeting room to use internet.
- See if a WIFI/MIFI booster can help increase your WIFI signal.

Resources:

- Affordable Connectivity Program for lower cost internet: <https://www.fcc.gov/acp>
- Free equipment (adapted phones) and training for deafblind individuals: <https://www.icanconnect.org/>
- Videophones provided by contracted companies: www.fcc.gov/vrs-providers
- Equipment through a state/territory/island program specializing in children/adults with special needs or specifically for DHH. Hearing Loss Association of America (HLAA) list: <https://www.hearingloss.org/hearing-help/financial-assistance/state-telephone-programs/>
- Smoke detectors/fire alarms may be available for free in some states/territories/islands through state/local government, American Red Cross, etc. See also, items for purchase at technology stores

For us, meaningful connection to other families facing similar additional burdens and who have the understanding of our children's rights and needs have empowered us to keep going."

Penni, Nevada

such as Diglo <https://www.diglo.com>, ADCO <https://adcohearing.com>, etc.

Although resources are limited in rural areas, our children can still thrive.

Karonica, Mississippi

Pro Tips from Rural Families to Providers:

- Develop close working ties with the rural communities you serve to help locate families in need of early intervention and other services. Statistically, children who should be receiving services are missing early intervention.
- Listen carefully to your families for the unique considerations for their child. Knowing one DHH child in your past does not generalize to the next DHH child you meet across modality, language, learning style and technology or other considerations.
- Learn what is available to your families statewide, regionally, and nationally. This is a career-long study.
- Assist your families in problem solving for greater access and needed services. The burden should be more heavily on providers and systems. Help families navigate those.
- Create opportunities for the DHH child to demonstrate self-advocacy skills and their knowledge of technology and access as they grow.
- Develop a “train the trainer” option that creates capacity for providers and include the family.
- If a professional is required to support a DHH child and that expertise is unavailable in your area, do not pass this on to parents and caregivers to fill this role.
- Intentionally invite and engage fathers, particularly with families who move often (military or migrant families).
- Share short, specific, just-in-time information. (See Illinois EHDI Snippets for examples of one-topic resources: <https://www.illinoisoundbeginnings.com/snippets>)
- Use reminder post cards, send summaries, texts, video and videocalls to assist in engagement.
- Consider utilizing national services to increase skills and networking with colleagues (e.g., Online Itinerant/Professional Academy <https://www.theonlineitinerant.com/>, the American School for the Deaf <https://www.asd-1817.org>) and Supporting Success for Children with Hearing Loss <https://successforkidswithhearingloss.com/>)
- Ensure families are invited and represented at policy decision tables.

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Families as Advocates and Leaders <https://eclkc.ohs.acf.hhs.gov/sites/default/files/pdf/rtp-advocates-leaders.pdf>