

For Professionals: Working with Families with a Late-Identified Child with a Hearing Difference

Purpose:

To provide information on childhood hearing loss and available supports so families have up-to-date information.

Developed from:

Interviews and focus groups with families of children who were late-identified with hearing loss.

Why:

The grief, experiences, and questions these families have may differ from those whose children were identified through newborn hearing screening. There may be “gaps” in information and experiences that should be addressed.

Late ID of hearing loss impacts multiple professions. Collaboration amongst the child’s care team to ensure these critical topics are shared with the family is urgent. If there is a topic outside of your scope or comfort, consider which members of the team can support the family.

High priorities noted by families:

- Explain late-identified vs. late-onset
- Provide information in writing
- Give the [CO Resource Guide](#) as background information
- Refer to the [CO-Hear](#) (Colorado Hearing Resource Coordinator) for Early Intervention if under age 3 if over age 3, refer to private services and public school supports and explain timelines.
- Work together with other providers to give consistent messaging to the family

“I wish all providers knew what to offer late-identified families. I felt like I had to teach myself all about my daughter’s needs.”

Rural parent of child with UHL identified at age 5 years

Focus on helping a family close any gaps:

If family chooses amplification, support them in understanding the impact of all day use, troubleshooting, and upkeep of their devices

- Share the family always has the right to second opinions if there are concerns about quality of care, results, and/or provider expertise.
- Review the *Colorado Resource Guide* for roles of “Who Can Help?” to give a big-picture of potential supports.
- Refer to Deaf/Hard-of-Hearing (DHH) mentors ([Ascent Program](#)) for birth to three or school services with Deaf Child’s Bill of Rights if school age) to assist in creating a more DHH friendly environment.
- Discuss listening bubble (i.e. child may miss parts of conversation occurring more than 3-5 feet away from them or in noise).
- Ensure family knows the full array of communication options and combinations of options.
- If using ASL or visual communication, refer to [sign language mentors](#) and share supports to increase fluency as quickly as possible.
- If using spoken language, refer to DHH-trained speech language therapists or Auditory Verbal Therapy ([Listen Foundation](#) and/or [Children’s Hospital Colorado](#)) as needed.

- Explain [30 Million Word](#) gap and options to increase through [meaningful turn-taking](#) (e.g., Child: *Doh Truck* (Go truck) Parent: *Does the truck go fast?*) Turn-taking, including waiting for a response, helps language building for all children and with delayed auditory input compared to other children of the same age with typical hearing.
- Explain incidental language (i.e., words/communication that happen in everyday conversation around child). For example, a child overhears parents animatedly discussing a movie and interprets parents' tone as fighting. Some words may not have been understood and the meaning lost. So be sure to explain concepts and situations.
- Explain figurative language (i.e., phrases that do not match the literal meaning). For example, "I am under the weather." Explain it means that someone is feeling ill, and it is a figure of speech meaning unwell.

Explain and support [pragmatic \(i.e., social\) language](#) development. Children who are DHH need additional support and opportunities to learn to use social language with others. Examples include engaging in imaginary play, expressing emotions, retelling stories, telling, and understanding jokes and adjusting how they communicate for their audience (e.g., formal for an unfamiliar adult, informal for a friend). Using mental state verbs is important (e.g., dream, imagine, opinion, thought) and learning the vocabulary of feelings.

[Handout on Pragmatic Language Development](#)

Help identify any other learning needs (DHH+):

Refer for additional supports and evaluations as developmentally or medically necessary.

Connect to parent support:

- Parents report family to family support was their most impactful resource. Connect to [CO Hands & Voices Guide By Your Side](#) for emotional support and education/resources who can reinforce the above learning, plus:
 - Share an experienced family's journey with late identification
 - Share about local services and events, camps, etc.
 - Share and explain a list of abbreviations/acronyms
 - Help a family create a D/HH friendly home
- Connect to [CO Hands & Voices Advocacy Support and Training \(ASTra\)](#) before Child Find evaluation if a CO-Hear is not going to be present.
- Ask about funding difficulties (if present, refer to CO Hands & Voices [Parent Funding Toolkit](#) and social work).

Additional considerations for children three years or older:

- Connect to [Colorado Hands & Voices ASTra Program](#) as soon as possible.
- Let families know school district should share information about local school services (center based programs, mainstreaming), the [Colorado School for the Deaf and the Blind \(CSDB\)](#), [Rocky Mountain Deaf School](#), and [homeschooling supports](#).
- Share about [Child Find evaluations](#) for IEP (Individualized Education Program) or 504 Plans (including the option to begin preschool at age 3 and access to supports for your child's unique needs).
- Explain the roles and responsibilities of educational audiologists, DHH teachers, and others on child's educational team.
- Share that additional technology options may be available to help with access in educational and community settings.

"We need specific resources for late ID in our area, a parent group, and steps to take to close our kids' gaps."
Suburban parent of child identified at age 3 years