

Phonak

Parent guide

Guide for understanding best practice recommendations for children with unilateral hearing loss

By Janet DesGeorges, Executive Director of Hands & Voices, a parent-support organization for families who have children who are deaf/hard of hearing. Thank you to the families worldwide who have children with UHL who reviewed and recommended content for this guide.

February, 2020: Janet DesGeorges

Created from the *Consensus practice parameter: audiological assessment and management of unilateral hearing Loss in children.*

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<https://www.tandfonline.com/doi/full/10.1080/14992027.2019.1654620>

Introduction

The purpose of this document is to facilitate effective communication between families and providers, develop a shared understanding of the impact of UHL, and generate a mutually acceptable evaluation and management plan based on the unique and individualized needs of your child and family.

This document offers guidance so that you can be well informed, and work effectively with your child's providers to ensure the best outcomes. As parents, you need to know all your options and to understand what those options might mean for your child and family. You need to know and understand the benefits, risks, and uncertainties about each option and consider how important these are to your family. At the end of the day, recommendations should be individualized for your child. These considerations include: difficulties your child is experiencing, degree of hearing loss, configuration of hearing loss, and values and desires of your child and family. It is recommended that you explore and utilize the information from this guide in partnership with your hearing care professional and/or other providers.

The source of information for this parent guide

An international panel of experts on the screening, assessment, management, and monitoring of children with unilateral hearing loss convened on October 24, 2017, following a day and a half of presentations on the same. Evidence reviewed was gathered through literature searches using web search engines specifically designed for academic and health care resources and two recent systematic reviews of the literature were considered (Appachi et al., 2017; Anne, Lieu, & Cohen, 2017).

The expert panel created and published guidelines in the Consensus Practice Parameter. This resource is new and your hearing care provider may not yet be aware of them. You might want to send them this link prior to discussing this document with them.

Additionally, some of the information contained in this document was contributed by Hands & Voices, a parent-support organization for families who have children who are Deaf/Hard of Hearing, including families who have children with UHL.

This parent guide can:

- Help you understand recommended practices for children with UHL
- Help you assess services based on the principles recommended by an expert consensus group
- Empower your family to advocate for appropriate services
- Improve your partnership with hearing care professionals
- Help you process decisions and recommendations regarding UHL

Definitions of terms you will see in this document

- a. unilateral hearing loss (UHL) – any degree of permanent hearing loss in one ear, regardless of etiology, with typical hearing in the opposite ear; includes the concept of single-sided deafness.
- b. pediatric population – for purposes of this guideline, refers to children birth through 18 years of age.
- c. contralateral routing of signal (CROS) hearing aid – a type of hearing aid that is intended for use by those with typical or near-normal hearing in one ear and an opposite side un-aidable ear. Sound is transmitted from the side of the un-aidable ear to the ear with better hearing.
- d. bone-conduction devices – the class of bone-conduction devices that transmit vibration via transcutaneous or percutaneous means (surgical or non-surgical devices; transcranial).
- e. remote microphone systems (RMS) – wireless microphone systems that convert audio signals into radio signals and transmit them to a receiver at the ear. Sounds can be transmitted via frequency modulation (FM) or digital modulation (DM).
- f. single-sided deafness (SSD) – term coined by a hearing technology manufacturer to refer to complete sensorineural hearing loss in one ear. For purposes of this guideline, the term profound unilateral hearing loss is used.
- g. profound unilateral hearing loss – hearing loss in one ear with a pure tone average (PTA) of >90 dB.
- h. unaidable unilateral hearing loss – hearing loss that because of profound degree, very poor speech recognition, or intolerance for amplified sounds cannot be fitted with traditional hearing aids.

The following definition of unilateral hearing loss (UHL) may also be helpful

Unilateral hearing loss means that one ear has normal hearing and the other ear has hearing loss. The ability to hear with two ears is called binaural hearing. Binaural hearing is important for locating where a sound is coming from in the environment and understanding conversations in background noise. The brain pathways that support binaural hearing start developing at birth. Unilateral hearing loss affects the ability to use information about the difference in loudness and timing of sounds between the two ears. As a result, a child with unilateral hearing loss will have more difficulty figuring out the source of sounds in their environment and understanding conversations outside of a quiet, one-on-one situation. The

amount of hearing loss in the affected ear will influence what can be done to help. (2019: BC Early Hearing Program – Key Messaging for Clinicians)

Within this document are four of the five principles that were explored in the Consensus Practice Parameter. Although originally created to provide guidance for professionals, this parent guide will explore many of the same principles. For each principle, we explain what it means and provide considerations as you reflect on your family's own experience and the needs of your child. In addition, a list of commonly asked questions and answers are included.

There are five principles in the original document, which are:

1. Identification and assessment
2. Management and monitoring
3. Technology management
4. Information to be conveyed to families
5. Priorities for research – not addressed in this Parent's Guide- can be found in the original consensus parameter paper here: <https://www.tandfonline.com/doi/full/10.1080/14992027.2019.1654620>

The principles, what they mean and next steps

Let's look at each principle in the Consensus Practice Parameter to see what it means for children and families. For each of the four principles you'll find:

- **Principle:** Components of the principle as it appears in the Consensus practice parameter
- **What this means to me:** Brief description of what the principle might mean to your family
- **Things to think about:** Ideas about what your family might want to consider
- **Additional resources**

1 Principles of identification and assessment

Principle	Identification <ul style="list-style-type: none">• Numerous published guidelines by various national organizations have outlined recommendations for newborn hearing screening and assessment of hearing loss in children. These guidelines, as well as additional guidance in the provision of family-centered early intervention should be considered by audiologists who provide services to children.• Recommendations include that hearing be screened by 1 month of age, hearing loss identified by 3 months of age, and intervention provided by 6 months of age. These recommendations hold true for all forms of permanent hearing loss, including unilateral hearing loss. Assessment <p>It is recommended that assessments be considered for the following areas (depending on your child's age):</p> <ul style="list-style-type: none">• known etiologies and risk factors• localization, which has implications for child safety as well as listening ability• speech perception in noise• balance function• early auditory behavior and preverbal vocalization• speech/language development• cognitive development• academic attainment
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	Sample assessment tools, including measures, purpose of instrument, target population/degree of hearing loss, and age range are available in the Quick Practice Guideline.
What this means to me	<p>When children with unilateral hearing loss receive timely and appropriate diagnostic and intervention services, their likelihood of having positive speech, language, and listening outcomes is improved.</p> <p>Identification</p> <ul style="list-style-type: none"> • If born in hospital, your baby should have been screened for hearing loss. If you were not given results of a hearing screening, or you are not sure if your baby was screened, you should contact your hospital and ask, making sure you get the results in writing and explained to you. • If your baby was not screened for hearing loss, discuss this with your physician and ask for an immediate referral for a screening, and then further evaluation by an audiologist, if necessary. • Once hearing loss is identified, your audiologist should connect you with early intervention services to determine your child's eligibility for services and supports. <p>Assessments</p> <ul style="list-style-type: none"> • Assessments to determine why your child has a hearing loss (e.g., genetic testing, cytomegalovirus [CMV] testing) and if the loss is expected to change with time should be considered. • Genetic testing might inform future decisions about communication, medical care, or equipment use. • Assessments to help you monitor your child's progress and determine your child's needs should be considered. (Many available tools use parent or teacher input to assess your child and can also help you understand some of the difficulties your child might or might not have, due to their hearing loss.) • Assessments should be considered throughout your child's ages and stages (e.g., entry into school, change in academic performance, different listening situations). as listening and learning environments change.
Things to think about	<p>I have a right to expect:</p> <ul style="list-style-type: none"> • All professionals involved with my family and child will understand assessment and treatment timelines and will meet all target dates. • My audiologist will connect me with early intervention services in a timely manner. • My team of service providers will consider and implement the necessary assessments to ensure that my child is progressing in their development and all academic needs are being met. • My audiologist will regularly administer standardized assessment tools to ensure that progress in all critical areas is monitored.
Additional resources	<p>2019 Joint Committee on Infant Hearing (JCIH) Position Statement https://www.audiology.org/sites/default/files/publications/resources/2019_JointCommiteeInfantHearing_Principles_Guidelines4EarlyHearingDetectionInterventionProgrs.pdf</p>

2 General principles of management and monitoring

Principle	Hearing care professionals should refer to accepted guidelines and provide referrals for additional evaluations including ophthalmology, otology, genetics, speech-language, and early intervention. However, the monitoring and management of children diagnosed with UHL requires consideration of the individual needs of each child in this diverse group.
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	<p>In addition to routine audiologic measures, a variety of tools are available to pediatric audiologists and other professionals responsible for monitoring auditory, speech, language and developmental milestones for children with permanent hearing loss, before and after provision of various technologies. For infants and young children, easy-to-administer parental questionnaires are available; for older children, self-report measures are available to assess functional auditory outcomes and quality of life.</p> <p>Although many children with permanent bilateral hearing loss are enrolled in early intervention programs and receive a variety of specialized services and regular surveillance, there is more variability in the provision of early intervention services for children with UHL. Many of these children receive no intervention services and minimal follow up after diagnosis despite evidence indicating that children with UHL are at risk for delays in speech, language, and academic achievement.</p> <p>The JCIH (2019) provides additional recommendations for management, monitoring, and early intervention.</p>
What this means to me	<ul style="list-style-type: none"> Monitoring and assessment tools are especially important when children with UHL are receiving limited or no intervention services from specialized providers. Outcome measurement tools designed specifically for children with UHL are lacking; however, a number of instruments have been developed that can be useful in evaluating functional listening in this population.
Things to think about	<p>I have a right to expect:</p> <ul style="list-style-type: none"> Once diagnosed with UHL, we will be referred to early intervention services. Our audiologist will recommend a thorough monitoring protocol based on concerns we have as a family and those determined by other factors associated with our child's hearing loss (e.g., cause of hearing loss, if known; degree of hearing loss, etc.) Not all children with unilateral hearing will develop language and/or education difficulties, and services might include monitoring, but no direct intervention might be required.
Resources	<ol style="list-style-type: none"> http://pediatrics.aappublications.org/content/pediatrics/120/4/898.full.pdf A Parent's Guide to Deaf and Hard of Hearing Early Intervention Recommendations: http://www.handsandvoices.org/resources/jcih-parent-guide.html

3 Principles of technology management

Principle	<p>Currently, there are no published guidelines stating which children with UHL should receive hearing assistive technology (HAT), what type of technology should be used, or what type is most efficacious. The following recommendations are based on the consensus paper from which this document is derived. It is important to note that families should be counseled as to the possibility of changing management options, as needed or indicated.</p> <p>Traditional hearing aids</p> <p>For permanent hearing loss on the affected side, conventional air-conduction hearing aid fitting is recommended as a first line treatment, if the affected side is moderate to severe in degree, regardless of child's age. If the affected side is minimal to mild in degree, it is recommended that audiologists refer to the Clinical Decision Support Guideline (Bagatto & Tharpe, 2014) for guidance. Here is the link to the guide you can share with your audiologist.</p> <p>Bone-conduction devices</p>
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For infants and young children with unilateral microtia or atresia and for whom conventional air-conduction hearing aids cannot be fitted, a bone-conduction device should be considered.

Remote microphone systems (RMS)

RMS provide a means of overcoming the adverse effects of environmental noise, distance, and reverberation by placing a microphone/transmitter close to the mouth of a talker or connecting the transmitter to audio sources such as televisions or computers (Wolfe, Lewis & Eiten, 2016).

Classroom audio distribution systems (CADS)

CADS are designed to deliver an audible signal at a consistent level throughout a room. Proper set up and knowledge of a room's acoustics are necessary to ensure good sound quality throughout the space (American Academy of Audiology, 2011b).

Personal desktop RMS

Desktop systems are an option for children who cannot or will not wear ear level RMS but for whom CADS do not provide adequate amplification (Anderson & Goldstein, 2004; Anderson et al., 2005; Iglehart, 2004). They can provide greater flexibility than CADS and can be moved from one learning space to another more easily.

Contralateral Routing of Signal (CROS)

CROS systems are used when no benefit is expected from fitting a hearing aid to the ear with hearing loss, usually due to the magnitude of hearing loss or to poor speech understanding. There is limited information about either the effectiveness of CROS systems for children or the relative merits of the various options available (Appachi et al., 2017).

Cochlear implantation

Some children and their families might seek hearing restoration of the affected side with the ultimate goal of achieving some level of binaural hearing. In such cases, cochlear implantation (CI) is an emerging treatment option.

Though limited in number, preliminary studies of CI use in children with UHL are encouraging. However, the potential for non-use is not trivial, and special attention should be given towards counseling parents and their children on appropriate expectations. Emerging data suggest that children with acquired and perhaps congenital UHL will benefit from CI use through improved hearing on the affected side, localization, speech recognition in noise, and quality of life metrics, though should be interpreted with caution given the limited number of reports. Longitudinal data are needed to determine how much benefit is possible for children with UHL, especially those with losses present from birth.

Long-term implications for the child should be discussed in terms of:

- Cost (e.g., batteries/upgrades)
- "Lifelong patient" - a lifelong obligation for the child
- Identity issues with this cohort of children as they grow
- Do the benefits outweigh the risks?

Parents also need to be made aware that the child might still need a remote microphone system in the classroom.

What this means to me

- Technology considerations for children with UHL include:
 - Traditional hearing aids
 - Bone-conduction devices
 - Remote microphone systems (RMS)
 - Classroom audio distribution systems (CADS).

	<ul style="list-style-type: none"> ○ Personal desktop RMS. ○ Contralateral routing of signal (CROS) ○ Cochlear implantation <ul style="list-style-type: none"> ● Evidence-based research for technology may be limited in some cases and must be thoroughly explored for you to be able to make an informed decision regarding the choice (if any) of technology. ● You may find (for example, on social media sites) many different types of technology recommendations from other parents. These opinions should be taken with caution as others' recommendations may not be appropriate for your child's unique needs.
Things to think about	<p>I have a right to expect:</p> <ul style="list-style-type: none"> ● Technology options and evidence (or lack thereof) will be discussed based on my child's individual needs. ● Our audiologist will have experience working with children with UHL and the technology considerations for this population. ● If the UHL is known to be associated with progressive hearing loss, our audiologist will consider how the various technology options perform as hearing changes. ● For some children, detection of sound – not just speech perception – might be a desirable outcome of an aided ear for safety purposes. ● Our audiologist will consider our child's future needs as well as current concerns, so quality decisions can be made towards the best value of investment (both time and money).
Resources	<ol style="list-style-type: none"> 1. Questions to ask your Audiologist: https://www.cdc.gov/ncbddd/hearingloss/freematerials/Audiologist_Questions_ENG.pdf 2. <u>Hearing technologies for children with unilateral hearing loss. Table 2 in <i>Consensus practice parameter: audiological assessment and management of unilateral hearing Loss in children</i></u> https://doi.org/10.1080/14992027.2019.1654620

4 Principles of information to be conveyed to families

Principle	<p>Audiologists have an important role in providing support, information, and resources to parents throughout this journey with their child. To meet the needs of individual families, services need to be family focused, and the process should be modified based on unique family issues, dynamics, and desires (Munoz et al., 2012)</p> <p>Hearing care professionals should be able to provide families with information to help them identify reputable online resources and be aware that because management of UHL is not clearly defined, they might encounter a variety of opinions about the best options for this type of hearing loss. The 'best' management options will vary depending upon the individual child's hearing loss, their family's needs, beliefs, and resources. Because not all information on the internet is peer reviewed or scientifically validated, families are encouraged to discuss their research or concerns with their audiologist.</p> <p>What questions should families be asking and who should they ask?</p> <p>Families should ask all questions that are important to them including questions in the area of diagnosis, family concerns, management of devices/technology, support systems, now and in the future (see English et al., 2017; CDC, 2012).</p>
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	<p>Families receive information from a variety of sources including:</p> <ul style="list-style-type: none"> • professionals • other families who have children who are deaf or hard of hearing • deaf and hard-of-hearing adults • written and digital/online information and resources <p>When information is delivered to families, it is essential to remember that family-provider partnerships include establishing trust, fostering family investment and effectiveness, and focusing on family-identified concerns (priorities, hopes, needs, goals, and wishes).</p>
<p>What this means to me</p>	<p>Our hearing care professional should be able to discuss the following questions with us:</p> <ul style="list-style-type: none"> • What are the possible consequences of our child's hearing loss? Are all children affected the same way? • What are the potential benefits, limitations, and risks of the technology for helping our child's hearing and communication? What do we know, and what do we not know? • What are the consequences of proceeding or not proceeding with a particular technological intervention? • Is it possible for us as parents to change our minds in the future (e.g., proceed with a surgical versus a non-surgical intervention)? • When and how might we begin to see a benefit (or a disadvantage) from fitting? • If device fitting is declined by our family, have we received enough information to help with our decision? • How do we address our feelings and emotions associated with our decision? • What are factors that may impact successful device use (e.g., influential others, bullying)? • What is the cost? What are the hidden costs such as repairs, spare parts, and compatibility with other technology? • Will we be able to use the features we have paid for once we are home and in day-to-day usage? • If others will also have to use the technology (e.g., a RMS), what support is needed to help with this? • Are there other health concerns impacting our child that will influence success with technology? • Which HAT features benefit our child in which environments and at what age? • When is it time to invest in new technology or wait until next year's version comes out? • What are the most advantageous and useful features that our child might need in their unique settings?
<p>Things to think about</p>	<p>I have a right to expect:</p> <ul style="list-style-type: none"> • Hearing care providers will be able to answer our questions, and/or direct us to someone who can. • I can be in touch with others who can support our family journey, (e.g., other parents, parent support organizations, and D/HH adults). • Hearing care providers will understand that our reactions to a hearing loss diagnosis are not necessarily related to the degree of hearing loss. We as parents of a child with UHL can be just as concerned for our child's future as parents of a child with a severe or profound bilateral hearing loss.
<p>Resources</p>	<ul style="list-style-type: none"> • The Question Prompt List: https://www.phonakpro.com/content/dam/phonakpro/gc_us/en/products_solutions/documents/QPL.PDF • JCIH The What Else Checklist for Audiologists (CDC): https://www.cdc.gov/ncbddd/hearingloss/freematerials/Checklist.pdf

- Decision Guide to Communication Choices: http://www.handsandvoices.org/articles/GoOn/V13-3_cdc-decisionguide.htm
- H&V Communication Considerations: <http://handsandvoices.org/comcon/index.html>
- H&V We Are Hands & Voices: Parent Stories: <http://www.handsandvoices.org/resources/products.htm>
- H&V Book of Choice: <http://handsandvoices.org/resources/products.htm#boc>
- www.handsandvoices.org
- www.gpodhh.org

Frequently asked questions

1. We just got the news that my child has hearing loss! What should we do?

Hearing a doctor or audiologist say, "Your child has a hearing loss", most probably has come as a shock to you. Most people do not know much about hearing loss and what it means for their child and family. As the professional who delivered this news to you talked further, you might not have heard much of what he or she was saying. In your mind, questions might have started to churn:

"Can it be corrected?", "What caused it?", "Will it get better?", "Will it get worse?", "Can he learn to talk?", "Can she go to regular school?", "If we have more children, will they have hearing loss, too?", "Can he get married?", "Will she be able to get a job?"

The answers you get to some of these questions might not be what you want to hear; "No, this type of hearing loss cannot be medically or surgically corrected." Or, "you might receive an answer that is comforting like, 'We have every reason to believe that your child's language will develop normally but we will need to monitor that over time.'

You want the best for your child, and now you are not sure you know what to do.

The professionals who evaluate your child's hearing will have recommendations for you: see an ear specialist, meet with early intervention professionals, and/or have more testing done. As you follow these recommendations, you will meet people who can help answer your questions and explain the decisions you must make. The information they give you and opinions they express might sometimes create more confusion for you and other times bring you relief and better understanding.

Additionally, seeking out other families who have been through this can be of tremendous support. One such organization, Hands & Voices (www.handsandvoices.org) has specific supports for families who have children with UHL. Also, The Global Coalition of Parents of Deaf/HH Kids has connections worldwide. (<http://www.gpodhh.org/>)

2. When I was told that my baby had a UHL, I was shocked. How do other parents react?

Parents experience this news in many different ways. Most children (90-95%) who are diagnosed with hearing loss are born to hearing parents, so this news is usually unanticipated. The important thing is to know that you are not alone, and there are other families who have been through what you are going through who can serve as a support to your feelings and emotions, and professionals who can also support you.

In the days and weeks following the diagnosis of your child's hearing loss, you may feel like you are on a roller coaster. Your feelings may swing from despair to hope, from sadness to anger, from feeling incompetent to feeling confident. As you carry out your daily routines - finishing a chore or arriving at a destination - you might realize that your mind was somewhere else, thinking about your child and what you should do. You might also find within yourself unexpected sources of strength to do what has to be done in spite of feeling that you are living under a cloud.

You will be making many decisions in the days ahead. Give yourself the time you need to make decisions that feel right for your family. Keep in mind there are very few decisions you will make that you cannot change. (source: www.cohandsandvoices.org/rmap/roadmap/pages/port9.htm)

3. When I go online, I often find families who have gotten different messages from their hearing health care professionals than I have received from mine. Why is that?

This can be frustrating for families – seeing that different things are offered to other kids with the same level of hearing loss. When there are few definitive evidence-based practice recommendations, professionals use their professional judgment and experience to make recommendations to families. Additionally, because of the unique needs of an individual child, recommendations that suit one child, might not be appropriate for your child. It may be useful to seek a second opinion regarding recommendations for your own child, as an option. The objective of the Consensus Practice Parameter is to provide guidance to clinical audiologists on individualizing the management of children with UHL.

4. What should I say when people/professionals say to me, "Don't worry, he/she still has one 'good ear'"

When we think about why someone would say this, it is usually about whether or not a child has good access to language. Although "the one good ear" does provide access to sound, you (and eventually your child) will have to educate people continually about the difficulties localizing sound and hearing in noise, the associated listening fatigue and what that means in a given situation. Ideally, you will find a pediatric audiologist and other team members who are well-versed in UHL, but outside of that circle, the public is not aware of these unique needs. Additionally, it is important to look at the positive aspects of the experience of unilateral hearing, focusing on what a child CAN do versus what they can't do, and families can still remain positive and vigilant at the same time with regard to the management decisions they are making for their child.

5. Do all audiologists have expertise working with infants and children?

Not all audiologists work with, or have experience working with, infants and children. The diagnostic hearing evaluation should be performed by a pediatric audiologist who has the technical expertise and desire to work with infants and children. They should be skilled at performing tests to determine the type (part of the ear affected), degree (how much hearing loss exists), and configuration (frequency or pitches that are affected) of a child's hearing loss.

6. Should I still seek out parent-to-parent support groups? I'm not sure I will fit in, since my child 'only' has UHL?

Most parents find some level of parent-to-parent support valuable, whether that be active (attending an event or workshop) or passive (seeking out a website or online discussion group or other types of knowledge). The world of hearing loss has great variety in both unilateral and bilateral losses including degree of loss, presence of other conditions, and whether children are attending home school, private, or public school. Parents often have more in common than would appear on the surface. You can also ask for supports available specific to UHL.

7. Will my child's hearing level get worse? Will it progress to both ears?

This is a question that comes up for many families, and answers can be vague because there is often no clear way to know whether your child's hearing loss will progress. This is an important question to ask your hearing care provider who can review your child's cause of hearing loss, tests that have been or can be conducted, as well as genetic testing. This is also why monitoring is so important – so that if your child's hearing does get worse, you can be aware of it in a timely manner to take action and modify your child's intervention, if needed.

8. I'm frustrated because everyone says, "Let's just 'wait and see' if any delays occur." Isn't there something we can be doing now?

Families who choose a 'watchful waiting' approach should be equipped with information about key developmental milestones and when and how to act if they are concerned. More useful terminology may be 'watchful waiting' or 'active monitoring' rather than 'wait and see.' This is the same as all of the child's developmental milestones – we assume that our children will achieve typical developmental milestones, but we still keep an eye on them to make sure this is the case. The same is true for children with UHL. We assume that they will achieve typical developmental milestones, but they are at higher risk for language delay so more active monitoring is required. This includes regularly checking with the appropriate professional that the child is meeting developmental milestones and implementing

strategies to address any delays. 'Watchful waiting' doesn't mean doing nothing. As in all child development, parents should be active in promoting their child's language and listening skills (e.g., providing a language-rich home environment, minimizing background noise, such as radio or television, when talking).

If you have any questions about this document, or want further explanation of its terms or content, contact janet@handsandvoices.org

"Yes, the journey is different than we expected, but we have the privilege and responsibility of building a foundation for our children that will enable them to accept themselves for who they are, to communicate confidently in the world around them, and to get out there and change the world! . . . I am so proud of who my daughter has turned out to be and so grateful for all the support we've had along the way that has allowed her to be successful."

- Parent of an adult deaf child

Full citations and references are available within the Consensus practice parameter document found [here](#):