Who Can Help? Finding Information and Support

At Alberta Hands & Voices, we recognize that parents want the best for their children who are Deaf and Hard of Hearing. Parents need support and information from a wide variety of sources. Below is an illustration of some of the different ways parents can find support.

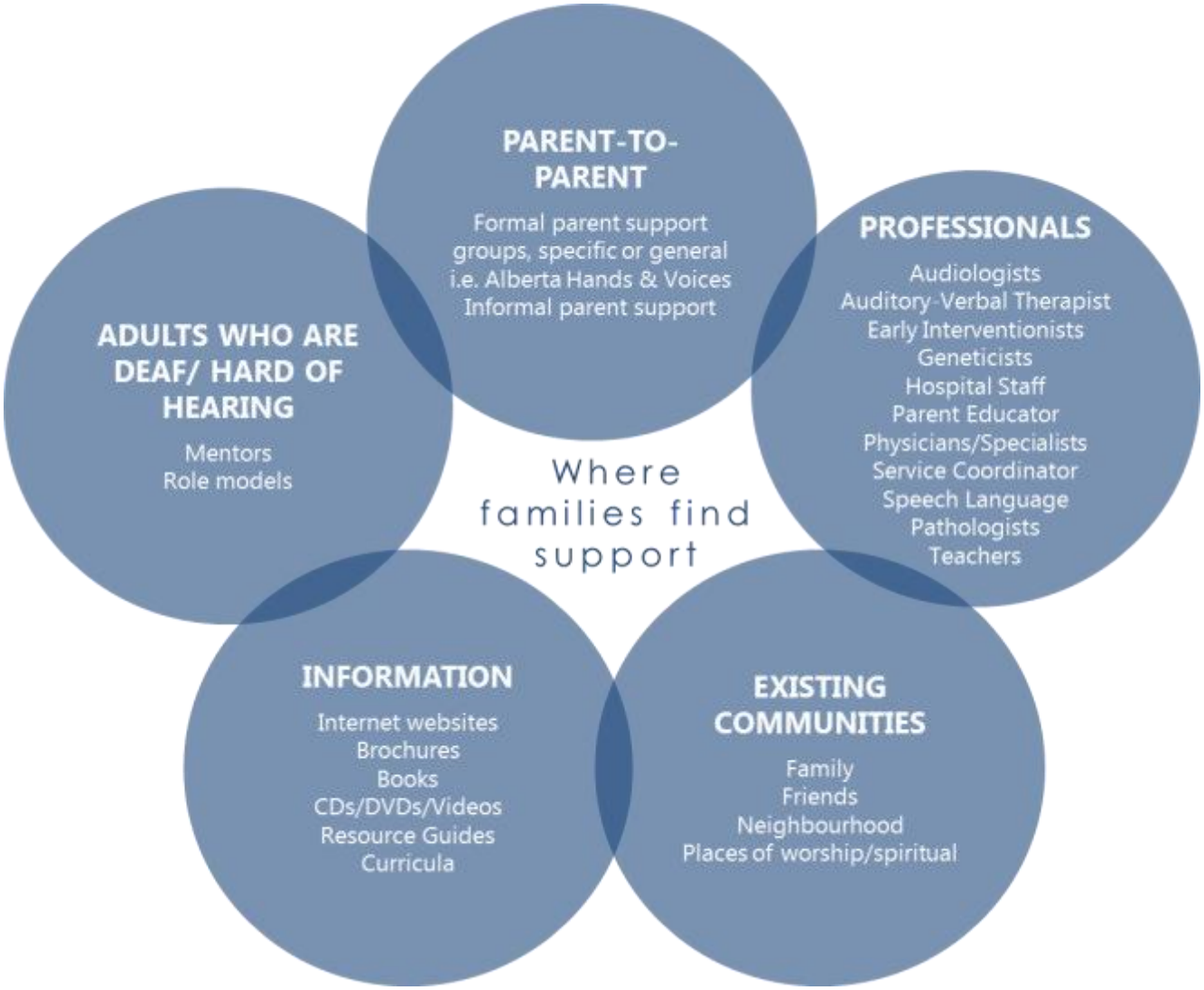

Figure 3. Family Support Guide

Parent-to-Parent

As shown above, **Parent-to-Parent** contact is an important source of information and support. This is what Alberta Hands & Voices is all about!

Other parents may help with:

- Sharing experiences they have had with professionals and early intervention programs.
- Telling you about people and information sources they have found useful.
- Listening to you.
- Sharing their feelings related to parenting a child with hearing loss and how their feelings have changed over time.
- Telling you about their child's achievements. Celebrating your child's achievements.
- Getting together with you so your children can play together.

Adults who are Deaf or Hard of Hearing

Families have a varying degree of previous exposure to adults who are Deaf or Hard of Hearing. Typically, the opportunity for families to create a relationship with someone who has real life experience of being Deaf or Hard of Hearing cannot be provided by anyone they know. There are many valuable insights that a role model may bring to a family, including:

- Sharing the day-to-day realities of living with hearing loss.
- Successful models of career paths and educational experiences.
- Stories about real-life challenges that must be overcome.

- Renewal of hope for their child living a full and successful life as an adult who is Deaf or Hard of Hearing.
- Helping a family create a perspective of decision-making based on their child's needs.

Families often like to meet Deaf or Hard of Hearing adults who have the same degree of hearing loss and/or use the mode of communication that the family is pursuing. Yet families also benefit from having exposure to Deaf or Hard of Hearing adults who may communicate differently than their own child. This helps the family realize that a person can achieve success regardless of the communication method or mode used.

Adults who are Deaf or Hard of Hearing who grew up a generation ago have had different life experiences and opportunities than the children of today. Some things may have changed, yet many aspects of the journey remain relevant. Some of the common experiences include:

- Growing up in a family as the only child who is Deaf or Hard of Hearing.
- Sibling issues.
- Developing self-advocacy skills.
- Overcoming discrimination. Families have many questions, particularly in the beginning, about what this means for their child . . . from the simple, "Can Deaf people drive?" to the complex, "How did you make friends growing up?"
- Advocating for societal acceptance and inclusion.

To connect with Deaf or Hard of Hearing adults, contact Alberta Hands & Voices or see the *Resources* section of this toolkit. The *Resources* section lists several local, provincial, national and international groups and organizations that can provide you with contacts or information.

Extended Family or Existing Communities

When everyone in the family is on the same page, things run more smoothly. Whether that means asking your Auditory-Verbal Therapist to tape sessions so all family members can see them, starting a blog, posting to Facebook, or sending out a weekly email about your child's latest accomplishments and goals, the more your extended family knows, the more helpful they can be to you.

Use technology like Skype, FaceTime, or even a simple phone call to help your child practice important communication skills and stay connected to family members who live far away. Distant family members can create experience books for your child, write letters, or send emails that can serve the dual purpose of working on language skills and strengthening family bonds. The more your extended family feels a part of your child's life, the better they will be able to understand and help you cope with the hearing loss.

While you can do your best to educate them, it is unrealistic to assume that every family member will achieve your level of understanding. Instead, pick one specific thing that you can ask of each family member that will capitalize on their strengths while slowly shaping their behaviours into those that will be better for your child. For example, an uncle who works long shifts and isn't home much might not have the energy to digest your email summaries, but he might agree to a phone call or coffee date to get updated. Once on the same page, you can show him that you want him to be involved in the family by asking him to come over and play a game or read a book. The vast majority of family members *want* to help, they just don't know *how*. Give clear, simple, one-task directions and help them become part of the team.

Just as individual family members have strengths, take time to recognize your family's strengths as a whole, outside of the realm of hearing loss. Are you close-knit? Do you have family members who can step in to care for siblings while you attend appointments? Does your family deal with challenges with a great sense of humor? Are you a resilient group? While your extended family may not be perfect in all the ways you'd like them to be as you deal with this

new challenge, realize that everyone has some strengths, and use them to their fullest!

Professionals are another source of support and information. But who are these professionals, and how can they help? **The remainder of this article will describe professionals' roles and the different ways that professionals may be of help to you.**

Audiologists

Audiologists are trained to evaluate and rehabilitate individuals with hearing loss and related disorders.

Audiologists can test a child for hearing loss. They can describe the test results and help you consider different treatment options. An audiologist will be able to give you suggestions about hearing devices and some may sell and fit hearing aids for children. Some audiologists can also provide you with information on auditory/hearing training and different options to communicate with children with hearing loss. The audiologist may work with your family and a team of professionals, such as a speech-language pathologist, ENT (ear, nose, and throat doctor), early intervention specialist, and other professionals, to provide you and your child with the services you need.

Audiologists may help with:

- Hearing disorders in infants, children and adults.
- Amplification such as hearing aids and assistive listening devices.
- Auditory processing disorders or issues with how the brain processes sound.
- Tinnitus or noise or ringing in the ears. (See the *Your Child Has Tinnitus* article in this toolkit for more information).
- Hyperacusis and Misophonia or sensitivities to particular sounds.

- Balance disorders including dizziness or vertigo caused by Ménières disease, ear infections and trauma to the brain.

Questions You May Want to Ask Your Audiologist

Questions About Hearing Loss:

- How much hearing loss does my child have? Please explain the type and degree of loss for each ear.
- Please explain the audiogram or report.
- Is the loss permanent?
- Does my child need more testing?
- How often should my child's hearing be tested?
- Can you tell me if my child's hearing loss will change or get worse?
- What could have caused my child's hearing loss?
- How will the hearing loss affect my child's speech and language development?
- Who will you be sharing the results with (i.e., pediatrician, etc.)?
- How do I describe these results to my family?
- May I have a copy of the hearing test results?
- Do I need to make a follow-up appointment?
- What should I tell my child's teacher about the test results?

Questions About Treatment:

- Does my child need hearing aid(s), cochlear implant(s) or other hearing devices? What are my choices?
- Does he or she need treatment in both ears?
- What is the cost? What funding support is available to me?
- What can my child hear with the hearing devices? How do you test if the hearing devices are working just right for my child?

- How often do you need to check or adjust the devices?
- How often will my child need new hearing devices?
- Which part of the hearing device (such as the earmold and tubing) will need to be replaced regularly?

Auditory-Verbal Therapists

Auditory-Verbal Therapists have a primary goal of maximizing a child's verbal development.

Auditory-Verbal Therapists/Clinicians are professionals who have been trained in one or more of the disciplines of speech-language pathology, audiology, and education of the Deaf and Hard of Hearing. They have expertise in the use of acoustic emphasis of speech sounds and language patterns with the primary goal of maximizing a child's verbal development. The guiding principle applied by an Auditory-Verbal clinician is that all therapeutic and educational decisions lead to the child's maximum participation in the hearing-speaking society.

Auditory-Verbal Therapists may help with:

- Deciding if the Auditory-Verbal approach is right for your child and family.
- Integrating listening into a child's development of communication and social skills.
- Supporting a child's auditory-verbal development through one-on-one teaching.
- Continuously assessing and evaluating a child's development and, through diagnostic intervention, modifying the program when needed.
- Providing support services to facilitate educational and social inclusion in regular education classes.

Questions You May Want to Ask Your Auditory-Verbal Therapist

- How is Auditory-Verbal Therapy different from other kinds of therapy?
- Can Auditory-Verbal services be used in conjunction with other methods?
- What age is best to begin Auditory-Verbal Therapy?
- What services are available to my child?
- Are there any costs involved? If so, is funding available?
- How often should my child go to therapy? How much time will be involved?
- What are the requirements or expectations of parental/family involvement?
- What results can be achieved by using Auditory-Verbal Therapy?
- What are the limitations of the Auditory-Verbal option?
- Can you give me an example of a treatment goal and lesson plan?
- How and how often will we follow-up on my child's Auditory-Verbal development?

Ear, Nose and Throat Physicians or Otolaryngologists

Otolaryngologists are physicians trained in the medical and surgical management and treatment of patients with diseases and disorders of the ear, nose, throat (ENT), and related structures of the head and neck.

An ear, nose and throat (ENT) doctor (also called an otolaryngologist) may be able to tell you if there is a medical condition in your child's outer, middle, or inner ear that may have caused the hearing loss. The ENT will ask you questions and do a medical examination. The doctor can also answer any questions about medical treatments. The best care for your child will be provided by ENTs who have training and experience to evaluate and treat infants and young children.

The ENT may help with:

- Determining if there is a medically treatable condition in your child's outer ear or middle ear that is causing the hearing loss.
- Answering your questions about medical or surgical treatment of different types of hearing loss.
- Scheduling further procedures (i.e., urinalysis, CT scan) to rule out specific causes of the hearing loss.
- Placing ventilation tubes in your child's eardrums if he has chronic middle ear disease that is not resolved by antibiotics in a timely manner.

Questions You May Want to Ask Your ENT Specialist

- What type of hearing loss does my child have? Please explain the terms.
- Should I make appointments with other health professionals? For example, an eye doctor or a geneticist?
- Do you think our family should have genetic counselling?
- Does my child need other tests? For example, scans (CT, MRI); blood, heart (EKG) or urine tests. What will these tests tell you about my child's hearing loss?
- Can you tell if my child's hearing loss will change or get worse?
- What caused my child's hearing loss?
- How do I describe these results to my family?
- What treatments are available? For example, ear tubes or cochlear implants?
- Would my child benefit from hearing aid(s), cochlear implant(s) or other implantable devices? Where can I get more information?
- How often should my child return for a check-up?

Educators or Teachers of the Deaf and Hard of Hearing

Teachers of the Deaf and Hard of Hearing have had specialized training in the education of students who are Deaf or Hard of Hearing.

Teachers who have had special training in the education of students who are Deaf and Hard of Hearing may form part of your support network. An Educator or Teacher of the Deaf and Hard of Hearing provides direct and consultative services to children of all ages with hearing loss, their families, teachers and other support staff. They may work in a variety of settings and positions, such as an itinerant teacher, a teacher in a provincial school for the Deaf, an early intervention specialist or educational consultant.

An Educator or Teacher of the Deaf and Hard of Hearing may help with:

- Assessing a child's communication and language skills.
- Advocating for students who are Deaf and Hard of Hearing.
- Teaching speech, auditory skills, writing, reading and language within the appropriate academic goals of the curriculum.
- Teaching a variety of subjects.
- Using a variety of communication methodologies to meet the needs of students (such as ASL or Auditory-Verbal).
- Troubleshooting and monitoring technology including hearing aids, cochlear implants and other assistive technology.
- Assisting with the development of an Individual Program Plan (IPP).
- Supporting the social and academic integration of students.
- Providing families and school staff with information and support.
- Providing information regarding the impact of hearing loss in the classroom to teachers and hearing peers.

For more information on **Individual Program Plans (IPP),** see the *Getting Ready for Kindergarten* section in this toolkit.

Questions You May Want to Ask Your Teacher or Educator

- What communication option(s) do you use (for example: Signing Exact English (SEE), American Sign Language (ASL), Cued Speech, Auditory-Verbal, etc.)?
- What is the model of service delivery? (Do you work directly with students, or provide more of a consultative role? If you work directly with students, how often will you work with my child?)
- What type of assessments do you complete?
- What kind of supports can you offer?
- What kinds of accommodations do you recommend for my child?
- What other professionals do you work with (i.e., speech-language pathologist or guidance counsellor)?
- What are my responsibilities as parent/caregiver/guardian?
- Can you suggest any other resources in the community for our family?
- Can I contact you with questions?

Genetics Team

A "genetics team" is made up of a clinical geneticist, a genetic counsellor, and other healthcare professionals. A **clinical geneticist** is a doctor who specializes in diagnosing and caring for people with genetic conditions. A **genetic counsellor** is a healthcare professional who talks with people about the risk for genetic conditions and provides counselling and support. Members of the genetics team work together during a genetics exam.

The purpose of a genetic testing or exam is to find out if the cause of your child's hearing loss is genetic. About sixty percent of all hearing loss in babies are caused by

A genetic counsellor talks with people about the risk for genetic conditions and provides counselling and support.

changes in genes. Genes contain the instructions that tell a person's cells how to grow and support the body. Some changes in a gene can cause hearing loss. Hearing loss can also be caused by infections, certain medications, and risks such as prolonged loud noise in the environment. For many children, the cause of hearing loss may not be known.

The genetics team will ask you questions about your child and family. They will do a complete physical exam and may recommend that your child and you have a blood test. They may suggest your child see another doctor or specialist to better understand the cause of your child's hearing loss. Knowing the cause may help you and all the professionals who work with your child better plan for his future needs. They may also be able to inform you and your family of the chance of having another child with hearing loss. Sometimes, however, the cause of a child's hearing loss cannot be found even after a complete evaluation.

Questions You May Want to Ask Your Genetics Team

- What will the results of genetic testing tell me? Does a negative test result mean that my child's hearing loss is not genetic?
- Can the results of genetic testing tell me if my child's hearing loss will get better or worse?
- How will genetic tests be done? What other kinds of tests are needed in order to find out the cause of my child's hearing loss?
- Will my child need to come back to your office after testing? If so, why?
- Why is it important to know if members of my family have hearing loss, what type of hearing loss, and when they started developing the hearing loss?
- How is hearing loss inherited?
- If no one in my family has hearing loss, how can my child's hearing loss be genetic?
- Should my other children have genetic testing, too? Why or why not?

- If I have another child, what is the chance that he or she will have hearing loss?
- Should I share test results with other members of my family? Could other people in my family also have children with hearing loss?
- Where can I learn more about genetic testing for hearing loss?
- Where do I meet other families whose children have the same type of genetic condition as my child?

Primary Care Physicians

Medical professionals, such as paediatricians, family physicians, primary care doctors, and nurse practitioners, are trained to diagnose and treat medical conditions in people. Your child's medical professional oversees your child's overall growth, health, and development.

Your child's primary care physician will help decide which specialists your child should see.

In addition to receiving routine care, a child with hearing loss may need to see specialists who will look at the child's specific health needs. Your child's primary care physician will help decide which specialists your child should see and when to see them. These specialists may look at eyes, language or speech needs, genetics, or other areas.

Your child's primary care physician may help with:

- Referrals to other specialists as needed (ENT specialist, genetics counselling, etc.)
- Answering your questions about medical or surgical treatment of different types of hearing loss.
- Treating your child - or referring to ear specialists - when your child has middle ear disease that increases the degree of hearing loss.

Questions You May Want to Ask Your Primary Care Physician

- Will my child need more tests because of the hearing loss? For example, brain scans (CT, MRI) or blood or urine tests? What will these tests tell you about my child's hearing loss?
- Are there other specialists knowledgeable about childhood hearing loss my child should see?
- How do I get referrals to see other specialists if my child needs their services (e.g., speech, audiology, ENT, genetic, ophthalmology)? To get

the referrals, do I need an appointment with you first or can I request them by calling your office?

- Have you received any reports about my child's hearing loss (e.g., from audiology, ENT)?
- Will I get copies of other specialists' reports?
- Are there any medications that can harm my child's hearing?
- Will ear infections or fluid in the ears affect my child's hearing loss? Should the condition be treated differently because of my child's hearing loss?
- Will you need to see my child more often because of the hearing loss? How often?
- Other than my child's hearing loss, do you have other concerns about my child's development? Is his or her development on target?
- Can you tell me about early intervention services that are available in my area?
- Do you know of any additional community resources or support groups?

Speech-Language Pathologists

Speech-language pathologists are trained to evaluate and rehabilitate individuals with speech and language problems.

A speech-language pathologist (S-LP) may be a part of your child's life if you have concerns about speech and/or language development. Some S-LPs focus on spoken language only, while others focus on spoken language and sign language. One who has training and experience to work with children with hearing loss would be optimal.

Speech-language pathologists work in schools, early intervention programs, hospitals, and in private practice. Services in school districts vary considerably across the province, and some parents have experienced a shortage of services.

Some speech-language pathologists work in the area of tele-health for families in rural areas. S-LPs in private practice may be the answer for families who can't receive services through public health or school districts. A listing of S-LPs in private practice is available through the Alberta Speech-Language Association of Private Practitioners or http://asapp.ca. On this website you can search for private practice S-LPs who work with children who are Deaf and Hard of Hearing. Rates are usually billed on an hourly basis and may be partially reimbursed through your family's private or employer benefit insurance plan.

Speech-language pathologists may help with**:**

- Speech delays and disorders including articulation, phonology (speech sounds used in language) and motor speech disorders (physical inability to produce speech or speech sounds).
- Language delays and disorders including expression and comprehension in oral and non-verbal contexts.
- Fluency disorders including stuttering.
- Voice and resonance disorders**.**
- Swallowing and feeding disorders in adults and children.
- Cognitive-communicative disorders including social communication skills, reasoning, problem solving and executive functions ('Executive functions' is an umbrella term for the neurologically-based skills involving self-control and self-regulation. These processes that have to do with managing oneself and one's resources in order to achieve a goal.)
- Pre-literacy and literacy skills including phonological awareness, decoding (making sense of printed words), reading comprehension and writing.
- Communication and swallowing disorders related to other issues. For example, hearing loss, traumatic brain injury, dementia, developmental, intellectual or genetic disorders and neurological impairments.

Questions You May Want to Ask Your Speech-Language Pathologist

- What kind of training and experience do you have working with children who are Deaf or Hard of Hearing? What age groups have you worked with?
- Will you work with my child directly?
- What communication option(s) do you use in therapy (for example: Signing Exact English (SEE), American Sign Language (ASL), Cued Speech, Auditory-Verbal, etc.)? What is your experience and comfort level using these communication options?
- What is your approach to helping my child communicate?
- How do you test my child's speech and language development? How often will you check my child's progress?
- When can we talk about my child's progress?
- How do you decide the amount of time my child will spend on speech production, language (spoken or signed), and auditory (hearing) training?
- What are my costs for the different types of therapies? What funding support is available to me?
- Can you give me an example of what a typical session looks like?
- Can you tell me where I can learn more about the different types of communication options?
- What goals or outcomes do you think are most important for my child? How is this determined?
- How can I be a part of my child's treatment?
- What are my responsibilities as parent/caregiver/guardian?
- What tips can I use or activities can I do to support my child's communication at home?
- What exercises can I do at home to ensure my child continues to learn?
- How can my child's teacher support the S-LP's recommendations?

- Can you suggest any other resources in the community for our family?
- Can I see a private S-LP at the same time my child is receiving services from a school or health centre?

Early Invervention Specialists

It is important that children who are Deaf or Hard of Hearing begin early intervention services as soon as possible.

Early intervention services support families to help their children reach their full potential. These services can be offered through a public or private agency such as the Connect Society or Alberta Children's Hospital (see the *Resources* section later in this toolkit). Your child may receive services at home, a clinic, a daycare centre, a hospital, or the local health department. It is important that children with hearing loss begin early intervention services as soon as possible. With appropriate intervention services and support, your child will develop communication and language skills that will last a lifetime.

An early intervention specialist may help with:

- Describing the services offered through their early intervention program and costs, if any, associated with services.
- Describing how your family members will be involved in early intervention services: defining your roles in early intervention and their expectations about your family's participation.
- Answering, when possible, your questions about how your child's hearing loss will affect his ability to learn, to communicate, and to participate in school and society.
- Discussing with you how both your child's strengths and needs and your family's strengths and needs will be assessed and when these assessments will take place.
- Giving you a timeline for when services will begin and end.
- Describing the curriculum that will be used to promote your child's acquisition of listening and communication skills.
- Describing how you and other caregivers will be given opportunities to acquire information and skills that will help you promote your child's development of listening and communication/language skills.

- Listening to your observations and concerns about your child and discussing these with you.
- Working with the audiologist to help your child learn to use amplification and make sure the child's hearing devices function properly.
- Keeping records of a child's progress in the acquisition of communication skills.
- Providing you and your child with high-quality, individualized early intervention services that lead to your child acquiring communication/language skills.
- Giving you support during difficult times.
- Working with you to define your child's educational needs when your child is ready to "graduate" from early intervention.

Questions You May Want to Ask Your Child's Early Intervention Team

- What is early intervention? What services do you provide?
- Can you describe the intervention activities to me?
- How long and how often are the intervention activities?
- Where do I bring my child for the intervention activities?
- Why is it so important for my child to start intervention this early?
- How much will early intervention services cost? Is funding available?
- How do you help my child learn how to communicate?
- Can you tell me about sign language?
- Are there other ways my child can learn to communicate?
- Does your program have staff trained to work with very young infants and toddlers with hearing loss?
- Will you send my child's progress reports to her primary care physician?
- Where can I learn more about children with hearing loss?
- What will happen when my child is too old for your program?

Adapted from:

-*BC Association of Speech/Language Pathologists and Audiologists*

-*Canadian Association of Educators of the Deaf and Hard of Hearing*

-*Cochlear Implant Online*

-Centers for Disease Control and Prevention (CDC)

-*Listening for Life*

-*NCAM: A Resource Guide for Early Hearing Detection and Intervention*

-*The Ready Guide: Getting Started, Indiana EDHI Program*