



WHAT'S INSIDE

Section 2

What's in This Toolkit?

Before starting to work on the toolkit, we had several brainstorming sessions with parents and professionals. We came away with excitement, but also with the realization of the daunting task before us. We came to realize *we couldn't* include *all* of what parents and professionals were asking for. What you will not find in the toolkit is:

- Information that would be conveyed in conversations with a Parent Guide and/or a professional team. *Examples: Which communication approach is best for my child? Effects of having a child with a disability on spousal relationships and roles. Strategies for dealing with behaviour.*
- Information that will become outdated very quickly. *Example: Product reviews for hearing aids.*
- Information that is covered elsewhere, and is covered well. *Example: What is a cochlear implant?*
- Success stories of Alberta families who have chosen a specific communication approach or program. *These important stories are better suited to the future Alberta Hands & Voices website.*

For the toolkit, we focused on including material parents want to know, but don't know who to ask or can't find easily. The toolkit covers:

- Questions that come up over and over again on the Alberta Hands & Voices Facebook page. *Examples: Any advice for swimming lessons? My child is going into kindergarten - what do I need to know? How do I explain her hearing loss to her new teacher?*
- Topics that are not covered well elsewhere, or are not readily available. *Examples: Listening fatigue. Speechreading instruction for children. Incidental learning. Tinnitus in children. Unilateral hearing loss. And many more!*

- Topics that provide a foundation for further knowledge. *Example: Types of hearing loss. Coping with emotions after hearing loss is diagnosed.*
- Topics that Parent Guides will need to know about. *Examples: Causes of hearing loss. Auditory Neuropathy Spectrum Disorder (ANSD).*

As you can see from the topics above, the information could be “too much information,” or not relevant to a specific family. Perhaps now would be a good time to outline how we envision this toolkit will be used, and by whom:

- Most of our existing, active members are families of children whose hearing loss was diagnosed some time ago. They are anywhere from 2-5 years down this road, and they are still looking for more information.
- With universal newborn hearing screening programs, we anticipate many more young families will need services. At the time of this writing, our hope is that Alberta Hands & Voices Parent Guides will be a valued component of the professional team for the universal newborn screening program. Parent Guides will need training on a variety of topics - especially Alberta-specific information. This toolkit aims to fill this need.
- Parents of children whose hearing loss was recently diagnosed also need high quality information. Because these parents may not know about us, their community audiologists and other professionals will likely be the main source of information. When the new-and-improved Alberta Hands & Voices website is revamped in the second phase of this project, audiologists and other professionals may be able to compile a toolkit that meets the needs of a specific family by selecting and printing parts of the document that is before you today.
- Reading English may present varied difficulty to different parents. Where possible, the material is presented at a grade eight reading level. However, some content is technical and we will not meet the needs of these families in this regard. We hope we will be able to attract Parent Guides that can provide culturally and linguistically appropriate services and supports to families to fill this gap.

Nomenclature

For simplicity in writing and reading, we alternated the gender of pronouns. One section will use "she," the next will use "he," and so on. Of course, every section applies to both girls and boys.

We used the word "**hearing devices**" to mean hearing aids, cochlear implants, or bone-anchored hearing aids (BAHAs).

We capitalized Deaf and Hard of Hearing. We recognize that "deaf" is different from "Deaf"; however, in children, identification with these terms is evolving. As a parent said, "Sometimes I call her Deaf. Other times I refer to her as being Hard of Hearing. But mostly, I call her Sarah." An exception to the capitalization occurred when we referred to a source that uses a different convention (such as in the article summaries for the Lending Library).

Where Do I Start? How Do I Use this Toolkit?

You may want to start with your questions. Check the Table of Contents for topics of interest to you. Many parents report they spend hours researching on the Internet trying to find answers. Unfortunately, judging the accuracy and relevancy of information from the Internet can be difficult. This toolkit was created with the intent to direct you to accurate information, and save you time as well.



If you have no specific questions, we suggest starting with the *After Diagnosis* section. This information serves as a foundation for later, more advanced, topics.

Keep in mind this toolkit will evolve over time. At the back of this toolkit is a questionnaire. We would appreciate your feedback so we can make improvements. Please take time to complete the questionnaire and send it back to us. In doing so, you will help other families who will use the toolkit in the future.

Let's get started!