NORTH DAKOTA

HANDS & VOICES™

Resource Manual

JOIN SHARE LEARN

“What works for your child is what makes the choice right.”

INDEX

North Dakota Hands & Voices Resource Manual

North Dakota Hands & Voices along with professionals in the state have created this resource manual specifically for parents and guardians at the time of diagnosis of hearing loss.

We are a parent-driven organization and understand how difficult this time can be for families. We hope that you find answers to your questions regarding hearing loss and your child's development. Most importantly, we want you to know you are not alone.

Please feel free to contact us with any of your questions or needs.

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STORIES

Parent Stories & Family Experiences

Throughout this publication you will find personal stories from North Dakota families with children who have hearing loss. We hope you find support in the experiences of other families and comfort in the fact that there are other parents with whom you can talk.

Though these stories do not reflect all the communications options or choices that are available, the common thread is families finding their way in the journey, much like you.

If you wish to be connected with a local family, please do not hesitate to call or write to North Dakota Hands & Voices.

Structure of the Ear

THERE ARE FOUR AREAS IN THE EAR WHERE PROBLEMS WITH HEARING CAN OCCUR:

1. Outer ear:

The ear (pinna) and ear canal lead to the eardrum and funnel sound into the middle ear. Problems in this section of the ear can be seen by otoscopy (looking in the ear with a small light). Outer ear malformations may cause the ear canal to be closed off or wax could be blocking the sound.

2. Middle ear:

This is the space behind the eardrum. It transmits sound from the eardrum, through a chain of three little bones, to the inner ear (cochlea). The middle ear is an air-filled space, but sometimes fluid can collect here causing hearing loss.

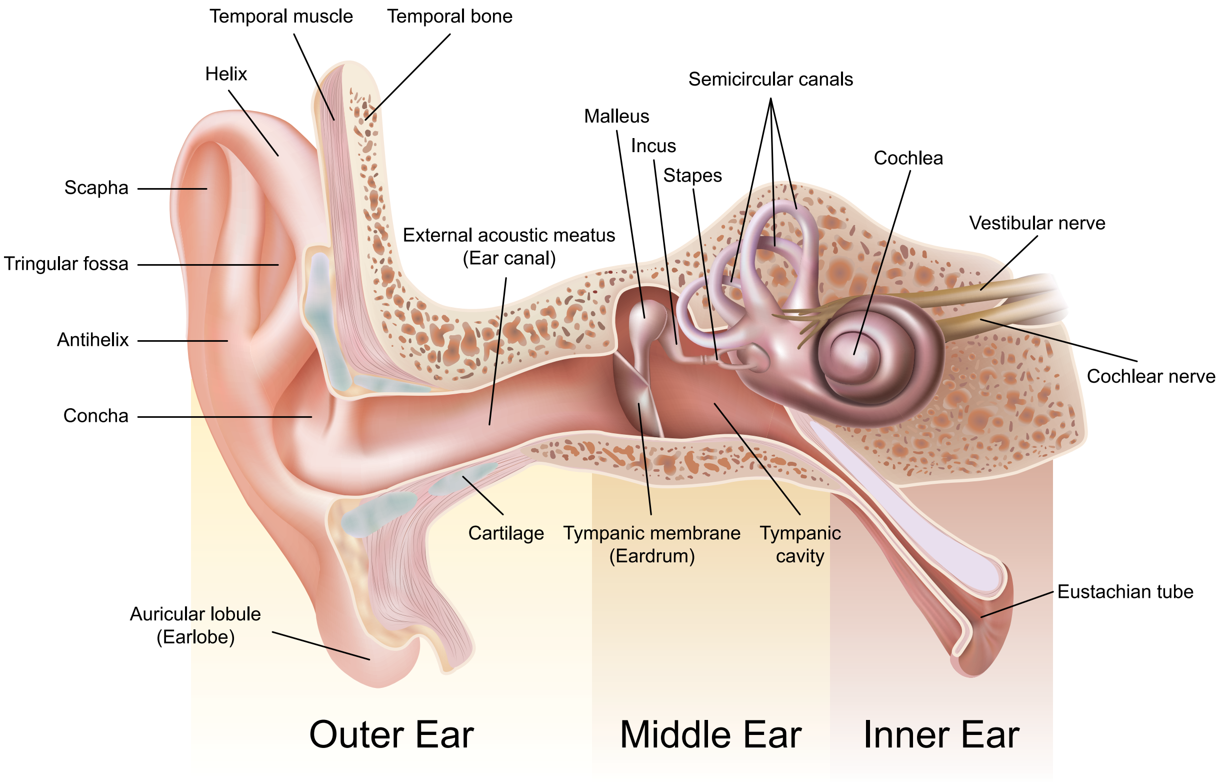
3. Inner ear:

The inner ear houses the cochlea (snail shaped organ of hearing). The cochlea has tens of thousands of hair cells that transmit sound by electrical pulses that stimulate the hearing or auditory nerve. The auditory nerve then sends a signal to the brain. Missing or malformed hair cells can prevent the sound from being transmitted normally to the brain.

4. Auditory nerve:

This nerve starts at the cochlea and travels to the auditory sections of the brain. All the tiny electrical pulses from the cochlea need to be transmitted to the brain for processing. When the auditory nerve is not working properly, sound may be unclear, muffled, or distorted.

Anatomy of the Ear



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Tests of the Ear

THERE ARE DIFFERENT TESTS USED ON A CHILD'S EAR:

Objective tests include tympanometry, otoacoustic emissions (OAE), and auditory brainstem response (ABR). These evaluations can be completed on a child at any age who is sleeping or resting. Around 6 months of age, children undergo behavioral testing. Audiologist may use more than one test to determine hearing abilities in children. See below for brief descriptions of the tests that your child may undergo.

TYMPANOMETRY: an assessment of the middle ear system, including the eardrum. A probe is placed into the ear, sound and pressure are applied to the ear, and a response is recorded from the eardrum in less than a minute. This test helps the audiologist predict things like middle ear fluid and assess the function of pressure-equalization tubes when present.

OTOACOUSTIC EMISSIONS (OAE): an assessment of the sensory cells in the cochlea (hearing organ). A probe is placed in the ear and different sounds are presented. A healthy ear will create a sound in response and these echoes, or emissions, are measured within a couple minutes. This is a common screening of hearing at birth. The presence of emissions suggests hearing is in the normal to near normal range. The absence of these emissions suggests further testing is necessary to rule out hearing loss.

AUDITORY BRAINSTEM RESPONSE (ABR): an assessment of the hearing nerve that estimates hearing abilities at the level of the brainstem. Band-aid-like electrodes are placed behind the ears and on the forehead of the child, sound is presented to the ear through headphones, and responses from the cochlea and auditory nerve are recorded. This is the gold standard for determining hearing levels in children too young for or not cooperative in behavioral testing. Hearing abilities can be determined in each ear and at different pitches. It is critical children are sleeping soundly or sedated for this assessment as any movements can lead to inaccurate results. This evaluation can take 1-2 hours.

BEHAVIORAL EVALUATIONS: an assessment of hearing abilities where the child participates in the testing process. Infants around 6 months of age can be trained to turn toward a reinforcing toy or video when a sound is heard. This allows the audiologist to determine how quietly a child can hear the sounds presented at each ear and at different pitches; however, a child's attention to this task can vary and multiple appointments are typically necessary to gain a full understanding of the child's hearing.

Degrees of Hearing Loss

3

THERE ARE DIFFERENT DEGREES OR LEVELS OF SEVERITY THAT WE USE TO DESCRIBE HEARING LOSS:

1. Mild

The child begins to respond to sounds at a level between 20 and 40 dB on the audiogram. Some speech sounds and softer sounds like a faucet dripping and birds chirping may not be heard by someone with a mild hearing loss. Sounds that are moderately loud to a normal hearing person will sound soft to a person with mild hearing loss. A child with this degree of hearing loss will have trouble hearing speech from a distance or from another room, and may have trouble hearing speech when it is noisy.

2. Moderate

The child begins to respond to sounds at a level between 40 and 65 dB on the audiogram. Most speech sounds and louder sounds like a clock ticking and a vacuum cleaner may not be heard by someone with moderate hearing loss. Sounds that are loud to a normal hearing person will sound soft to a person with moderate hearing loss. Speech will be unclear unless it is loud. A child with this degree of hearing loss will likely have limitations in speech development. Speech may also be difficult to understand without amplification.

3. Severe

The child begins to respond to sounds at a level between 65 and 90 dB on the audiogram. Most speech sounds will not be understood, and other sounds like the telephone or a dog barking may not be heard by someone with a severe hearing loss. Sounds that are very loud to a normal hearing person will sound very soft to a person with severe hearing loss, and speech will only be heard if it is shouted in the ear. Speech will be mostly unintelligible for children with this degree of hearing loss without amplification.

4. Profound

The child begins to respond to sounds at a level greater than 90 dB on the audiogram. Very loud sounds like an airplane flying overhead or a lawnmower will not be heard by a person with profound hearing loss. A child will rely on visual information rather than hearing for communication and will have unintelligible speech without amplification and intense specialized instruction.

4 Types of Hearing Loss

THERE ARE DIFFERENT TYPES OF HEARING LOSS:

1. Conductive

This type of loss is due to a blockage in the outer or middle ear, preventing sound from being appropriately conducted to the inner ear. Causes: wax blocking ear canal, ear infection, otosclerosis (stiffening of the middle ear bones), perforation (hole) in eardrum.

2. Sensorineural

This type of loss is due to problems with the hair cells in the inner ear and/or some distortion in the processing of the signal from the nerve to the brain. This type of hearing loss is permanent. Causes: loud noise, strong antibiotics, severe infections, structural abnormalities or anatomical malformations and genetics.

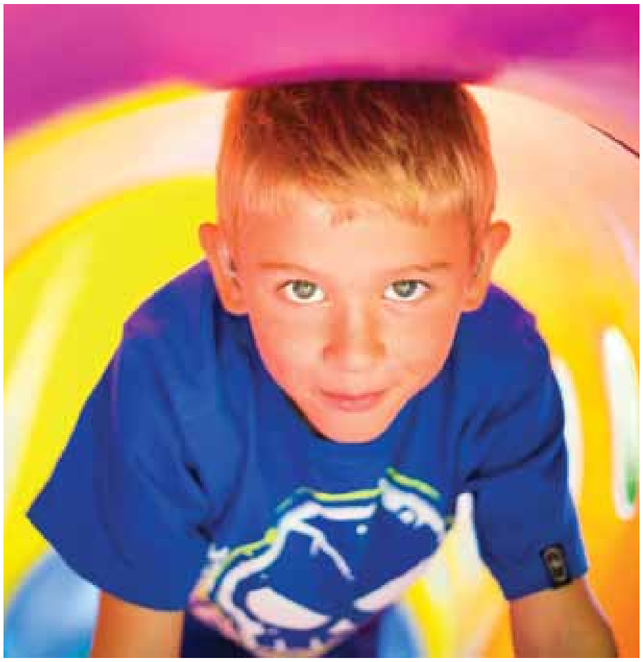
3. Mixed

This type of loss is a combination of conductive and sensorineural hearing loss. Sound is not transmitted normally from the outer ear to the inner ear and there are problems with the inner ear and neural parts of the hearing system.

4. Auditory Neuropathy

This type of loss occurs when the auditory nerve either fails to process or incorrectly interprets the signals from the sensory cells of the inner ear. This can result in intermittent hearing, various degrees of hearing loss and hearing loss that fluctuates.

5 Causes of Hearing Loss



The exact cause of a child's hearing loss can be difficult to diagnose, and most often the cause is unknown. Some causes include: treatments used to save the life of a sick baby, an infection experienced by the mother while pregnant, microtia (absense of outer ear), atresia (ear canal is closed or very narrow) or genes passed down from the parents. Hearing loss can occur along with other problems present at birth, such as with the eyes, heart, and kidneys. It is critical that care be established with an ear, nose, and throat (ENT) physician once hearing loss is diagnosed in a child.

It is also important to discuss options for genetic testing, imaging studies, eye exams, and other testing with your primary care providers to determine the cause of hearing loss and to rule out any other health issues.

Our Journey

Sophia's story from a Mother's Perspective

I am not a patient person and I don't like to wait for answers or test results. When they told me that Sophia failed her newborn screening, I asked the nurse every chance I got if they had repeated the test yet and if she had passed. The answer was always the same. An appointment was scheduled two weeks later for a recheck and I was told it was probably just fluid. I had to put it out of my head and try to focus on my new baby but I couldn't get it out of my head. I kept thinking that Sophia didn't startle in the hospital when my cell phone caused a noise so loud I nearly jumped out of my skin. In fact, she had never startled at all. I started trying to make her startle (banging pots and pans behind her head) and watched her like a hawk for any reaction at all to noise. Despite my efforts, there were no signs that she was hearing anything.

My family assured me that she could hear; that they saw her startle; and that everything was fine, but I knew better and I knew this was going to be more than fluid. I was forced to wait.

Finally, when Sophia was 3 ½ months old, an ABR was performed. With an official "profound bilateral hearing loss" diagnosis, we quickly took action to schedule appointments to see if Sophia was a candidate for a cochlear implant and explore other options. Things seemed to go quickly at that point but not without obstacles. After many tests, decisions and appointments, we decided to proceed with simultaneous bilateral cochlear implants. Sophia's implants were turned on in the fall of 2011 when she was 11 months old. That Thanksgiving she had been using her implants for almost two months when she finally said her first intelligible word – "Mama". It was the most beautiful mama I had ever heard and it gave us so much hope.

Other words soon came. It is amazing how much these words meant to us and that they were the milestones that we lived by. Now we reluctantly have to tell Sophia to be quiet in church. After all the effort of getting her to talk, I am telling her not to. We are excited to see what each day brings and are so blessed to have Sophia in our lives. We have gotten through all of this with the support of family, friends, and the professionals who work with Sophia who have all been our sounding boards and who are all willing to do what it takes to help Sophia reach her full potential.

In addition to seeking out local supports, we also utilized tele-intervention to obtain services from a school whose focus was solely oral communication. We have realized that what Sophia needed and what our family needed is not a one size fits all deal. You will need to do what is right for your family. Get connected with other families and professionals to help your child succeed no matter what path you choose.

For our family, we definitely have a new "normal" and went through many changes as a family. Initially we were devastated with all the unknowns: will we have to move; will we have to send her away to a school; will she ever have a boyfriend or go to prom (silly – we know); what lies ahead for us; and can we handle this. But today we feel so much better because we are informed about what lies ahead. Today we feel lucky and blessed. Many things have been put into perspective.

Communication Options

6

COMMUNICATION OPTIONS FOR CHILDREN WHO ARE DEAF OR HARD-OF-HEARING:

Health professionals, educators and experienced parents typically agree that:

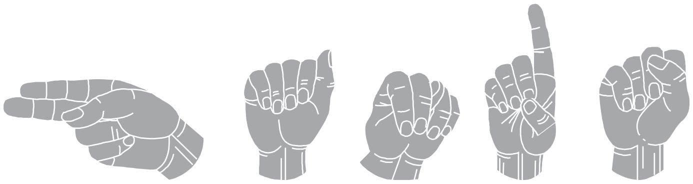
1. The earlier hearing loss is identified, the better a child's chances are for acquiring language whether it is spoken or signed language.

2. Interaction by holding, facing, smiling and responding to a child is important from the very beginning.

3. Each child is unique. Understanding the full nature of the child's hearing loss is important and how each family member or caregiver will communicate with a child is a personal choice.

4. Exploring communication options for a child is necessary. However, changes can be implemented at any time. Working with a variety of professionals is necessary to make communication option decisions.

5. Multiple hearing tests may be necessary to determine the child's degree and type of hearing loss. This information may be helpful in understanding what communication options will be most appropriate for your family. Information gathered from the tests will help determine whether a child would benefit from hearing aids, cochlear implants or other amplification options.



Communication Options:

Communication is the way a child receives and expresses language. It is essential that families and caregivers understand their child’s communication options early on so that language can be modeled and facilitated naturally, meaningfully, and abundantly. The way in which a child who is deaf or hard of hearing communicates is sometimes referred to as a “mode of communication”. For many children, a combination of different modes of communication will meet their unique communication needs.

A family’s communication choice is a personal decision that deserves respect and support, as parents and caregivers usually approach this decision with much thought and consideration. Factors that influence the decision making process may include: the communication mode of the family, cultural factors, age of the child when hearing loss is identified, access to amplification, anatomical factors, and cognitive factors. It is important to recognize that a child’s communication needs may change over time and for a number of reasons. Families should feel assured that making adjustments to communication choices is natural and normal.

Communication Options Include:

SPOKEN LANGUAGE:

- Auditory/Verbal: This approach focuses on listening (auditory) skill. Hearing aids, cochlear implants, or other hearing technologies are used to help the child hear spoken language. Signs are not used in this approach.

- Auditory/Oral: This approach emphasizes the teaching of spoken language through the use of hearing, speech and oral language development. Emphasis is on speech reading and visual cues from the face and body. While guestures may be used, signs are not used in this approach.

Parents and caregivers who have listening and spoken language goals for their child should know that stimulation of the auditory system is essential. Early and consistent use of appropriate amplification will be a critical factor in the child’s listening and spoken language development.

CUED SPEECH: This approach combines a system of simple hand cues made around the face to indicate the sounds of English spoken language. Since many spoken words look exactly alike on the mouth (e.g. pan, man), these cues allow the child to see the differences between them.

SIGN LANGUAGE: These approaches emphasize the child’s use of signs and fingerspelling to communicate their wants and needs. This may include American Sign Language, Signing Exact English, Pidgin Signed English, and Simultaneous Communication.

- American Sign Language (ASL): American Sign Language is a visual language, separate from English. It is a natural language with distinct grammar, syntax, and art forms. Information is conveyed through the use of handshapes, locations, movements, palm orientations, and non-manual grammatical signals (eyes, face, head and shoulders).

- Simultaneous Communication: When a person uses sign language and spoken English at the same time. When signs are an exact match to the spoken message this is referred to as Signed Exact English. When a person signs some of the words in a spoken message it is referred to as Pidgin Signed English.

TOTAL COMMUNICATION: This approach includes the use of all modes of communication (natural gestures, body language, speech, listening, sign language, auditory training, speech reading, and finger spelling). Today this term is not utilized as much and most use the term Simultaneous Communication (signing while talking).

7 Amplification Options

AMPLIFICATION OPTIONS MAY INCLUDE:

1. Hearing Aid:

A hearing aid can be appropriate for children with mild to profound hearing loss. It sits behind or on top of the ear and is connected to an earmold. The hearing aid has a microphone that picks up speech and environmental sounds, amplifies or increases speech sounds based on the child's hearing loss, and sends it through an earhook, the tubing of the earmold, and into the child's ear.

2. Osseointegrated Device:

The osseointegrated device is designed for individuals with conductive, mixed, or unilateral profound sensorineural hearing loss. The implant replaces the function of the outer and middle ear system. There are two parts: the surgically implanted post or magnet and the speech processor. The speech processor snaps on or magnetically connects to the internal component in the temporal bone. The speech processor has a microphone which picks up sound and delivers it to the inner ear via vibration of the bones in the skull. Young children may wear the speech processor on a headband.

3. Cochlear Implant:

A cochlear implant may be an option for children who have severe to profound sensorineural hearing loss and do not gain enough access to speech from hearing aids. The cochlear implant takes the place of the damaged part of the inner ear. It has two parts: the internal implant and the speech processor worn on or near the ear. The internal part is surgically implanted in the inner ear (cochlea). The speech processor is worn on the ear or body and connects with the internal device by a magnet. The sound picked up by the microphone is transmitted to the internal device. Unlike a hearing aid, the sound is coded electronically and sent to the internal device, which stimulates the hearing nerve.

4. FM Systems:

An FM system can be used in combination with amplification devices. Even with hearing aids, cochlear implants or osseointegrated devices in place, children can struggle to understand what is said when background noise is present. The FM system includes a microphone worn by the main speaker or teacher. The child has a receiver that connects to the amplification device. The sound collected is transmitted to the child, decreasing the effects that distance and noise have on speech understanding.

Technology is only the first step in developing language. It will be critical that early and appropriate therapy be provided to ensure each child develops language in order to communicate.

Sherri's Story

Even though I was a certified audiologist with training in Speech Pathology and Elementary Education working for the North Dakota School for the Deaf, was married to a Deaf man, and was actively involved with Deaf culture, the impact of learning that I had a child who was Deaf was still profound. Nothing prepared me for the journey of parenting a child who is Deaf.

When I heard the words "Matthew has a profound sensori-neural loss", my own hearing turned "off" instantly and I heard nothing further. I shed many tears like other parents, my dreams were "shattered", and I knew that my child was facing a much more difficult path than I had hoped for him. In my mind, I wondered if it would have been better not to know so much about Deafness and what would truly lie ahead.

Most parents who have children with hearing loss will tell you that their gut instinct told them that "something was not right with my child" and following months of doctor and audiology appointments, the validation of this new reality was finally faced—my son had progressive hearing loss--"Deafness".

I began practicing what I had been teaching to the families I had worked with from the Infant Program at the School for the Deaf. The reality of keeping hearing aids on a child all waking hours (when you were able to find them!), talking and talking more to provide stimulation and narration, and controlling the "listening" environment was my new mommy mission. Poster boards of "Who", "What", and "Where" inundated our home, accompanied by the labels and signs of all familiar objects, people, and places . Throughout all waking hours, my focus was on communication….listening, speaking, and signing. I even signed all conversation while I was on the phone, to ensure that if Matthew glanced in my direction, he would know what I was talking about on the phone—true access!!

I set out to prove that with appropriate accommodations and support, my child would read above the average fourth grade level expected for children with profound hearing loss. We created language stories as we cooked, planted flowers, folded laundry, and completed daily tasks. Structure was the new normal routine at our home, including a family calendar of all events, knowing what would happen today, tomorrow, and so on.

Looking back on the past twenty-three years, the educational process was truly a marathon, a feat I didn't think we would ever complete. There were many challenges and obstacles along the way; however, we endured and made it to the graduation FINISH LINE. Matthew accomplished things I could never have dreamed would come true—inclusion starting at the age of three, fully mainstreamed into public school by high school (with supports), Honor Roll all four years of high school, a member of the National Deaf Olympics West Basketball team, a college degree completed, and now independence---a full-time job in his field of study!!

As parents, we can all look back and wish we had done things differently, "I should have, could have, would have...". However, I know I was put in this role to experience first-hand what it was like to be a parent of a child who is considered to have a disability; but who has nothing but ABILITY.

As you begin your journey, here are a few pieces of advice from this mom:

*Ask lots of questions of other parents and professionals—educate yourself!
*Make choices that fit your family's needs-- no one knows your child like you do!!
*Know that you can revise any educational plan at any time, and don't be afraid to call a team meeting!
*Know that you made the best decisions at that time, and you can change your opinions at any time.
*Enjoy being the parent and not always the TEACHER! Let your child lead!
*Treat your child who is Deaf like your other children—keep your expectations clear and in check!
*COMMUNICATE….COMMUNICATE…and COMMUNICATE MORE!! Every experience is a learning opportunity!!

The motto from Hands & Voices should resonate in your head at all times: *"What works for your child is what makes the choice right!"*
Know that you are not alone on this path….there is unconditional love, hope, and much joy ahead! Enjoy each moment!
We celebrated Matthew's wedding in 2014 and he and his wife are expecting their first child.

Milestones

WHAT SHOULD MY CHILD BE ABLE TO DO?

Age	Speech/Language	Hearing
Birth to 3 Months	*Produces sounds such as fussing, crying, burping and cooing *Cries differently for different needs such as pain and hunger *Quiets and/or smiles when spoken to	*Startles or cries to loud sounds *Quiets or smiles to familiar voices *Increases or decreases sucking behavior in response to sound *Stops crying to listen
4 - 6 Months	*Vocalizes excitement and displeasure *Vocalizes 'ma' or 'mu' *Experiments/plays with sounds such as yells, gurgles, blows raspberries and bubbles	*Coos, gurgles and makes a variety of sounds *Looks toward loud voices or sounds *Enjoys rattles and toys that make sounds *Pays attention to music *Responds to changes in the tone of voice
7 - 12 Months	*Enjoys imitating sound sequences *Babbles 'bababa', 'mamama', 'dada' *Imitates sounds such as a cough or tongue clicking *Begins changing babbling to real words *Begins using more vowels such as: /ah, oo, ee, u/ and consonants such as /m, b, d, p/ *Uses one or two words such as "dada", "mama" and "hi" *Uses social gestures such as waving "bye-bye" and raising arms to be picked up *Gives objects upon verbal request	*Turns eyes/head/body and looks in the direction of soft and loud sounds *Listens when spoken to *Begins to imitate and repeat sounds such as "baba", "mama" and non-speech sounds such as blowing raspberries *Responds to name *Responds to simple requests *Looks at familiar objects when named *Understands "no-no" *Enjoys games such as "Peek-a-boo" and "Pat-a-cake"
12 - 18 Months	*Uses many different consonant sounds at the beginning of words such as /m, b, d, p, h, k, g/ *Tries to imitate simple words *Answers simple questions with gestures or words *Puts two words together such as "more book", "no mama", and "mama up" *Names objects upon request *By 18 months, uses 20-100 meaningful words; 50% of these words are nouns	*Readily turns toward all sounds *Shows interest in sounds on radio and television *Listens to simple stories, songs, and rhymes *Follows simple directions such as "Give me the ball."

Age	**Speech/Language**	**Hearing**
18 - 24 Months	*Uses /m, p, b, w, n, t, d/ correctly in the beginning of words and phrases *By 2 years of age is 50% intelligible *Begins to use “mine” *Uses one or two word questions such as “Where kitty?,” “Go bye-bye”, “What’s that?” *Asks for common foods by name *Names most common objects *Uses 200+ words	*Enjoys being read to *Understands when being called from another room *Remembers what was heard in the correct order such as “Put the baby in the bed and the bottle in the fridge.” *Follows conversation when the topic is known *Answers questions about a picture or book *Points to body parts or pictures in a book when asked *Understands simple verbs such as “eat” or “sleep” *Uses two-word combinations such as “more milk” *Begins to use pronouns such as “mine”
24 - 30 Months	*By 2 ½ years of age is 60% intelligible *Uses 3-word sentences frequently *Begins using verb endings such as “mommy walking” *Answers simple questions *Refers to self as “me” rather than by name	*Answers questions about a story *Understands “not now” *Understands many action words such as “run” and “jump” *Begins to use articles such as “the” and “a” *Knows spatial concepts such as “in”, “on”, “under” *Knows descriptive words such as “big”, “happy”, “sad” *Uses more pronouns such as “you”, “I”, “me” *Speaks in two and three word phrases *Uses question inflection to ask for something such as “My ball?” *Begins to use plurals such as “shoes” and “socks” and regular past tense verbs such as “jumped”
30 - 36 Months	*Repetitions which could be confused with stuttering such as “I-I-I” and “M-M-M-M” may occur *By 3 years of age is 80% intelligible *Speech is becoming more accurate but may still leave off ending sounds *Begins the “why” questions *Asks ‘wh’ questions such as “what’s that?” *Uses question inflection to ask for something such as “My ball?” *Begins to use plurals such as “shoes”, “socks” and “blocks”	*Engages in short dialogues *Has the ability to respond to questions such as “Tell me about your trip to Disneyland.” 

Ashden's Story

Our journey into the world of hearing loss began when our son Ashden was screened at birth and received a diagnosis of profound bilateral sensorineural hearing loss at about 3 months of age. Although it has been 9 years, the memory is still vivid. Nothing could have prepared us for the intense emotions that overwhelmed us. The weeks and months that proceeded "D-day" (Diagnosis Day) were some of the most challenging days for our family. Would Ashden ever hear our voices? Would we ever hear his? Would he feel disconnected to us in any way because he couldn't hear? Those were the questions that kept us awake many nights.

As Ashden's infancy unfolded, our concerns multiplied. He experienced delays across all aspects of his development. We had reason to believe that the hearing loss was not the only condition we would be dealing with. He began working with a physical therapist twice weekly at 3 months of age, in addition to weekly early intervention services. Occupational and speech therapy began at five months. It felt as if we had a revolving front door. There were days I grieved the loss of a "typical" infancy for him (and myself), but I felt reassurance knowing he was receiving the services he needed to facilitate his growth and development. Time was on our side. We assembled a team of professionals who specialized in hearing loss and developmental delays to provide knowledge, support, and guidance. Gradually, we came to terms with the new normal. Our confidence grew as we learned how to meet his needs.

We consulted with our audiologist regarding hearing technology and were informed that Ashden might be a candidate for a cochlear implant. We learned that cochlear implants (CIs) had the potential to provide good access to speech and sound, and that some children who are implanted at an early age, and receive quality auditory/oral programming, are able to develop age appropriate speech and spoken language skills. When Ashden was 6 months old, we toured a school that specialized in oral programming for deaf children. We observed toddlers and preschoolers learning how to talk, and having a lot of fun doing it! We felt hope! Our dream was to provide him with as much opportunity as we could- to make his world as big as possible. For our family, this meant choosing a cochlear implant so Ashden might have the opportunity to listen and speak. We knew the outcomes were varied, but we were committed to doing everything we could do to maximize his success.

While undergoing the evaluation for a cochlear implant, we learned of additional complications. Scans revealed that Ashden's internal ear structures were atypical. Surgery would be more difficult, and results may be less certain than the "typical" cochlear implant case. We decided to proceed with caution and adjust our expectations accordingly. Ashden received his first cochlear implant at 9 months of age. Activation day brought a mix of emotions. Ashden seemed to give us some indication that he could hear, yet computer measurements indicated almost no neural response. Despite our best efforts to prepare for the worst, we felt confused and devastated. Our audiologist explained that in some cases, neural responses improve over time. We didn't feel very optimistic, but we made a conscientious effort to choose hope. Ashden's neural responses improved gradually over a period of many months. From the moment his cochlear implant was turned on, we bathed him in speech and language. Under the guidance of therapists who specialized in auditory/oral education, we developed a lifestyle in which everyday activities became opportunities for listening and language. We continued with therapies across all aspects of his development.

Ashden's toddler and preschool years were characterized by persistent developmental delays, yet slow, steady progress in the areas of language, cognitive and physical development. Shortly before his third birthday he began to walk (finally!), received his second cochlear implant and was given a diagnosis of Autism Spectrum Disorder (ASD). The secondary diagnosis was not a surprise to us, as we had been observing features of autism in Ashden for many months. Learning that he had two conditions that would significantly impact his ability to communicate strengthened our resolve even more.

In order for Ashden to receive the intensive programming that we felt he needed, we enrolled him in a school that specialized in auditory/oral programming. We made the weekly trip together for nearly three years. It wasn't easy and we made significant sacrifices, but we got through it one week at a time. Ashden transitioned back into our public school district his kindergarten year with significant language support from an auditory/oral teacher of the deaf. He has developed many characteristics of complex language and has consistently exceeded our expectations! He is in second grade, and his academics are near grade level. However, he still receives a significant amount of language services from a teacher of the deaf. Due to the complex interaction between his hearing loss and autism diagnosis, it is difficult to discern the source of continued language delays. We know that his hearing is more compromised than the typically implanted child, and certainly his ASD presents unique social, learning, and language challenges. We have made peace with the fact that we will never fully understand all the answers, and we focus only on the fact that he continues to make steady gains. To us, Ashden's progress has been nothing short of a miracle!

We have a profound sense of gratitude for the specialists who have been a part of our lives since the earliest days, some of whom are still on Ashden's educational team. Our journey has been unique, as yours will be too, and the road hasn't always been smooth. Creating a support network with other families has played a critical role in gaining knowledge, maintaining our personal well-being, and in obtaining quality programming for our son. Please know that you are not alone on this journey, and other families are waiting to come alongside you and support you in whatever way is most helpful to your family. We have observed that options for families and services for children with hearing loss have improved nationally and across our state, and that has been an encouraging and exciting development! Organizations like North Dakota Hands & Voices are ready and willing to provide support and information to guide your family every step of the way.

NORTH DAKOTA HANDS & VOICES™

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Vision Statement
We envision a world where children who are deaf and hard of hearing have every opportunity to achieve their full potential.

Mission Statement
Hands & Voices is a parent driven organization that supports families with children who are Deaf or Hard of Hearing without a bias around communication modes or methodology.

North Dakota Hands & Voices is funded in part with grant money from the North Dakota Department of Health's Division of Children's Special Health Services.