



AFTER DIAGNOSIS

Section 3

Initial Decisions

Even though you may have suspected, finding out that your child is Deaf or Hard of Hearing can come as unexpected and/or unsettling news. Most parents of children who are Deaf/Hard of Hearing have no previous experience with hearing loss. What will it mean for you and your family?

In the days and weeks following the diagnosis, you may feel like you are on an emotional roller coaster. Your feelings may vary quickly and widely. As you carry out your daily routines - finishing a chore or driving to the grocery store - you may realize that your mind was somewhere else. You may also find within yourself unexpected sources of strength to do what has to be done.

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. And remember, research clearly shows that communication choices should not be solely based on the degree of hearing loss. The options and decisions facing any family are theirs alone to make, with information and support from professionals. There is no one "right" way to empower a child to succeed. His needs, as well as the needs of the family, will change with time. It is very important to see this all as a work in progress. Don't be afraid to remain open to new ideas, and even change your approach if necessary.

Adapted from:

[-Colorado Resource Guide, Colorado Hands & Voices, 2011](#)

Some important things to consider about making decisions include:

- Are you making the best decision you can at this time by investigating all the information available?
- Are you making a decision that works for your child and family's situation?
- Are you basing your decision on evidence and facts?

- Are you consulting with a variety of sources (for example, early interventionists, specialists, other parents, adults who are Deaf or Hard of Hearing, current research, community service providers, specialized program service providers, etc.)?
- Is this information complete, and as unbiased as possible? “Complete” means learning about all available options and trusting your family’s ability to make good decisions that work for your child. “Unbiased” means the information your family receives from others is not intended to convince you to choose one option over another, but rather to inform you of all the options and each option’s pros and cons.
- Answers to these questions vary from child to child and family to family. Discovering answers to the above questions usually involves:
 - Knowing where you are now (supported by results of various assessments of hearing and communication, as well as your observations).
 - Knowing where you want to go (your goals for your child) and how you are going to try to get there.
 - Regularly evaluating where you are along the way and measuring the development of abilities that show what is working (reassessment).
 - Making adjustments necessary to reach your goals.

There is no one universal method of intervention that works well with all infants and children who are Deaf or Hard of Hearing. Research shows that the most important factor in success is your active participation. The benefits of parent involvement include higher reading scores, higher grades on homework, improved attitudes towards school, and improved relationships between school and home. The Alberta Hands & Voices mantra is “whatever choice is right for your child makes it the right choice.” Educate yourself about your options, and stay involved in the journey. We are here to help you along the way.

Adapted from:

[-BC Family Hearing Resource Society](#)

[-The Ready Guide: Getting Started, Indiana EDHI Program](#)

Coping

There are many ways parents typically cope when they learn that their child is Deaf or Hard of Hearing. Adapting to a diagnosis of hearing loss is different for each family. Many stages in the process are common. Here are some of the feelings that a parent might experience:

- **Sadness:** "I spent the first two weeks crying, almost constantly."
- **Anger:** "My partner goes off to work for 10 hours. I wish I could escape too!"
- **Frustration:** "I feel as if no one really understands our situation."
- **Disappointment:** "My sister doesn't know how to help me."
- **Relief:** "I'm glad they were able to identify my baby's hearing loss early so that I can do something about it."
- **Guilt and Self-Reproach:** "I kept wondering what I did wrong to cause this."
- **Anxiety:** "I kept wondering and worrying if I was doing enough for him."
- **Comfort:** "I was pleased there were options and resources available to him."
- **Fatigue:** "All I wanted to do is sleep; I felt tired all the time."
- **Helplessness:** "I felt unable to do simple tasks."
- **Shock:** "I could hear what the audiologist was saying to me but I had no reaction. I felt as though I was standing outside my own body, uninvolved in the situation."
- **Yearning:** "I wished for a perfect child."
- **Hopeful:** "Our son is happy and healthy as he is. We have much to be thankful for."

Coming face-to-face with the reality of a diagnosis may look like:

- searching for a sign that the diagnosis is wrong or searching for a cure
- denying the facts or the significance/permanency of the diagnosis
- putting emotions aside while doing what needs to be done immediately
- feeling anger at professionals or others who bring the news of the diagnosis and force facing reality

Adjusting to a new reality may look like:

- wanting to talk with other parents of children who are Deaf or Hard of Hearing
- feelings of anxiety decreasing and a feeling of control over your life returning as you learn how you can help your child
- accepting your child as he is
- thinking of a child's diagnosis without pain (though some parents report they continue to experience sadness or longing from time to time, but it happens much less frequently)

Incomplete grieving can cause parents to get stuck in one part of the process and can stop them from moving forward in their lives. If you are experiencing some of the feelings described above, you may benefit from getting additional support. Many parents find it helpful to talk with other parents who have children who are Deaf or Hard of Hearing. You can contact Alberta Hands & Voices to help you connect to other parents. Other potential ways to get support are included in the next section of this toolkit.

Adapted from:

[-BC Family Hearing Resource Society](#)

Counselling Support

Organization	Contact	Description
Alberta Health Services: Mental Health and Wellness Services Province Wide	1.877.303.2642 Mental Health Help Line http://www.albertahealthservices.ca/amh.asp	Contact to get more information about mental health programs and services and referrals to other agencies if needed.
Catholic Family Services Calgary	403.233.2360 www.cfs-ab.org/	Focuses on providing affordable services (including counselling) to all families and individuals in need regardless of age, culture or faiths.
Catholic Social Services Edmonton; Lloydminster; Red Deer; Wainwright; Wetaskiwin	See website for contact numbers www.catholicsocialservices.ab.ca/	Many programs available for Central Alberta – including Children with Disabilities Family Support Program.
City of Edmonton Counselling Services	780.496.4777 http://www.edmonton.ca/programs_services/for_family_individuals/counselling-services.aspx	Provides short-term counselling and referrals if needed.
Counselling Centre Calgary; High River	403.691.5991 http://www.calgarycounselling.com	The Calgary Counselling Centre and High River Counselling Centre are charitable organizations committed to providing compassionate, professional and affordable counselling services.
Employee Assistance Programs	Contact your employer and/or insurance program	Many workplaces offer individual and family counselling to staff and their families. This may be at no charge or reimbursement may be available through your employee benefit/insurance program.

The above table is a short list of counselling resources available to you and your family, but it is by no means complete. Investigate other organizations, like your church, school, a private clinic or local YWCA. You may also want to ask other parents of children who are Deaf or Hard of Hearing or your family physician or audiologist for a referral/recommendation.

Services may be provided individually or in a group setting. Some programs are free and some charge on a 'sliding scale' that is income dependent. Be sure to ask about their fee structure before booking an appointment, as well as the title and qualifications of the counsellor (who may be a volunteer, social worker, psychologist or other type of therapist).

Counselling is similar to other rehabilitation processes in that it requires hard, thoughtful work. It can be difficult to ask for help and the period after the initial diagnosis can be a particularly emotional time. If you have any other questions or concerns, don't hesitate to contact Alberta Hands and Voices. **If you have an urgent Mental Health matter, contact the Mental Health Help Line at 1.877.303.2642 to receive immediate assistance.**



Now What?

Making it Through the First Year

Adapted from Krystyann Krywko, Ed.D.

Five years ago, I found myself standing in the same shoes that you are in today – after I found out that our son is Hard of Hearing. At the time, both my husband and I had typical hearing (I now wear hearing aids). Neither of us had any knowledge of raising a child who is Hard of Hearing, or contact with other families.

The first year after my son’s diagnosis went by in a blur. We had so much to learn. We also had to deal with our emotions as we made decisions about treatment and communication approaches. There was a sense of urgency because our son was three years old when he was diagnosed, which meant he had already missed so much exposure to language.

It was a year of trial and error. We met with specialists and therapists. We watched while our son was tested and observed. We learned new terminology and the jargon of raising a child who is Deaf/Hard of Hearing (DHH). We learned how to troubleshoot hearing aids at 7:00 a.m. We became experts at keeping hearing aids in the ear of an active three-year-old. We answered our first questions from curious parents and children on the playground who wanted to know what our son had in his ears. We continued to fill our son’s world with sound, language, and music.

I look at my son now and think about all those fears I had that never came true. My son has friends, loves sports, enjoys reading, and he is comfortable in his own skin. I think about all the lessons I have learned along the way and would like to share some of them with you as you start out on your own journey.

DO connect with other parents whose children are DHH. Alberta Hands & Voices can offer suggestions on how to meet other families in your area. If you live in an isolated part of the province, you can always join groups on Twitter,

Facebook, and LinkedIn that offer virtual networks of families who are raising children who are DHH.

DON'T change your parenting style. Try to keep things as normal as possible. Most of the changes in parenting will be centered on the additional responsibilities of having a child who is DHH, such as maintaining hearing equipment, scheduling appointments, advocating for your child's needs, and attending Individual Program Plan (IPP) meetings.

What won't change is the support your child will need. She needs to know that your relationship and her place in the family will remain the same. Give her extra hugs when she needs them, but don't fall into the trap of over-compensating by treating her differently. She should have just as many responsibilities and expectations as your other children.

DO keep an open mind when you receive information from professionals and other parents. When we were first told that my son should go to a special school for children who are DHH, we were resistant. We wanted him to attend our community school. But when we visited the school for children who are DHH, we were amazed at how it was set up. Now we couldn't imagine sending him anywhere else.

DON'T search the Internet obsessively. While it is important to gather additional information about your child's diagnosis, be careful not to go overboard. Whether you are reading about a new research finding or advice on a parent's blog, it is important to recognize that your child's DHH diagnosis is unique. Some unique variables include: her age when you discovered that she is Deaf or Hard of Hearing; the amount and nature of residual hearing; and her personality - whether she is engaged, curious, and active, or more shy and withdrawn.

Ask your audiologist for some reliable websites to start with. Alberta Hands & Voices will also point you in the right direction.

DO teach your child to self-advocate. This can start as soon as your child receives hearing aids/cochlear implants or starts to work with an educational interpreter in the classroom. Let her know it is important to tell a grown up if something is wrong with her hearing equipment. Practice at home by taking a battery out of one of her hearing aids before she puts it on. Give her a couple of minutes to see if she notices anything different. If not, say "Surprise! I took your battery out. Do you notice anything different about your right ear?"

Let her know that it is okay to ask someone to repeat if she doesn't understand. There will be times when the speaker is either talking too quietly or background noises are too overwhelming. Provide her with language she can use, such as saying, "Excuse me, can you please tell me that again," so that she can begin to feel comfortable asking others to repeat. If your child communicates in sign language, she will need to learn how to communicate with others who have typical hearing and no knowledge of sign.

These are just some of the lessons I have learned over the years of raising my son. If you are looking for more information please visit my website – www.kidswithhearingloss.org.



I am an award-winning education writer and researcher, specializing in hearing loss and how it affects children and families. Originally from Calgary, Alberta, I spent 15 years living in New York City where my husband and I started to raise our family. We recently left the hustle of the city behind, and now live in Westchester County, New York.

Emotional Sticking Points of Parenting a Child who is Deaf or Hard of Hearing

Adapted from Krystyann Krywko, Ed.D.

As a parent, it was emotionally overwhelming for me when I found out that my son was Hard of Hearing.

I am not alone - over 90 percent of children who are Deaf or Hard of Hearing (DHH) have parents with typical hearing. This means that very few families have first-hand experience. Also, most families don't have contact with other families in the same situation.

It may be tempting to ignore your feelings and put them aside. After all, your child's needs come first. Another common reaction is to feel overwhelmed and unsure of the next steps.

When parents' emotions are not addressed properly, they can become "sticking points" and it can be hard to move forward. Dr. Stanley Greenspan, author of *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*, believes that parents of children with special needs have the added responsibility of understanding themselves before they are able to help their child. He refers to this practice as "observing yourself."

Dr. Greenspan suggests that we all have ways of feeling and behaving that are automatic. These emotional responses are very much a part of who we are as parents. Emotional responses are learned from our own families, as a result of circumstances in our lives, and from the culture in which we live.

Below is a brief description of some emotional "sticking points."

Accepting the Diagnosis

The moment of diagnosis is often the most difficult sticking point. Even if you were the one who suspected that your child might be Deaf or Hard of Hearing, it can still be emotionally challenging. Your child's diagnosis might feel like a negative moment in your life, but it is actually a very positive step in moving towards finding her the help she needs.

Moving Forward with your Emotions

The tricky part during this stage is to work through your own emotions even as you move forward. You might have all sorts of pre-conceived ideas floating around in your head about a certain approach, or you might have negative feelings about the terms "special education" or "special needs." It is important to keep an open mind.

Practice Your Game Face

In the beginning, you might need to fake your excitement when your child puts her hearing aids or cochlear implant processors on in the morning. You might need to force yourself to smile as you answer a friend's questions about your daughter's diagnosis. Do whatever it takes so that your child views being Deaf or Hard of Hearing as a positive part of her life. The fact that she is Deaf or Hard of Hearing may be all you can think about at the beginning. As you grow and change, it will slowly begin to fade into the background. Don't worry; talking about it will become easier with time!

Find Help for Yourself

It's important to acknowledge where you are at the moment. This journey is a marathon, not a sprint. Do not think that you need to have everything figured out in the first week after a diagnosis, or even in the first year.

The experience of others can help. Other parents who have already entered this world can share their advice, expertise and can identify with the emotions that

you are dealing with. Alberta Hands & Voices offers a support network of parents and professionals. You can find the support that you need.

Whether you are just beginning your journey or if you have been on the road for a while, this was just a quick overview of emotional sticking points.

For a more detailed explanation of these sticking points, please visit my website at www.kidswithhearingloss.org and download your own copy of my free mini-ebook, *Five Emotional Sticking Points of Parenting a Child with Hearing Loss*.



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Fathers and Grief: Raising a Child with a Hearing Loss

Adapted from Krystyann Krywko, Ed.D.

This article explores how fathers deal with their emotions when they first find out their child has hearing loss. There are few studies that focus on grief and hearing loss, and most focus on the reactions of mothers.

So, in order to help me fill this knowledge gap I turned to friend and colleague Paolo Brusa, who lives in Italy. Paolo is married with two children, Alice (age 9) and Lorenzo (age 7). Lorenzo was diagnosed with hearing loss around the age of two. Despite the miles across the ocean, Paolo's story is very similar to mine and so many others who had children who were diagnosed late.

Paolo is a psychologist, and his wife is a Jungian psychotherapist, and what makes their story so interesting is that they are in the position to analyze what they are going through at the same time as they are living it.

Paolo, thank you for taking the time to speak with me about your son. It can be difficult to put into words the mix of emotions that are first felt after your child is diagnosed with hearing loss. Emotions at this time are often contradictory and come flooding in at strange moments. How did you respond when you first found out about your child's hearing loss?

Agreed. I experienced all kinds of emotions during this time. My reaction was very mixed, which is common. Over the course of a few days I experienced:

- **Sadness:** It was a grief for the deep awareness of how things would be difficult from this very moment onward. This grief was mainly for my son, but also for my daughter, my wife, and myself. There was an intense melancholy for all the possibilities that were radically shut down and disappeared in that very moment.

- **Clarity:** The diagnosis also provided clarity on what the problem was, and this was reassuring in a way. That moment of diagnosis gave birth to thousands of new questions. Will he be able to learn? To talk? What will the future hold? We had these questions because like so many parents we had no idea what having a child who couldn't hear would be like. We really were starting from ground zero at the very beginning.
- **Responsibility:** A deep sense of responsibility to my son, in order to be supportive and nurturing and trying to avoid the trap of becoming heavy and stuck. Also, a deep sense of responsibility to my wife, whose grief as a mother was profound. And, also to my daughter, because she needed all the love and attention and care as well, without any distractions.
- **Anger:** There was also anger and rage and hate too. For all the time that was lost because doctors were unable to see what was happening to my son.
- **Awareness:** There was also a weird feeling of awareness, a sort of mix between deep inner peace, knowledge, and realization. I knew deeply that it would be hard, that some possibilities were gone forever. My son's childhood would be different, and complex, and hard in some ways. There was nothing I could do about that. But at the same time I also deeply knew that the most important things in life are bound to the quality of the life we live. You are not what you are missing, or lacking; you are what you are.

Those are a lot of emotions to work through, but I remember myself going through similar reactions. Do you feel your experiences as a psychologist helped you at this point in the process?

Well, there was another thing that I knew. A couple of years ago I was working as a psychologist in charge of two projects funded by the European Union Commission. During those years, I worked with families of people who had severe disabilities. It became clear to me that an individual's destiny is something totally distinct from an individual's problem. So, I think this knowledge did help me adjust to what the future might bring.

So, based on your experiences as a psychologist, how do you think men process grief differently?

Once men let themselves process grief, I don't think there are that many differences. Really, the differences have to do more with a cultural stereotype meeting gender-related issues, and how men do or don't acknowledge their grief. This idea that men are so tough and strong and that they can't allow themselves to show things. It's important for men to learn to be a bit more sensible with their emotions. To educate themselves to look deep into themselves, not to fear emotions but to enjoy them, whatever they are, free of any judgements. And to really let their partners see and understand what they might be going through.

How can fathers begin to accept and work with the emotions they are feeling?

Generally speaking, by simply telling the truth: to themselves; to their wives and partners; to their children. In my work I always remind people that emotions are just emotions, and that instead of trying to work against them, we can learn how to cope with them. Plus, I believe that as you work with your emotions, this allows for the opening of new paths of acceptance and possibilities for everyone in the family. But, there has to be space for these new possibilities to arise; and if you are stuck in your emotions, that space won't be there.

That leads right into my next question. How can fathers become "unstuck" from the grief they are feeling?

Whenever a person is experiencing a situation of great difficulty, it is normal to want to retreat and to stay stuck in a place where you would feel more secure and confident. This of course implies a certain degree of other defenses, such as the denial of the situation.

Of course, some of the most common questions parents of a child with hearing loss have concern the possibility for the child to hear and communicate. In many cases, the child is at an age when they simply cannot "properly" communicate to reassure their parents.

I suggest men focus on their body and find ways to use it to establish the first direct contact with their child who is Deaf. One very easy example is when the father reads a fairy-tale or sings a lullaby, they can lie their child on their chest. They can then start to gently tell a story, or a sing the lullaby. Their child will naturally establish the contact, feel the vibrations from their father and get cuddled by these warming vibrations.

This happens to be the basis of any communication: passing something in one way or another from one to another. When men experience this way of communicating with their child they tend to discover how emotions are precious, together with their acceptance and enjoyment. They find themselves “unstuck,” and can embrace their child, their wife, and themselves too.

That's great. It's so important to establish that connection in any way you can. Do you have anything else you would like to share?

When the grief starts to storm out our perspectives, someone has to hold to the roots, to ingrain the tempest into a sense of possibility, which needs to settle down, so that adults can become effective parents.

This can be quite a challenge to accept that things happen, and that even in difficult situations, individuals can always work to transform their pain into grief, and onward into something that can be positive. Since, my wife and I found out our son was Deaf our lives changed, and we were somehow forced to re-direct it, and re-define it.

We rediscovered what is really important, what and where the real meaning of life stands, and how this has nothing to do with an ability or a disability, but with the openness one has in accepting his/her own life, and fully live all the arising emotions.

We re-designed our priorities, focusing on what it is important to be, more than on what it is important to have. To live a full life is the right of each human. This is valuable for me as a father, as a husband, and as a psychologist. It is valuable for my wife, and for my family. It is valuable for my daughter and for my son.

Accept the truth, and tell the truth, is quite an honest way to be. The acceptance of the wholeness of what life offers me is the best way I found to be open to my children.

For a more detailed explanation of how fathers deal with their grief, please visit my website at www.kidswithhearingloss.org.



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Parenting the Child who is Deaf or Hard of Hearing

All children need three types of inner resources in order to have emotional wellness:

- Good feelings about themselves and others.
- An understanding of right and wrong.
- A variety of resources for solving problems.

Strategies for Enhancing the Parent/Child Relationship

01. Be Predictable

Children thrive in a predictable environment. Routines and schedules carried out with consistency will provide stability and security. This is also true with parenting behaviour - consistent messages and consistent, reasonable consequences result in a child who trusts his parents. Consistency can be especially important for some children who have limited communication skills. Because of the increased potential for misunderstandings, structure is essential.

02. Communicate Clearly

To communicate clearly, consider the following:

- Make sure your words and actions are sending the same message.
- Young children need to have things spelled out for them - to teach an abstract concept like "sharing," use examples.
- If there is a communication challenge because of hearing loss, acknowledge the need to develop strategies to close the gap.

- Consider creating a 'quality control' test to make sure your message was understood as intended, including consequences. Have her repeat back what she understood.
- Role-play to teach productive, appropriate questioning techniques that will be essential at home, at school, and everywhere.
- Try to limit over-explaining. Use concise, simple language without going into extraneous details. For example: "When you are done cleaning your room, you can have a popsicle." versus "When you are done cleaning your room, and we need to have your room clean because we are having company for dad's work and we wouldn't want to be embarrassed, right? Then, you can have a popsicle."

03. Understand Behaviours

By being good observers, parents can gather information that will help them understand what a child's problem behaviour means. Parents may falsely assume that negative behaviour is due to a child's hearing loss. However, it is important to identify if the issue is due to normal growth/developmental stages (in other words, age appropriate) or a child's inability to hear or communicate.

Look for a pattern. What happens before the behaviour starts? When, where, and with whom does it occur? Is there a physical cause such as hunger or fatigue? Was the communication experience unsuccessful - resulting in frustration, anger and lashing out? Does he feel threatened, hurried or ignored? Is he seeking attention in an unappealing way? Is he having trouble expressing himself and projecting his negative energy in a physical way? Which is needed - punishment or a shoulder to cry on?

04. Acknowledge the Positives

It's easy to take for granted what we approve of, and hard to ignore what we don't like. This makes it easy to neglect opportunities to praise good behaviour and focus on bad behaviour. Let your child feel and see your approval. Turn 'no' statements into 'yes' statements, i.e. "I love how careful you're being with that

antique vase.” It is generally better to reward desirable behaviours than to use consequences on undesirable behaviours. It is also best, if possible, to provide the reward immediately after the desired behaviour has occurred.

Parents often feel uncomfortable when they hear the word “reward” and think it means rewarding only with material items such as toys or money. However, the easiest and most important way for you to reward your child is to provide positive attention to your child during or after he or she has completed the appropriate behaviour. You can acknowledge the desired behaviour (“I noticed you played quietly when I was busy with Dad,”), express appreciation or approval (“I like it when you put your dirty clothes in the basket,”), praise the behaviour (“Well done! Good job!”), or show interest in your child and her activities by describing the child’s behaviour or acknowledging the child’s feelings (“You cut up the carrots into little circles,” or “You like to put your shirt on like that”). Even something as easy as a smile or gentle touch from you will provide an instant reward to a child.

05. Set Up a Safe Environment

Children love to explore and thrive in tactile environments where things can be pulled on, climbed over, taken apart and put back together again. This isn’t being naughty - this is their nature. Make her environment safe. The more appropriate things available to explore, the fewer problems with inappropriate behaviour she will have. Consider how this applies to adolescents and even teenagers. A safe environment is one where the rules and limits are defined and understood. Can she have the car Friday night? Yes, if we know whom she’s with, where she’s going, and when she’ll be back.

06. Set Sensible Limits

Neither parents nor children want to live in a police-state atmosphere in which there are so many rules it’s impossible to avoid breaking them. Generally, very young children can remember only a few rules and a great deal of adult

supervision is required to enforce them. Make the language simple and direct, like: "Use words, No hitting."

The limits expand as the child grows older. Going outside established limits is an exercise in trust between parent and child. If your adolescent or teenager demonstrates responsible behaviour, he should be rewarded with certain privileges. If he demonstrates a lack of responsibility, the limits may need to be more tightly drawn and defined until trust is built again. Disciplining without feeling guilty is a major challenge, particularly for parents of children who are Deaf or Hard of Hearing. However, limit setting for children is essential to learn to adapt to the "real world."

07. Defuse Explosive Situations

Step in while your child is still calm enough to discuss a problem. Intervene before anger gets out of control. If certain situations are recipes for disaster, talk about them ahead of time and create some plans for coping and resolving. For children who are Deaf or Hard of Hearing, not being understood because of a communication gap can be a common occurrence, and one that lends itself to frustration and anger. Anticipate these kinds of circumstances. Often parents can help children avoid a meltdown by pointing out problem-solving alternatives that can be employed before the problem rises to a crisis state.

08. Teach Good Problem Solving Skills

There are good solutions to problems, and not-so-good solutions to problems. How do you get your child to know the difference? Start by clearly labeling unacceptable behaviour and explain why. Follow up with positive suggestions for what to do next time. For children under four, it's best to simply state what you want them to do next time. For older kids who can express themselves and think abstractly, ask them what they could do next time that would be better. Suggest additional alternatives. As kids get older and more mature, they'll be able to employ these tactics more successfully if they've been practicing them since childhood.

If the problem stems from communication gaps, which is often true for children with hearing loss, use the same strategies and exploit every opportunity to expand the child's language base around conflict resolution. Knowing how to express himself and state his position will increase your child's sense of empowerment to successfully solve problems.

09. Don't Threaten or Overreact

Too often, parents threaten, giving the warning of a consequence over and over again without enforcing it, making it ineffective. Giving lots of attention to problem behaviour can create another whole set of problems. Telling a child to go to a time-out place or removing her from the play area where she misbehaved delivers a consequence for bad behaviour without creating an attention-getting incentive to do it again.

10. Seek Professional Help when Needed

Most children grow out of common behavioural problems with the patient guidance of parents and other caring adults. For a small percentage, the problem behaviours persist and can become severe. Professional help is an excellent resource that can provide support and a constructive plan of action. See the *Counselling Support for Children and Families* section in this toolkit for available resources.

11. Be Patient and Realistic with Your Child and Yourself

Be realistic with your expectations – are they too high or too low? Continual evaluation of your expectations is needed to ensure they are appropriate. Misbehaviour happens. It's human nature to learn from our mistakes. A key to healthy psychological development lies in the child's ability to do just that. Self-awareness, self-care and stress management will result in better parenting. Your consistency, patience and love will provide him with the support needed to emerge into mature, autonomous adulthood.

12. Don't Neglect the Other Relationships in Your Life

The chances of raising a healthy and happy child are increased with healthy and happy role models for parents. Your other children, spouse/partner, siblings, parents, friends and other family members can be mainstays of support for both you and your child. However, your child will only see value in these relationships if you are engaged. You can refer to other articles in this toolkit, such as *Support for Siblings* and *Who Can Help? Finding Information and Support*, for materials on how to involve and relate to others. Parenting a child who is Deaf or Hard of Hearing can also put unique stressors on a marriage or partnerships. For more information on this topic, see [For Better or For Worse: Keeping Relationships Strong While Parenting Deaf and Hard of Hearing Children](#) on the [Hands and Voices](#) website.

Adapted from:

- [Allison Freeman, Seven Pitfalls in Parenting Your Child with Hearing Loss](#)
- [Kathy Eugster, Providing Structure for Your Child: How to Assert Your Parental Authority](#)
- [Thelma Harms, Wisconsin's Babies & Hearing: An Interactive Notebook for Families With a Young Child Who Is Deaf or Hard of Hearing](#)

Support for Siblings

There is no doubt about it. Having a child with special needs changes your family. It is often pointed out that most parents with children who are Deaf or Hard of Hearing have typical hearing themselves. What is usually not mentioned is that most children with special needs have typically developing brothers and sisters. Brothers and sisters are too important to ignore, for these reasons:

- Brothers and sisters will be in the lives of family members with special needs longer than anyone. Brothers and sisters will be there after parents are gone and special education services are a distant memory.
- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve. Even the most family-friendly providers often overlook brothers and sisters. Brothers and sisters are left in the waiting rooms of hospitals and clinics - literally and symbolically. True "family-centered" care and services should actively include siblings.

There is no doubt that having a child with a disability adds extra stress to parenting. It also adds extra stress to being a sibling. It is important to be aware of the stress involved and watch the siblings to make sure they are also being the best they can be.

The [Sibling Support Project](https://www.siblingsupport.org/) (<https://www.siblingsupport.org/>) facilitated a discussion on SibNet, the listserv for adult siblings of people with special needs, regarding the considerations that siblings want from parents, other family members, and service providers. Below are themes discussed by SibNet members and recommendations from the Sibling Support Project.

01. The Right to One's Own Life

The basic right of siblings to their *own* lives must always be remembered. Parents and service providers should not make assumptions about responsibilities typically developing siblings may assume without a frank and open discussion.

02. Acknowledging Siblings' Concerns

Like parents, brothers and sisters will experience a wide array of emotions regarding the impact of their sibling's special needs. Siblings may worry about how the child with hearing loss will manage in school. What is my responsibility? What about when playing board games? How many extra tries does he get? The answer should be that every child has the same number of chances – the child with hearing loss has to learn to play by the same rules as everyone else. But if he does not understand what he was supposed to do, the typical sibling should try and help him figure it out.

03. Expectations for Typically Developing Siblings

Some typically developing brothers and sisters react to their sibling's special needs by setting unrealistically high expectations for themselves - and some feel they must somehow compensate for their siblings' special needs.

Siblings should not feel they have to sacrifice for the child with hearing loss. It is tempting to tell a child with typical hearing how lucky he is. He did not choose this and should not be made to feel bad when he wants extra attention.

Sometimes siblings feel as if they cannot get their parents' attention, and they may wonder what they need to do to get parents to focus on them. They may question if they are allowed to feel jealous, angry, or annoyed at their sibling. They may feel they cannot ask for things they want or need because the child with hearing loss needs so much. Parents can help their typically-developing children by conveying clear expectations and unconditional support.

04. Expect Typical Behaviour From Typically Developing Siblings

Although difficult for parents to watch, teasing, name-calling, arguing and other forms of conflict are common among most brothers and sisters. Much of this conflict can be a beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights

will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. However, when conflict arises, the message sent to many brothers and sisters is, "Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise." Typically developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.

Siblings may feel irritated by questions such as: "Why does your brother speak so funny?" "What are those things he is wearing?" "What is wrong with him – is he retarded?" Such comments can be hurtful, and siblings need to know what to say in response. Consider roleplaying to practice the right behaviour. There is nothing wrong in telling someone the truth and educating that person about the child's hearing loss and what it takes to help them.

05. Expectations for the Family Member with Special Needs

Parents can help siblings now by helping their children who have special needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with special needs regarding chores and personal responsibility as they do for their typically developing children.

06. The Right to a Safe Environment

Some siblings live with brothers and sisters who have challenging behaviours. Other siblings assume responsibilities that go beyond their age level. This can place all parties involved in a vulnerable situation. Siblings deserve to have their own personal safety given as much importance as the family member who has special needs.

07. Opportunities to Meet Peers

The same common-sense support and validation that parents get from formal and informal Parent-to-Parent programs would allow brothers and sisters - like parents - to know that they are not alone with their unique joys and concerns.

08. Opportunities to Obtain Information

Throughout their lives, brothers and sisters have an ever-changing need for information about their sibling's special needs, treatment and implications. Parents and service providers have an obligation to proactively provide siblings with helpful information appropriate for their age and reading level.

Parents and professionals working with families need to talk directly and honestly with siblings. We need to explain what hearing loss is, at the level the child understands, and answer questions honestly. Teach the sibling how to monitor technology and let them help. Try and explain why it is necessary for the child with hearing loss to use technology and why he needs to go to therapy. A sibling may be a good communication partner and may be able to assist in therapy. Since parents should be part of the therapy session, therapy time is not a good time for the parent to spend with the sibling alone, but the sibling could attend therapy and be part of a communication triad. Not every sibling will be good at this but many will.

09. Sibling's Concerns about the Future

Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. When brothers and sisters are "brought into the loop" and given the message early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. This includes having a say in whether and how they will be involved in the lives of their siblings who have special needs as adults, and the level, type, and duration of involvement.

10. Including Both Sons and Daughters

Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings - including brothers - should be considered.

11. Communication

While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. Books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and

Siblings Without Rivalry (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

12. One-on-One Time with Parents

Siblings may feel that they are not getting their fair share of parent time. They are right; it is not fair. However, it is something that cannot be avoided. It is probably impossible to find equal time for each child, but each child in the family should have special time – time they can spend with parents doing something they want to do.

13. Celebrate Every Child's Achievements and Milestones

Over the years, the Sibling Project has heard from siblings whose parents did not attend their high school graduation - even when their children were valedictorians - because the parents were unable to leave their child with special needs. More than one sibling has had wedding plans that were dictated by the needs of their sibling who had a special need. One child's special needs should not overshadow another's achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

14. Parents' Perspective is More Important than the Actual Special Need

Parents would be wise to remember that their interpretation of their child's special needs will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviours for their typically developing children.

15. Include Siblings in the Definition of "Family"

Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has special needs - the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, providers can claim to offer "family-centered" instead of "parent-centered" services.

16. Actively Reach Out to Brothers and Sisters

Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, education, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of all family members, seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues. For more information, see their website at <https://www.siblingsupport.org/>.

Adapted From:

- [Hearing Health and Technology Matters, Providing Support to Siblings of Children with Hearing Loss](#)
- [Professional Audiological Services, Helping Siblings Adjust to Hearing Loss](#)
- [Wisconsin's Babies & Hearing: An Interactive Notebook for Families With a Young Child Who Is Deaf or Hard of Hearing](#)

Additional Resources

Hands & Voices: Communication Considerations A-Z: Siblings

<http://www.handsandvoices.org/comcon/articles/pdfs/siblings.pdf>

NCHAM E-book: A Resource Guide for Early Hearing Detection and Intervention: Chapter 20: Secrets for Deaf and Hearing Sibling Success: Giving Them an Early Start for a Lifetime Together

http://www.infantheating.org/ehdi-ebook/2015_ebook/20-Chapter20Secrets2015.pdf

Ten Ways to Give Attention to a Sibling of a Child with Special Needs

<http://www.friendshipcircle.org/blog/2013/11/04/10-ways-to-give-attention-to-a-sibling-of-a-child-with-special-needs/>