

# Chapter 14

## Family Support & Cultural Competence

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This chapter will address some of the factors that contribute to a family's positive experience in the early days of discovering that they have a child who is deaf or hard of hearing.

The “1-3-6” model in Early Hearing Detection and Intervention (EHDI) systems was established to give timelines and structure to the screening (by 1 month), identification (by 3 months), and entrance into early intervention (by 6 months) for children who are deaf or hard of hearing. Within the model is a process in which families must navigate between medical institutions, government and private agencies, their own family construct and community, and other variables to successfully begin the journey of raising a child who has a hearing loss.

“Family Support” is often the term used to define the practices that ensure the holistic nature of the process for families is sustained through the timelines and varying entities that the family encounters. The definition for an individual family of what has supported them through the process is unique to each family. The distinctive nature of families—configuration, cultural considerations, beliefs, values, emotional reactions, coping styles, family dynamics, and other issues—play a role in how effectively a family will be able to navigate the system and help define which sorts of support will be most beneficial to that family.

Family support should come from a wide variety of sources and can be categorized as coming from five distinct areas:

- Professionals.
- Other families who have children who are deaf or hard of hearing.
- Deaf and hard-of-hearing adults.
- Information and resources.
- Existing communities surrounding a family before a child is diagnosed.

Cultural considerations can and should be incorporated into all of these areas for families. This chapter will address some of the factors that contribute to a family's positive experience in the early days of discovering that they have a child who is deaf or hard of hearing. Families must quickly learn new skills; adapt to a changing perception of what they thought their parenting would encompass and/or who their child would be; and be able to successfully make important medical, communication, and other decisions. Most families have little or no familiarity with—indeed most have never even seen—a deaf or hard-of-hearing child.

## Deafness Is Different

Families require different types of support based on their unique needs. They also need specialized forms of support because of the “disability” itself. It is commonly recognized that over 90% of children who are born with hearing loss have hearing parents. Due to the fact that there are different perspectives on the experience—from deafness being a “medical condition” to a “culture and community”—new families need a variety of perspectives from different viewpoints to come to a conclusion about their own personal perception of their child’s condition. The continuum of perspective is not an either/or experience for many families. They may choose to seek medical intervention for their child, while at the same time begin to explore the social, educational, and cultural implications of the population that their child is now a part of. The quality and quantity of information a family needs to form their own sense of what this experience means for them and their child comes from a variety of sources. The cultural identity and belief system of a family influences and gives meaning to this process.

## Professionals Supporting Families

EHDI begins, for most families, in a “medical model.” Typically, an infant is screened in a hospital by medical staff and then sent for rescreening and diagnostics to medical professionals (audiologists, physicians, ENTs, etc.). Other professionals begin to encircle the family: speech-language pathologists, early interventionists, teachers of the deaf, service and care coordinators—a dizzying array of professionals all with different areas of expertise, education, knowledge, and perception of what the family needs. Professionals differ in their own understanding and viewpoint of what the meaning of deafness is—a medical condition to be cured and/or a culture or experience to be embraced and celebrated.

Often, professionals assigned to a family’s “case” may have little experience with hearing loss. Families must not only process information but sift through varying opinions and recommendations from professionals that may be steeped in one viewpoint or another.

Families feel supported by professionals when they perceive the relationship to be a collaborative partnership built on trust (Stonestreet et al., 1991). This process takes time and involves many things, including mutual respect, honest and clear communication, understanding, and empathy. Professionals who develop active listening skills help to create positive connections with families. Professionals are reported to be a huge source of support for families when this occurs (Jackson, 2009). An example of this is the competent, medically trained, technologically savvy audiologist who knows how to deliver hard news to a family in an empathetic and caring way. Families value an audiologist who knows how to explain medical and technological options, while at the same time honoring the realization that parents are the ultimate decision-makers for their child. This delicate balance can be a challenge for professionals who are trained in the “craft” of service provision, but usually not given explicit training in the more esoteric art of “family support.” Professionals who have the ability to incorporate dynamic family support and direct service provision congruently create a structure for success.

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## Family Support within the Medical Home Model

The support that families receive from the professionals in their lives includes support from the Medical Home Model. The American Academy of Pediatrics describes the medical home as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. A medical home combines location, the course of action, and people who serve a family.

It is imperative that physicians have a basic working knowledge of the EHDI process for families, so that they can be a partner with families in linking them to the resources specific to deafness and hearing loss. Physicians play an important role with families in ensuring that follow-up rescreening and diagnostics have occurred. Because deafness is a low-incidence disability, physicians generally do not have the necessary expertise to assist in the complex communication and educational choices that families need to make. The physician's role as a supporter to families, particularly in meeting the timelines of the 1-3-6 model, is extremely important.

support as one of the strongest measures of family support (Jackson, 2009). There is something incredibly unique and important in receiving support from other parents and families who have children that are deaf or hard of hearing and have "been there." There is a sense of an equitable relationship between the experienced parent and the referred parent (Ainbinder et al., 1998). Because of the low incidence of hearing loss, families of children who are deaf or hard of hearing often feel isolated from each other and do not typically have support opportunities in their already-established community. Meaningful parent-to-parent or family-to-family contact includes the following:

- A way to share information.
- A safe place to brainstorm and express feelings.
- A place to validate feelings.
- An increased sense of confidence and empowerment.
- An increased acceptance of the situation and hope for the future.
- An increased capacity to cope.
- A means of learning practical parenting skills.

### A parent speaks out about the professionals that served them ...

"What really pulled our family through our son's initial diagnosis was the amazingly dedicated individuals in our early intervention system and medical profession that greeted us with smiles, information, and encouragement. An audiologist who so kindly greeted us and embraced our child and then walked us through the process of what we could do for our deaf child; a service coordinator and therapist who not only 'worked' with our child but listened to us and our needs. Finally, a team of individuals following the standards and regulations set by the law who empowered us to do for our child and our family what we were so afraid we would never be able to do."

*—A parent from Georgia*

## Other Parents of Children Who Are Deaf or Hard of Hearing Supporting Families

The family is the social context into which children who are deaf or hard of hearing are born. The impact of a child's hearing loss affects not only the child, but the parents, siblings, extended family, and community as well. When this experience "happens" to a family, everyone is impacted. No one quite understands this as well as other families who also have a child who is deaf or hard of hearing. On reflection of the early intervention years, families rank parent-to-parent

Whether parents/family members have the opportunity to speak one-on-one, chat online, or attend support groups or other activities, communicating with other parents and families is a valuable component of the circle of support. National organizations, such as [Hands & Voices<sup>1</sup>](#) (and the Hands & Voices Guide by Your Side Program), [Alexander Graham Bell Association<sup>2</sup>](#), [Family Voices<sup>3</sup>](#), and [American Society for Deaf Children<sup>4</sup>](#) have models for providing parent-to-parent support. Support models range from formalized programs—where trained parents embedded in the system provide systematic, knowledgeable support—to the informal matching of families in a given community by professionals who know other families with a similar story. The most successful models of parent-to-parent support are programs that are parent-led and driven.

## An experienced parent speaks out about meeting a new family . . .

"Recently, I visited with a young family with a 2-month-old daughter. This is their first child, and she is severe-to-profoundly deaf, as far as they can tell. She is currently fitted with hearing aids, and the family is leaning toward cochlear implants. The mother's main fear is that her child will be teased. I remember this exactly as my first fear as well. The mother and I clicked at that very moment, because when I told her, 'I felt that exact same way,' a smile appeared on her face that hadn't been there for the first 20 minutes of the meeting. This encapsulated our remaining hour and a half. The father is a doctor, and although he knows medicine, he is new to the fears of parenthood and the realization that the child he holds isn't the one he expected. They were starved for information, both technical and emotional. I encouraged them that the decisions they are making are theirs. This family is scared—scared of the unknown. Their child is the center of their universe. They were so excited to be talking to someone who has walked the path they are embarking on. They were so sweet at the end when I said, 'When can we meet again,' their words were, 'We don't want to impose.' 'Impose? You are in no way imposing on me. This is part of the journey that my daughter has brought me to!' Thankfully, I was trained successfully and felt confident in providing support. I truly believe that this family deserves the same advantage of creating their own path that I did."

*—A trained parent from the H&V IL GBYS Program*

## Adults Who Are Deaf or Hard of Hearing Supporting Families

There are many valuable insights that a role model or mentor who is deaf or hard of hearing can bring to a family.

Many parents ask the question, "What does the future hold for my child who is deaf or hard of hearing?" Most children who are born deaf or hard of hearing are born to hearing parents. Families have a varying degree of previous exposure to and experience with deaf or hard-of-hearing individuals prior to having their own child. The opportunity for families to create a relationship with someone who has had the actual life experience of being deaf or hard of hearing typically cannot be provided by anyone in a family's network. As one family succinctly put it, "My own deaf child was the first deaf person I had ever met." There are many valuable insights that a role model or mentor who is deaf or hard of hearing can bring to a family, including:

- Sharing the day-to-day realities of living with hearing loss.

- Successful models of career paths and educational experiences.
- Real-life challenges that must be overcome.
- Renewal of hope for their child living a full and successful life as a deaf or hard-of-hearing individual.
- Helping a family create a perspective of decision-making based on their child's needs not a hearing person's desires.

Families can become enmeshed in therapies, learning new information, and dealing with the unknown of raising a child who is different than they are. Having a deaf or hard-of-hearing role model in their lives helps to ground them in the "here and now," while at the same time giving some structure and better perspective about the future. Families often like to be matched with 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. 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 deaf person can achieve success, regardless of the communication method or modality used. Some states have formalized deaf or hard-of-hearing role model programs, such as SKI-HI<sup>5</sup> in Utah and the [Deaf or Hard-of-Hearing Connections Program](#)<sup>6</sup> in Colorado. The [Hands & Voices Guide by Your Side Program](#)<sup>7</sup> features a program element for trained deaf or hard-of-hearing adult role models being utilized by some of the programs. Some programs also use deaf or hard-of-hearing adults as sign language instructors or facilitators.

Do deaf and hard-of-hearing adults who grew up a generation ago and may have had different life experiences and opportunities than the children of today still have something to contribute to contemporary families? Some things may have changed, yet many aspects of the journey remain the same and make this model of support still relevant and appropriate. Some of the challenges that remain the same include:

- Growing up in a family as the only deaf or hard-of-hearing child.
- 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?”

#### A parent speaks out about support from a deaf adult . . .

“When we first received our son’s diagnosis, I looked at the doctor; he was hearing . . . I looked at the audiologist; she was hearing . . . And as we walked out, I looked back at the receptionist, and she was hearing. I had no idea what this (raising a deaf child) would look like until you (deaf adult) walked in the door.”

—A parent from Colorado

## Information and Resources Available to Provide Support to Families

Providing support in an *unbiased* manner has almost become a cliché when discussing provision of information to families. Perhaps the most important aspect of providing family support is the attitude and intent of the information supplied by a person in a supportive role. Providing information in an objective and comprehensive manner creates the opportunity for families to make informed decisions based on their own established priorities and beliefs. Influencing families towards decisions that someone else wants or believes is best for the child may, in the short-term, not be tremendously difficult. In the long-term, taking away parents’ investment in decision-making creates gaps of follow-through by the family, a lack of ownership in the process, and ultimately a lack of success for the child.

When supporting families, professionals, other parents, deaf and hard-of-hearing adults, and others are often faced with the dilemma of how much information to give a family and at what point in the process. Every family is unique, and while some families feel overwhelmed and burdened with the amount of initial information they are given, others report that they were not given enough information. Giving families information and resources in a timely manner means that a family has access to resources and information when *they* are ready for it, not when a system decides it should be given. It is best to follow a family’s lead in determining when and how much information to provide. Giving families the power to take information or leave it, rather than “gate keeping” certain information, gives ownership of the process to families. Referring back to information given and the repetition of key concepts in a variety of ways is critical to a family’s growing understanding of all aspects of hearing loss.

Families are not the same as they were 10 or 15 years ago. Today's families are busier and more complex. Access to information has also been completely transformed by the Internet and other media. Support to families across the spectrum—from professional support through telemedicine to parent-to-parent and deaf or hard-of-hearing adult support via blogs and listservs—has increased the opportunity for families to gain access to information and resources, including research on the topic of deafness. This brave new world brings many advantages, but at the same time can lead to confusion for families. Inaccurate, incomplete, or misleading information is readily available. Knowledgeable professionals or parents must provide guidance to help families meaningfully process all this information.

In one recent article (Jackson, 2009), families report that parent-to-parent support is the most beneficial avenue for processing the information they are receiving. For families just starting out, most states have comprehensive resource guides and other helpful information. Some parents still report that basic information was not delivered to them when they needed it. It is the responsibility of everyone involved in the EHDI system to ensure that families have access to accurate, timely, and relevant information.

#### A parent speaks out about the information and resources that were provided . . .

“There are so many resources available here. I am very impressed with the parent support group. It provided us with vital information. EHDI was there to help us obtain the knowledge we so desperately wanted and needed to help us sort through all that information and assist us in getting early intervention started. Getting access to good information and resources is what allowed us to move through the system fast and get to services quickly. We don’t want to think about how differently things would have turned out if it weren’t for that support.”

—A parent from Wyoming

## Existing Communities Supporting Families

Families do not come to the EHDI system as a blank slate. They arrive with pre-existing communities that have provided them a support system (i.e., extended family, religious organizations, community resources, neighborhoods, friends, and others). Unfortunately, those communities may have contributed to dysfunction and challenges as well. Communities continue to exist and be important to families. Families are often put in the immediate position as the “authority” on the experience when they are relating information back to these communities.

While support to parents in the early days is often seen as an essential component to the process, little thought is given to the fact that these parents must often be the conduit of information back to their pre-existing communities. Several simple solutions exist to help families provide information back to their own community, including providing multiple copies of resources they can share, professionals inviting extended family members to join in during direct service provision, parent groups connecting grandparents with other grandparents, and more.

For families, some of these pre-existing supports remain the same, and sometimes they change. For example, a mother may expect to gain parenting wisdom from her own mother and sisters or close friends. While some of the parenting paradigms remain the same when one has a child who is deaf, there are many unique considerations that parents may need to learn from one of their “new” community supports (i.e., the early interventionist or other parents of deaf or hard-of-hearing kids). Families come to terms with the diagnosis of hearing loss in their child through the spiritual context of their lives, and the “new” support systems must be sensitive and respectful of this process.

**A parent speaks out about existing communities ...**

"I don't know what I would have done without our extended family. Everyone stepped up to the plate and took this situation in our family as a challenge to learn how to communicate with our son. My mom was my lifeline, and though she felt this experience two-fold—as a mom and as a grandmother—she kept encouraging me and telling me I could do this."

*—A young, single, Spanish-speaking mom*

## Cultural Considerations and Competence

Cultural knowledge and understanding are important aspects to developing family support services for families who have children who are deaf and hard of hearing. An example of this is a reflection of culture provided by a trained parent in the [Hands & Voices Guide by Your Side Family Support Program](#). "There are three common cultural characteristics among Latinos that are very important:

1. Respeto = Respect
2. Confianza = Trust
3. Personalismo = Personalism

These three characteristics are of utmost importance when trying to connect with Latino families. When these cultural characteristics are disregarded, Latinos will most likely withdraw" (Ponce de Leon, 2007).

The [National Center for Cultural Competence](#)<sup>8</sup> (NCCC) recommends that organizations:

- Have a defined set of values and principles and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally. Have the capacity to:
  - Value diversity.
  - Conduct self-assessment.
  - Manage the dynamics of difference.
  - Acquire and institutionalize cultural knowledge.
  - Adapt to diversity and the cultural contexts of the communities they serve.
- Incorporate the above in all aspects of policy-making, administration, practice, service delivery, and involve systematically consumers, key stakeholders, and communities.

Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge, and skills along the cultural competence continuum (adapted from Cross et al., 1989).

The NCCC promotes the understanding that cultural and linguistic competence is integrally linked to quality of care—you can't have one without the other. Cultural considerations should not be "add-ons" to a system such as EHDI, but should be woven in the fabric of each state program based on its unique cultural needs. The stakeholders for each state should be a community of learners regarding cultural competency, whether it is the professionals that are serving families or experienced parents providing parent-to-parent support. Information and resources must be readily accessible and sensitive to the culture of each family.

**A parent speaks out about family support and cultural considerations ...**

"I have personally seen how positive support to families can make a difference. I have met families that were completely lost about their child's hearing loss and felt they were alone. I met a family that hardly ever took their deaf child out in public, due to the embarrassment that their child was not perfect. There is a limited acceptance of deafness in the Latino community. In Mexico, the deaf are not normally educated. I believe that cultural behavior needs to be 'translated,' and more emphasis needs to be placed on family, trust, respect, and personalism. After providing support and information to these families, they 'blossomed' and became active advocates for their children."

*—A Spanish-speaking parent guide*

## Working with Challenging and Under-involved Families

What is a “challenging” family? There are some basic characteristics of families that lead to successful outcomes for children who are deaf or hard of hearing. These include:

- Successfully dealing with the decisions regarding communication, language development, and technology in the context of the needs of the family and child.
- Having emotionally healthy attitudes regarding the acceptance of their child’s hearing loss and the ability to move forward.
- Surrounding themselves with appropriate information, services, and resources in order to receive the help needed to find success.

Service providers can become frustrated when working with a family who does not seem to be engaged and/or making progress in these areas. Terms like challenging, under-involved, and out of compliance are often used to describe these families.

Other definitions for these words include ...

- **Challenging:** Demanding, taxing, testing, difficult, tough, exigent, not easy, tricky.
- **Under-involved:** Under-concerned, no follow-through, apathetic, lazy, bored, indifferent.
- **Out of compliance:** Opposite of compliance (obedience, conformity, submission, acquiescence).

The following comments tend to reflect the experience from the practitioners’ point of view. The professional who has the ability to think about what is happening from the family’s point of view may begin to change their own attitudes and therefore utilize tools and techniques that can help a family make progress.

Often-heard comments about challenging families from the practitioners’ point of view ...

- “They are not complying with treatment recommendations.”
- “They don’t show up for appointments, and/or they are always late.”
- “Those parents are ‘deadbeat parents.’”
- “They don’t even bring in the equipment to the appointment.”
- “The family isn’t following through on their own choices” (regarding signing, technology, therapy, etc.).
- “They ask too many questions.” “They don’t ask any questions.”
- “They show too much emotion.” “They show no emotion.”
- “Those kids/families (referring to identifiable demographics) just don’t do as well.”
- “The family is questioning my expertise.”

Another way to think about families who challenge professionals who are serving them may include the following reflections:

Professionals’ reflections on challenging families ...

- “A parent who doesn’t think like I do.”
- “They don’t learn the way I teach.”
- “What they need is not what I have.”
- “They have more on their plate than just dealing with a deaf or hard-of-hearing child.”
- “The challenging behavior may have a root cause that we can address, if I take the time to find out” (i.e., emotional, cultural, past experiences).
- “Maybe just for today, the family is going to cope in the best way possible.”

Professionals who have successfully explored their own personal attitudes, assumptions, and preconceived ideas of families can then help a family who is struggling begin to succeed. The application of a positive attitude towards families also further enhances the relationship with families who are already on track.

Occasionally, service providers encounter families who have been offered and encouraged to enter into a relationship of partnership and are faced with a cultural mindset of deference to authority. This can lead to an assumption that it is impossible for families from these cultures to have an effective collaborative relationship with the professionals in their lives. Can and should families from this reference point still be encouraged to take on the role of an “equal partner?”

This idea can be explored through an example from the book *Outliers* (Gladwell, 2008). The chapter entitled, “The Ethnic Theory of Plane Crashes,” creates a correlation that may be useful in this exploration of thought. Over a 20-year period, there was an airline that had the worst aviation record in the world—though they had good airplanes and qualified and well-trained pilots. When investigators went back and looked through the records, it began to emerge that this airline was based in a country where deference to authority was a “high value” within that culture. In the cockpit in a relationship where a pilot and co-pilot are flying a plane, the co-pilot must be able to take over if the pilot is making mistakes. “The whole flight-deck design is intended to be operated by two people, and that operation works best when you have one person checking the other—or both people willing to participate” (Gladwell, 2008).

Information began to emerge that the co-pilot often hesitated to “take over” when needed, due to his inability to override the authority in the cockpit—the pilot. The co-pilot’s cultural propensity towards deference to authority—in this

particular situation—did not work. In one instance, when investigators listened to the dialogue from the black box between the pilot and co-pilot in critical moments prior to crashing, this deference was noted by the inability of the co-pilot to speak his mind about what he knew. As he began to piece together the fact that the plane was on a clear path towards flying directly into a mountain, the co-pilot said, “The radar has really helped us in the past,” as opposed to, “We are going to crash if you don’t pull up . . . NOW!”

Rather than living with the status quo of the mindset that existed in this culture, trainers were brought in. The trainers didn’t come in and try to dismiss or devalue the cultural value of deference to authority, but they understood that this situation must change. They retrained the pilots and co-pilots in the proper roles that must exist inside the cockpit. That airline turned around and to this day has one of the best safety records in the airline industry. The lesson for professionals and parents is that inside the relationship for getting to success with children who are deaf or hard of hearing, deference to authority can be respected; yet parents can be supported in the much-needed ability to work as equal partners with the professionals that serve them. Families must have a safe place to talk openly and honestly with professionals.

A family's life is changed from the moment they receive the news that their child has a hearing loss.

A family's life is changed from the moment they receive the news that their child has a hearing loss. A family's level of involvement is influenced by many factors. Most families are doing the best they can at any given moment. Families are not static. A family that is considered “challenging” and “under-involved” can move from that place to a more productive position of active involvement when surrounded by professionals and other parents who have positive attitudes and tools to help that family make progress and ensure that successful outcomes for children who are deaf and hard of hearing can be achieved!



## The Outcomes of a Supported Family

A well-adjusted, successful child who is deaf or hard of hearing is the product of a well-adjusted, successfully supported

### A parent speaks out about a successful journey ...

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

*—A parent of a grown deaf child*

family. The definition of success is for each family to decide, but access to competent language and communication, both receptively and expressively, a good education, a sense of well-being, hope for the future, and ownership of decisions families make must surely be aspects to "success" that the system for early identification of hearing loss seeks. The complexity of the process for families leads to an understanding that there must be multiple layers of support that envelop a family on their path to success. A respectful and collaborative approach from all stakeholders in the system and an understanding of the important role that each one plays contributes to the degree a family may feel supported as they begin the long and arduous journey of raising their child who is deaf or hard of hearing.

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- <sup>1</sup> [www.handsandvoices.org](http://www.handsandvoices.org)
- <sup>2</sup> [www.agbell.org](http://www.agbell.org)
- <sup>3</sup> [www.familyvoices.org](http://www.familyvoices.org)
- <sup>4</sup> [www.deafchildren.org](http://www.deafchildren.org)
- <sup>5</sup> <http://www.skihi.org/home.html>
- <sup>6</sup> [www.csdb.org](http://www.csdb.org)
- <sup>7</sup> <http://www.handsandvoices.org/gbys/index.htm>
- <sup>8</sup> <http://www11.georgetown.edu/research/gucchd/NCCC/foundations/frameworks.html>

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