

Chapter 20

Secrets for Deaf and Hearing Sibling Success: Giving Them an Early Start for a Lifetime Together

The Jacobs Sisters • Lisa Jacobs, MEd; & Sheila Jacobs, LMFT

An Introduction

We want to share our success as deaf and hearing siblings with two primary audiences: hearing families who may have never encountered deaf people until their own child is diagnosed as deaf or hard of hearing (D/HH) as well as the EHDI providers serving those families.

“Our Deaf and Hearing Sisterhood”

The Jacobs sisters proudly pose with their handmade ILY hand sculpture, which they made using both of their actual hands together!



Photos courtesy of Chris Funchess

NOTE: The term deaf or hard of hearing (D/HH) is intended to be inclusive of all children with congenital and acquired hearing loss, unilateral and bilateral hearing loss, all degrees of hearing loss from minimal to profound, and all types of hearing loss (sensorineural, auditory neuropathy spectrum disorder, permanent conductive, and mixed.

Deaf and hearing adults who grew up in both the Deaf and hearing worlds can be mirrors in which young Deaf children and their hearing siblings can see themselves.

The identification of a baby as D/HH can be difficult if a new parent has never lived with deaf people or knows that a vibrant Deaf community exists. It's crucial that new parents have access to the many communication opportunities available for their family and are offered a glimpse of the unlimited opportunities open to their D/HH babies as they become kindergartners, teenagers, and successful adults with careers, families, and children of their own.

In our own relationship, we have navigated a complexity of societal and attitudinal barriers day in and day out, over breakfast, lunch, and dinner, year after year, decade after decade, through life's many joys and challenges. Now in our 50s, we have a lot of stories to share with this new generation of deaf and hearing siblings and with those responsible for leading the way for the new families with newly diagnosed D/HH children. Early years are the foundation for a successful lifetime of sibling relationships. Siblings give us our first social experiences in how to communicate our needs, negotiate disagreements, and learn successful social skills we can take out to the neighborhood, playground, classroom, and later into our adult lives.

We need to connect the dots and provide communication bridges between young D/HH children and their hearing parents and siblings, as well as provide access to D/HH adults and their hearing siblings and families. A young girl's self-image depends on her access to successful, vibrant adult women. Successful African American men make a huge difference by mentoring African American boys. Deaf and hearing adults who grew up in both the Deaf and hearing worlds can be mirrors in which young Deaf children and their hearing siblings can see themselves.

In this chapter, we will provide some insight and tools for families and providers to ensure strong, healthy sibling relationships from cradle to grave.

About Us and Our Family

We consider ourselves best friends and each other's "surrogate mother" after

our deaf mother died from cancer when we were 18 and 20 years old. Sheila is the older hearing sister, and Lisa is the younger deaf sister by 18 months.

Our family is one of the 10% of families with deaf children

whose parents are deaf. We have family members who are hard of hearing, sign fluently, and don't have usable speech, sign, and talk, have progressive hearing loss, talked primarily, and learned to sign as an adult. We have hearing relatives who know a few signs, some don't sign at all, several tried to fingerspell for 30 years after they married into our family, and some do not have the eye and hand coordination to even fingerspell well. We have relatives who, with age, developed varying degrees of vision loss. As a result, our family communication had to adapt to this change in the communication needs of our deaf, hard of hearing, and deafened relatives with age-related low vision, progressive vision loss, and who became legally blind. We have successful deaf and hearing sibling stories to share with the 90% of families with deaf children whose parents are hearing and grew up with hearing siblings themselves.

We present this glimpse of the Jacobs family to give the "long view" to medical professionals and others working with 0-3 recently diagnosed D/HH children.

There is an understanding within the mental health field—school and family counselors, case managers—that there is value in looking at "where we come from"



Allen, Darby, Lisa, Ryan, Chris, Sheila, Nicholas—
Lisa and Sheila's immediate families

and identifying generational patterns. Having a number of deaf people within a family brings a unique and complex set of issues.

You might say that we grew up as a part of the informal “pre-EHDI” type of social network in America in the 1950s, ’60s, ’70s. We care deeply about D/HH babies and their families and believe we have an important contribution to make regarding the intervention strategies that are developed for these families.

The Relationship of the Deaf Community to EHDI: A Sociocultural vs. Medical View

Most EHDI programs understandably focus a majority of their time on parents’ emotional issues after getting the initial diagnosis that their child is D/HH. The family becomes dependent on medical providers to give them direction. There is great additional expertise available to them for pursuing opportunities to enhance their baby’s hearing and speech.

There is value in an early intervention program that includes family support and access to successful D/HH adults and their families. Medical providers often do not have a lot of experience with the Deaf community. They may not include American Sign Language (ASL) as a part of the communication opportunities they offer to parents. The ease with which new parents can begin signing with their baby could very well be a great way to begin the communication process. The general public has embraced the Baby Signs movement, which teaches hearing babies how to sign and express themselves long before they are able to articulate words clearly. It would be nice to receive the same response for D/HH babies. Parents must be given every opportunity to work through the grief process and begin bonding and communicating with their D/HH baby to assure full inclusion into the family.

What Is “Double Pride?”

“Double pride” refers to having pride in BOTH the deaf and hearing “parts” or “sides” of our personalities and lives. Sheila experienced ups and downs on her “bumpy road” to double pride. Sometimes she felt “deaf pride” about her “deaf side” and looked down at her “hearing side.” As a teenager, she—like many other hearing children of deaf parents—began to feel more “hearing pride” about her hearing side and looked down on their “deaf side.” These are aspects of what many call “internalized oppression.”

Many D/HH children of hearing parents continue to come to Sheila’s office with various mental health issues and experience “no pride” in either their deaf or hearing worlds! This can result in lifelong depression and anxiety, since they have no “double pride family” experience with parents who understand how to bridge this gap successfully, nor EHDI providers who could guide them successfully.

Double Pride Empowerment for Families AND for EHDI

There is great potential for the medical and the sociocultural models to join forces toward the goal of creating a more “double pride EHDI” with more double pride approaches. This partnership between the Deaf community and EHDI has been slow in developing. Could it be that, as in other medical fields—obesity, cancer, and disability—“patient organizations” are seen as auxiliary?

Medical treatment of D/HH patients is a unique category, because the lack of sound cuts D/HH people off from communication with their families and other people who do not sign. The need for sign language has led to the formation of a Sociocultural Signing Community nationwide. We want to be sure that every D/HH patient has easy access to



Lisa, Leo, Dorothy, Sheila Jacobs

“Double pride” refers to having pride in BOTH the deaf and hearing “parts” or “sides” of our personalities and lives.

the Deaf community. Medical providers must understand they need to work more collaboratively with the Deaf community and its leaders. Experts in related fields like deaf education and mental health who have successful experiences working with D/HH people can help to address their many challenges and achieve “double pride” at home, school, and work.

We cannot afford to marginalize those who understand and experience daily the importance of accessing a variety of family communication channels to help make day-to-day lives of the family go well. Often the lack of communication within a family with D/HH members can cause generations of communication dysfunctions.

Multigenerational Family Communication Patterns

Often hearing children of deaf parents are being asked by their grandparents, aunts, uncles, and cousins to interpret for many of the extended family gatherings and conversations, so their deaf parents can finally become a part of family communication. This happens when hearing siblings and parents do not get an early start in developing ongoing family communication strategies. Hearing children of deaf parents often become the family interpreter, and many express their emotional stress and even describe feeling traumatized at being put into this adult role at an early age.

Sheila calls this “family communication trauma.” This not only traumatizes the D/HH children but their parents and siblings as well. She encounters this often in her counseling practice and is trying to help families who have a lifetime of negative family communication habits to unlearn them. These families are yearning for easy fixes and to find new ways to get through the pain of the past. They yearn to create new, long-lasting, and loving ways to communicate in the depth and breadth that every family deserves.

This interdisciplinary approach would also solidify successful D/HH and hearing sibling relationships from cradle to grave. Siblings will most likely outlive their parents and need to know how to have a very positive attachment experience with each other. A comprehensive early start can help D/HH and hearing siblings to sustain life’s highs and lows together as brothers and sisters.

Strategies for Successful Deaf and Hearing Sibling Relationships

Our primary goal for this chapter is threefold. We hope to provide strategies to:

- 1 Build empathy between D/HH and hearing siblings.
- 2 Identify what each individual D/HH and hearing sibling needs in his or her own “tool kit” to be successful throughout their life.
- 3 Implement a “communication huddle” approach for families to set communication goals and predict obstacles before, during, and after an event.

Build Empathy between D/HH and Hearing Siblings

For D/HH and hearing siblings to have a good relationship, it is important that they are treated equally and given the same opportunities. This means the home the siblings live in needs to be visually and D/HH friendly and considerate of DeafSpace concepts.

While we were growing up, we would always take our visitors who had never been to a “deaf home” on a tour to show them the ways that we lived in our DeafSpace. We would demonstrate the old-fashioned TTY (teletypewriter) by making a phone call to our deaf uncle and let them look over our shoulder while we are typing on the TTY with him. We would show them that when

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It is a very important to equalize the “playing field” in your home so that the D/HH child can understand visually what is happening auditorally in your home.

the doorbell rings, signal lights flash on and off. For more information about DeafSpace, check out http://www.gallaudet.edu/campus_design/deafspace.html

It is a very important to equalize the “playing field” in your home so that the D/HH child

can understand visually what is happening auditorally in your home. *Table 1* lists some ways to consider organizing your family home so that both your deaf and hearing children have “equal access” to the television, telephone, and people ringing your doorbell.

Table 1 Ways to Organize Your Family Home

Oval/Circular Table

For families with more than four people, it's ideal to have an oval/circular table in the kitchen where the family dines. This allows for better visibility of everyone at the table.

Video Relay Service

The D/HH child should have access to a video relay service. This service allows deaf people who use sign language to communicate with voice telephone users through video equipment. A sign language interpreter interprets the calls. There is also a Voice Carry Over (VCO) feature for those who prefer to voice for themselves and speak directly to the other party while an interpreter signs what the hearing person is saying. Because of the conversation between the VRS users through the sign language interpreter at VRS, communication flows much more quickly than with a text-based call between the deaf and hearing person.



Closed Captioning

For the D/HH child to have equal access to television shows, closed captions need to be enabled.



Alert Systems Attached to Light System

Various alert systems in the house, such as the fire alarm, doorbell, and baby cry signal, should be attached to the light system in order for the child to have equal access visually to environmental sounds.



Shared Reading Project

As in any family, reading “aloud” and story time are important to the literacy development of children. The “Shared Reading Project” uses tutors to teach parents and caregivers how to read to their D/HH children using ASL. Hearing siblings benefit from this as well. Research shows that when hearing babies learn signs, it helps with their development, which means it is a win-win situation for both siblings. Further information regarding the Shared Reading Project is available at http://www.gallaudet.edu/clerc_center/information_and_resources/info_to_go/language_and_literacy/literacy_at_the_clerc_center/welcome_to_shared_reading_project.html



It's vitally important for siblings to develop effective ways to communicate with each other, settle differences, and share experiences. Developing a Sibling Communication Tool Kit can decrease communication gaps and forge a strong relationship.

Identify What Each Individual D/HH and Hearing Sibling Needs in Tool Kit

It's vitally important for siblings to develop effective ways to communicate with each other, settle differences, and share experiences. Developing a Sibling Communication Tool Kit can decrease communication gaps and forge a strong relationship. Siblings need tools that work with each other, with the immediate family, and with the extended family.

It's helpful for families to have a goal to plan sibling communication (i.e., to have "metacommunication." Stress-free and open discussions can lead to the simple concept of "Let's rewind and start again." Every family is unique and grows and changes over time. What works for one family may not work for another. What may work at an earlier stage may not work when the siblings become teenagers or young adults.

Parents can talk with siblings about how to plan, predict, and debrief after a family or community event. For example, parents can share their thinking about attending a cousin's birthday party, which will take place the next day. They can discuss how each child will probably do at that event, at that time of day, with a particular mix of personalities and ages. It's important to discuss "IT" (the D/HH-hearing communication). The family can also discuss what each sibling can do to check that their D/HH sibling is feeling included and how that sibling can reach out when feeling excluded.

Drawing communication pictures. There are various ways to plan for an upcoming event and debriefing afterwards. As part of planning, the parents can draw a picture of the upcoming event with all siblings present to discuss how they think each person will feel after the party. Discuss the drawings of each sibling. After the event, ask each sibling to draw a picture with all siblings in it to show how each person felt. Feelings can be color-coded—for example, green for happy, blue for sad, red for angry, and pink for confused.



Puppets and role-playing. Another way to plan and debrief is the use of puppets in role-playing situations. Siblings can be asked to pretend that they are ringing the doorbell at their cousin's home, and with the use of puppets show what happens when the door is opened, what happens next, etc. Use positive communication moments when the D/HH sibling feels included and discuss why it is positive. Use negative communication situations for positive learning—by making mistakes, we learn what not to do next time. The family can discuss what each person can do to create a more positive outcome.



Implement a "Communication Huddle" Approach

The family huddle is an effective way to build healthy families. For D/HH and hearing siblings to have successful communication, use communication huddles. The family is like a football team that gets in a huddle and plans their strategy before every play. The parents are the quarterbacks. After a huddle where plans are made for the next play, the team may not have gained any yardage. So in the next huddle, the quarterback may help the team understand why that last play did not work out. Creating healthy family communication in a life situation equals a touchdown! And who are the coaches? They are the providers across disciplines with knowledge of the whole game and the season—the big picture of a healthy family and a commitment to supporting hearing families with a D/HH child.

Communication huddles can strengthen the communication abilities of each sibling. Parents have their own communication abilities developed throughout their lives. When they demonstrate these skills, siblings can learn by seeing it in action.



Lisa's husband Allen Talbert (a deaf member of an all-hearing family) tells his story. Allen worked at the Model Secondary School for the Deaf as a Transition Counselor . . .

I'm Lisa Jacobs' husband, Allen, and we have been married for 25 years.

I am from a hearing family. I was born deaf in the early 1950s and am the youngest in my family with two older sisters, Judy and Diane. Since there are a number of years between Judy and the two of us, Diane and I spent a lot of time together at home and other activities, such as going on picnics and attending church services. My mom always tried to make sure I felt included. I have usable speech and grew up being able to talk on the telephone with amplification for short phone conversations with only my mother and sisters.

My mom was my staunch supporter who believed in me and supported me in my journey. She was advised that my family not sign with me, because it would be a detriment to my speech development. As a result, my family never learned to sign. However, they always tried their best to make sure I could read their lips and not be left out.

When I was about 5 years old, my mom decided to go with her instinct and sent me to the Western Pennsylvania School for the Deaf (WPSD) to attend school and live in the dorm. At the time, the school used the oral method with elementary- and middle-school-age students. However, we signed during after-school hours. It was there where I felt I had "full communication" with my peers, as we all used sign language. I also met classmates who came from deaf families. It was an eye-opener for me to visit their homes, because communication was "easy," and I had full access to information.

I would bring friends home during my high school years. Sometimes my family would not understand what they said, since they don't sign. They would either have me interpret for them or write notes back and forth with my friends. My mom remarked from time to time that she wished she knew how to sign, so she could communicate directly with my friends.

One Thanksgiving, I walked out on my family during dinner. This was due to my frustrations at not being able to follow the conversation. When I asked what was being said, I was given the standard response, such as "just a minute," or "I'll tell you later." At that time, I was working at the Boston School for the Deaf as the Coordinator of the Student Volunteer Program. I was several years out of college—having graduated from Gallaudet University in 1977. I felt good about my work and who I was as a deaf person. And then to be treated as if I was a child at Thanksgiving, I just "lost it." I had grown up thinking that as a child, I did not need to understand everything that the adults were saying. I assumed that once I became an adult that I would now be included in the adult conversations at our family meals. This is why I walked out. I did not want to continue to be treated like a child at our family meals anymore!

I stayed out for several hours. My mom was very upset about this situation, and we had a good talk about it. My mom then promised that it would not happen again. True to her word, she always told everyone to please face me when talking to us, so I could lip-read and be a part of the conversation. Family and friends became much more aware and tried harder to make sure I was included. If I was not able to follow the conversation, it's usually my mother or my sisters who would give me background information about what was being discussed. One of my sisters and her husband took a sign language class and surprised us when we visited them one Christmas—it was the best gift ever!

While growing up, I just accepted the way things were. I rarely got mad at my family, because I saw them as being sweet and helpful. I was able to talk with them over the phone, because I could hear their speech. However, when I got older, I could no longer hear their speech. We then had to use the TTY and Video Relay Service, and I noticed our conversations were shorter than usual. I suspect it is probably because it was no longer a direct conversation but through a third-party call, where my family had to hear other people's voices not my own. Now with Face Time, we can once again have direct conversations with each other!

When I dated my wife Lisa, who is fourth-generation deaf in her family, I realized I was never anxious when I was around them. Well, I did become nervous when I met them for the first time, but thereafter, it was easy to communicate with them. We can discuss just about anything in life, including complicated topics, such as politics and investments.

Rosa Lee Timm's ASL
production of "Happy"
by Pharrell Williams
<http://rosaleetimm.com/music-videos/happy-by-pharrell-williams-deaf-music-camp/>

Family communication huddles can be used to help families work together so that everyone feels included in all the family communication. Families can talk about the easy things first and fix it as a family. With these successes, others will follow.

It is common that one parent becomes the point person who handles most of the D/HH child's appointments, school needs, and family interactions. As a result, this parent often becomes the one who is the family expert on all the communication issues related to the D/HH child. That parent may become the family interpreter, family sign language teacher, and speech teacher who often become the bridge between the D/HH child and his/her hearing siblings. What appears to make things easier for the whole family actually limits the family communication opportunities.

It really is the parents' decision about family communication policies that can help set the stage not only for what parents say, but also what they do. Policies can be put into practice, and parents can become role models for all their children—providing ways to successfully communicate with their D/HH brother or sister.

The impact of sibling order needs to be considered as well (see *Table 2*).

Family Communication: Courses of a Communication Meal

One way of looking at the family communication experience is to use the analogy of courses served during a meal. Our many years of experience as D/HH and hearing siblings attending many family, school, and community events has helped us realize the stages of family and social communication are like a family meal.

Appetizer Time

First is "appetizer time," which is when our family



first arrives at our cousin's house, and we have greetings at the door and in the front hallway. At this point, we all can understand almost everything, because it is rote and predictable kinds of conversation.

Soup & Salad Time

Then it's "soup and salad" time, when the two families are mingling and socializing. The conversation is going "deeper and wider." It may be at this point that the D/HH family member starts to feel lost in the swirl of all the various conversations happening around him or her.



Entrée Time

Then it is "entrée time." This is when everyone sits down to have dinner together. It is also often the time when the D/HH family member feels the most left out. If the hearing relatives don't know how to include her in their conversations, the D/HH cousin feels stuck in one seat and can't move around like she did during the "soup and salad" course, which gave her the ability to choose where to stand or sit. She no longer feels in control of her communication menu at this point.



When people were up and moving around, she could more easily pick and choose from the various social conversations she is interested in trying to understand and participate. However, once she is seated at the table, an arrangement often made by the host, the D/HH family member feels locked in and stuck in a communication corner. She then has to try to make this communication seating arrangement work in her favor. More often than not, the following thoughts are running through her head:

Table 2

Impact of Sibling Order

First Child

If the D/HH child is the first child, then any hearing siblings that follow will always have grown up with a D/HH family member, and their parents will have already learned how to accommodate the D/HH child's communication needs.



Youngest

If the deaf child is the youngest, he or she is born into a family with older siblings who have already had a hearing family experience. When the new sibling with different communication needs is introduced into the family, the older siblings need to be able to “adapt” to new family communication needs. This is much more challenging for hearing siblings than for those who are born with an older deaf sibling in the family. In hearing families with older children, family members may begin trying to sign to accommodate the new family member but may move into a fast-spoken English conversation. This can leave the D/HH child lost, trying to lip read, and hoping that one family member will start interpreting as best as they can. Many deaf adults growing up in these families report that they just gave up and read a book or played a video game. The D/HH child is often told “we’ll tell you later,” but life gets busy and this promise is easily forgotten.



Only Child

If the D/HH child is an only child, both parents are motivated to communicate well with their child. The D/HH child is not competing with any sisters and brothers who have different ways of communicating.



Next Generation

An early start to hearing and D/HH sibling relationship building extends into the next generation. When parents predecease the siblings, the D/HH child may now be an adult, married, with children of their own. Having experienced healthy relationships with their own siblings growing up, these D/HH parents will have a strong, positive attachment and communication bond with their adult siblings. They look forward to quality time with their hearing and D/HH brothers and sisters. They're families and pass along the “double pride” to their children who are now cousins. As this new generation of children grows up, the positive experiences the D/HH parent had with his/her own hearing family will set the stage. D/HH and hearing siblings in these households will have developed creative ways to use various communication opportunities with their friends and future spouses.



- 1 I want to hurry up and eat so I can excuse myself.
- 2 I'd like to try to connect with the cousin on my side, so we can have a one-to-one conversation, but often get interrupted by other people talking and cracking jokes that I don't understand. I don't want to ask what they are saying, because I'll stand out. What I will do is just smile and laugh along with them, even though I am feeling somewhat abandoned within my own family.
- 3 I will make sure I am sitting with my D/HH husband, so that at least he and I can sign together and have a meaningful conversation during the meal. Our hearing cousins will then experience how we feel, since they can't follow what we are laughing about!
- 4 I look for cousins who are good at juggling other people who don't sign. I also look for cousins who do sign and are good mediators/family interpreters. I look to them, even though they may only be able to fingerspell or because they are super easy to lip-read.
- 5 I can't wait to talk to people who can sign fluently and interpret as well.
- 6 I guess I will show photos from my phone, so that I can connect somehow and ask to see photos on their phone as well.

Dessert Time

Finally, the dessert phase of the "family communication meal" arrives.

This is when the evening is wrapping up, and again, the conversation becomes much more predictable for the D/HH cousin.

In a family with strong D/HH and hearing sibling bonds like ours, the D/HH sibling usually starts asking follow-up questions to better understand the various



conversations she thought she understood. The hearing sibling can share highlights of the stories she had heard about the people they have in common. They arrive home and continue to share the excitement of the extended family event and can feel part of one great big family get-together!

An Early Start to Sibling Communication

Building an early start foundation for sibling communication is essential. Within families new to D/HH people, often a vocabulary approach is used. This is when well-meaning professionals lead families into the "land of point and label." Families end up knowing only how to sign very simple conversational topics that lack depth and breadth. They miss out on meaningful family experiences and the opportunity to bond in any significant way with each other.

To use another cooking analogy, providers inexperienced with the Deaf community, American Sign Language, and workable communication strategies for D/HH and hearing siblings might be really good at snack time. They are able to teach families how to have communication snacks, such as goldfish, pretzels, juice, and water.

As these children grow up, they need a "full meal" at least three times a day. They need to be able to talk about the things they are learning in school. They need to be able to share their excitement about a movie. They need to know how to sign all the video game characters that their siblings are talking about. They need to be able to talk about everything happening in their own lives, and also learn how to be a good sibling to their brother or sister who wants to share what's going on in their life. And not just one-on-one, but as a whole flock of siblings who are all talking as a group, joking around, and sharing cool things they are thinking about doing.

Hearing siblings want their D/HH sister or brother to be a part of all their conversations. It hurts them for their D/HH sibling to be constantly asking, "What

As D/HH children grow up, they need to be able to talk about everything happening in their own lives, and also learn how to be a good sibling to their brother or sister who wants to share what's going on in their life.

We are all in this together, and our first responsibility is to build a broader bridge to better serve families.

did you say?” or “I don’t understand.” Constantly misunderstanding things leads them to being left out. It’s sad to see, but it often happens that later in the D/HH and hearing relationship, the D/HH sibling is purposefully left out. If the communication tool kit is empty, hearing siblings don’t want to bother with all the ways their D/HH sister or brother is “out of it” at times.

We as D/HH and hearing sisters feel fortunate that we can be close and communicate very well about many things! We hope that hearing families with young D/HH and hearing siblings can be assigned a program provider—a good coach—to help them put together a communication toolbox for their D/HH and hearing children that will help establish a very successful trajectory that takes the siblings with their tool kits into every chapter of their lives together. *Table 3* lists tips for sibling and family communication, and *Table 4* lists recommendations for EHDI on moving forward to building partnerships.

Conclusion

Due to medical technology advances, families with newborns can learn that their baby has a significant hearing loss before leaving the hospital. An early start to providing information and advice to parents must begin immediately.

We are all in this together, and our first responsibility is to build a broader bridge to better serve families. In the middle of the cultural divide lies a world of common ground and opportunities for collaboration. We believe the answers are found in widening the circle of stakeholders, accepting our differences, and including everyone—those with little speech, those with little signs, and everyone in between.

A partnership of professionals with both medical and sociocultural perspectives can ensure the success of families with D/HH babies and their hearing sisters and brothers. Let’s respect each other’s perspectives and backgrounds. Let’s discuss our best practices and make plans TOGETHER as a new brand of “EHDI brothers and sisters” exemplifying a more positive collaboration and setting an example for the families and infants we aim to serve nationwide.

Please let us know how we can support your program and the families you serve. We believe the deaf and hearing sibling relationship is pivotal. There are many simple fixes that could make a world of difference.

Our contact information:

Lisa Jacobs: lisa.jacobs@gallaudet.edu
<https://www.linkedin.com/pub/lisa-jacobs/43/2ab/663>

Sheila Jacobs: Sheila@doublepride.com
<https://www.linkedin.com/in/sheilajacobsmt>
<https://twitter.com/sheila26462725>



1st Annual Deaf and Hearing Siblings Retreat 2011



“Sibling relationships...outlast marriages, survive the death of parents, resurface after quarrels that would sink any friendship. They flourish in a thousand incarnations of closeness and distance, warmth, loyalty and distrust.”

—Erica E. Goode

Table 3

Tips for Sibling and Family Communication

Tip 1	Tip 2	Tip 3
To include friends of both the D/HH and hearing children in the family, give them name signs, so everyone can follow the conversation about family friends more easily. To describe and introduce friends by using their name signs for them can enhance communication going forward. Over time, the family can communicate at a deeper level that includes keeping up with the social networks of each family member.	Get comfortable with silence and understand that the communication can be slow going. Both D/HH and hearing family members can experience situations that make them feel left out of the conversation. Hearing siblings may feel this when their D/HH brother or sister has friends over. The “shoe is on the other foot,” and they may want to escape the awkwardness by disengaging from their D/HH sibling and his friends.	Face the D/HH family members when you are communicating with them, so they can read your lips or see your facial expressions. It’s a good habit to develop early.
Tip 4	Tip 5	Tip 6
Be creative and patient when sharing jokes and funny stories. Humor is one of the most challenging topics to interpret or explain. There are often English references or double entendre. At the end of the joke, the punch line is often told more quickly, making it hard for the D/HH person to lip-read or follow. Often when the D/HH person asks them to repeat the joke, it’s not funny anymore. The same is true when the deaf sibling and friends joke using sign language.	When gathering with hearing relatives for the holidays, bring some things to show and tell, like photos to share. A photo album from a recent vacation that tells a story is easy for everyone to follow visually.	Charades, Reverse Charades, and Guesstures are games we and our families have enjoyed together.
Tip 7	Tip 8	Tip 9
Watch a movie with captions together.	Sign some holiday songs. When we signed “Rudolph the Red Nosed Reindeer,” it was the first time we saw 20 relatives all trying to sign at the same time, wow! It is fun to sign a familiar story together. If the family does not sign, use gestures, drawing, and/or acting.	Bake cookies together—activities work well for everyone to feel they are on the same page and yet can have individual conversations.
Tip 10	Tip 11	
Go on outings together, such as a ferry ride. These provide a nice balance between group and individual conversations.	There are issues built in to every relationship—challenges that face D/HH and hearing sibs. Have siblings take turns being the leader and the follower. This helps check who might be over-involved or under-involved in the relationship. And establish the balance with each other.	

Table 4

Recommendations for EHDI: Moving Forward

Recommendation 1	Recommendation 2	Recommendation 3
Involve experienced double pride mental health professionals. A new baby introduced in a family can be difficult, and if this baby is D/HH, issues within the family become more complex. The EHDI team often includes a parent advocate who has experienced EHDI services before the new parent. This is a valuable resource. However, this advocate is typically not trained to be a family expert to serve a wide diversity of families with a newly diagnosed D/HH infant. Imagine what a trained marriage family therapist could provide to the EHDI team! Licensed marriage and family therapists, LCSWs, and psychologists are experts in family dynamics and marital therapy. These professionals know how to handle a variety of symptoms, such as depression and anxiety, and are often aware of special education options and resources. This could be a culturally deaf counselor fluent in American Sign Language, or a mental health therapist who is well versed in all the communication opportunities available to the family.	Welcome active involvement of members of the Deaf community in EHDI programs. Include them on the EHDI team whenever possible. This may not be easy, but it will be worth the effort. Provide parents with early access to successful deaf professionals, parents, children and their families.	Rely on the established associations who worked on behalf of deaf children. This includes National Association of the Deaf (NAD); state organizations, such as California Association of the Deaf (CAD), as well as Parent Organizations: American Society of Deaf Children (ASDC), Hands and Voices, International Children of Deaf Adults Organization (CODA), and Kids of Deaf Adults (KODA).
Recommendation 4	Recommendation 5	Recommendation 6
If hearing siblings attend the same elementary school as their D/HH siblings, the teacher of the Deaf can simply invite hearing siblings to attend their deaf siblings' class for 1 hour per week as a "Study Buddy" or other communication activities that would strengthen the sibling communication.	Establish a family sign language program designed especially for families with D/HH babies, 0-3, with a special emphasis on positive communication with their sisters and brothers. EHDI providers who can focus on strengthening the D/HH child and siblings' ability to communicate well with each other could be one of the best EHDI investments of family coaching time.	Present both auditory and visual technology to the parents. Technology is rapidly increasing the number of communication opportunities. Auditory technology advancements have brought cochlear implant companies, hearing aid manufacturers, and medical equipment suppliers to the table. To increase opportunities for families, include all the strides that have been made in the visual technology field as well. Examples of visual technology advancements include captioned glasses that are available in movie theatres for deaf/HH people and open captions available in theatres and sporting events.

Resources

Deaf Community Support for Families: The Best of Partnerships,” Chapter 21, The NCHAM eBook: A Resource Guide for Early Hearing Detection and Intervention, http://www.infanthearing.org/ehdi-ebook/2014_ebook/21-Chapter21DeafCommunity2014.pdf

Early Intervention: The Missing Link in the Journal of American Sign Language and Literature, <http://aslized.org/journal/ei/>

Gallaudet University, <http://www.gallaudet.edu/>

Gallaudet University Facebook page, <https://www.facebook.com/Gallaudet1864>

Gallaudet University, Laurent Clerc National Deaf Education Center, http://www.gallaudet.edu/clerc_center.html

Gallaudet University, Laurent Clerc National Deaf Education Center & Visual Language & Visual Learning (VL2), http://www.gallaudet.edu/clerc_center/information_and_resources/collaborations/visual_language_and_visual_learning.html

Graduate Admissions, http://www.gallaudet.edu/rgs/graduate_school/graduate_admissions.html

Office of Regional & National Outreach, Gallaudet University, http://www.gallaudet.edu/outreach_programs.html

Parent Information Packet developed by Visual Language & Visual Learning (VL2), <http://vl2parentspackage.org/>

Undergraduate Admissions, http://www.gallaudet.edu/undergraduate_admissions.html

Visual Language & Visual Learning (VL2) Research Briefs for Educators and Parents, <http://vl2.gallaudet.edu/educator.php?total=21&id=2&page=1>

Double Pride

Double Pride: The Best of Both Worlds, <http://www.doublepride.com/>

Double Pride: The Best of Both Words Facebook page, <https://www.facebook.com/DoublePride>

National Organizations

American Society for Deaf Children, <http://www.deafchildren.org/>

Children of Deaf Adults Inc. - For Hearing Adult Children of Deaf Adults, <http://coda-international.org/>

Friends of Libraries for Deaf Action, <http://www.folda.net/>

Hands & Voices, <http://www.handsandvoices.org/>

Joint Committee on Infant Hearing – JCIH, <http://www.jcih.org/>

Kids of Deaf Adults - Based in Maryland for Hearing Children of Deaf Adults, <http://www.mdkoda.org/>

Kids of Deaf Adults - Based in Southern California for Hearing Children of Deaf Adults, <http://www.kodawest.org/>

National Association of the Deaf, <http://www.nad.org/issues/early-intervention/information-parents/sign-language-parents>

Deaf Hearing Siblings (Articles & Blogs)

Deaf and Hearing Siblings: Our Journey Together, <https://www.facebook.com/pages/CODAs-and-Their-Siblings/132461940129228>

Deaf and Hearing Siblings in Conversation. Book written by deaf and hearing siblings Marla Berkowitz and Judy Jonas. Other resources available on the website, <http://www.siblingconversations.org/>

Growing Together: Creating Language-Rich Environment - Interviews with Parents, Researchers, and Scientists, <http://www.youtube.com/watch?v=s9-ieU0vl0Q>

Hearing Parents w/Five Kids; One Deaf Twin, <http://shilohbuchman.com/life-with-a-deaf-sibling/>

<http://www.amazon.com/Hearing-Siblings-Conversation-Marla-Berkowitz/dp/078647825X>

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

Mark Drolsbaugh's Blog about His Deaf/Hearing Children, <http://xpressivehandz.blogspot.com/2014/02/the-tide-could-be-turning-for-deaf.html>

Organization – Sister-Brother Deaf, Inc.; Judy Jonas & Marla Berkowitz, <http://volunteer.truist.com/mcvc/org/10548991088.html>

Summer Camps

Camp Mark 7 - Summer camp programs for D/HH youth & children) and for hearing youth and children of deaf parents, <http://campmark7.org/>

American Sign Language

ASL Nook: A Nook Full of Signs, <http://aslnook.com/>

Signing Time, <http://www.signingtime.com/>

Stories of Connection: Finding Understanding. Many deaf people in the United States are gathering at Starbucks regularly and want to create a happy signing community in their local area. This video filmed in Hawaii is about the positive impact of community for one deaf woman who found her “home away from home,” <https://www.youtube.com/watch?v=mYdpsbfW-Fw&feature=youtu.be>

Through Your Child's Eye: American Sign Language – produced by California State University-Northridge & the California Department of Education, <http://www.csun.edu/~tyce/enindex.html>

