

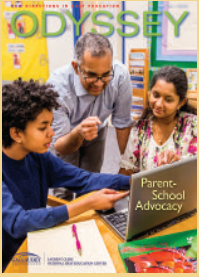
# ODYSSEY



## Parent- School Advocacy



# ODYSSEY



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The Clerc Center, a federally funded national deaf education center, ensures that the diverse population of deaf and hard of hearing students (birth through age 21) in the nation are educated and empowered and have the linguistic competence to maximize their potential as productive and contributing members of society. This is accomplished through early access to and acquisition of language, excellence in teaching, family involvement, research, identification and implementation of best practices, collaboration, and information sharing among schools and programs across the nation.

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**About the cover:** Research shows that children whose parents are involved in their education and who advocate for them learn to self-advocate and have higher rates of academic and professional success.

*We would like to thank all of our student, parent, teacher, and staff models from the Clerc Center, as well as Beth Angerman, Hadassah Fleming, and Anjali Vora, for their assistance in illustrating this issue.*



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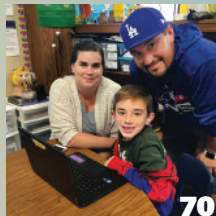
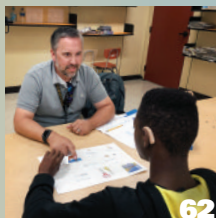
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# YOUR **ONE STOP** FOR **DEAF EDUCATION** **RESOURCES**

**EARLY  
INTERVENTION**

**PARENTS  
AND FAMILIES**

**RESOURCES  
FOR SCHOOLS**

The Laurent Clerc National Deaf Education Center is a federally funded center that provides information, training, and technical assistance for families of and professionals working with deaf or hard of hearing children.

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### IT TAKES A COMMUNITY OF ADVOCATES: Parents and Schools Working Together

All children come into the world with a unique set of abilities, their own personality, and their own ideas about how they will contribute to the world. Every parent watches their child grow and learn with a wide range of emotions—pride, worry, love, concern. They often question themselves: *“Am I doing enough? Am I doing the right thing? Have I asked the right questions? How can I be sure the school sees what I see in my child?”*

Advocacy takes many forms, but at the root of all advocacy is a deep sense of caring and purpose. In this issue of *Odyssey*, several of our authors have given us a glimpse into their personal journey as an advocate or having someone advocate on their behalf. You will see a human parental touch in each of them, but each story also shows how challenging it can be to find all the information one needs to be a successful advocate. Where are the gaps in resources for families? Where can families turn when they do not know what to ask or even for what they should be asking? What can parents do when they know their child has a need but are not successful in meeting that need? In Ukawia Johnson’s article, you will read about her personal story as a parent and advocate who had to challenge the system to ensure her son was getting the best possible education.

Other featured writers in this issue have shared their experiences supporting families, ensuring parents are at the table for every discussion, listening to families as they share what they are seeing at home—the successes and the challenges—and helping families navigate information and resources to make the best decisions for their children. As these children grow, these same professionals teach them to advocate for themselves, to be clear about what they need to be successful and who and how to ask. In Amanda Howerton-Fox and Jodi L. Falk’s article, you will read about their experience working with parents and families and the thought process behind how they developed their parent workshops.

As educators, we know that parent advocacy is critical to the success of the child and the Clerc Center. We have developed and maintained resources for families as a cornerstone of our work. Be sure to visit our Info to Go web page, <http://www3.gallaudet.edu/clerc-center/info-to-go.html>, and subscribe to our mailing list by visiting <http://clerccenter.gallaudet.edu>.

As you read these powerful articles, please send us your stories of parent and school advocacy. Find us on Facebook, Instagram, and Twitter. You are also welcome to reach us with your thoughts at [Odyssey@gallaudet.edu](mailto:Odyssey@gallaudet.edu).

—**Marianne Belsky** and **Nicole Sutcliffe**

Chief Academic Officer/Chief Administrative Officer  
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Gallaudet University



Marianne Belsky



Nicole Sutcliffe



**Amanda Howerton-Fox**, PhD, assistant

professor of language and literacy education at Iona College in New Rochelle, N.Y., has worked as a teacher of deaf and hard of hearing students, as a teacher of students who are learning English as a second language, and as a professional development provider in the New York City area. She is a certified reading specialist and earned her doctorate in deaf education with a concentration in applied linguistics from Columbia University. Howerton-Fox's research focuses on bimodal language and literacy development and preparing teachers to work effectively with students whose languages or dialects have been historically undervalued by our nation's schools, including students who are deaf or hard of hearing and use American Sign Language.

# Supporting Families in Program Transition and the Hard Truths of Early Language: What Should We Say to Parents?

*By Amanda Howerton-Fox and Jodi L. Falk*

St. Joseph's School for the Deaf in the Bronx, N.Y., has been undergoing significant changes in our approach and our curriculum, and including parents has been an informative and critical part of the process. For decades, we employed a Total Communication approach to educating our students. However, just over two years ago, the administration invited representatives from Gallaudet University's Laurent Clerc National Deaf Education Center to come and talk with the educational staff—including our teachers, teacher assistants, speech-language/audiology personnel, and mental health professionals—about the design and potential benefits of an ASL/English bimodal bilingual program.

An initial six-hour training that focused primarily on theory and practice was followed by two years of consulting with the Clerc Center, addressing the design of effective bimodal bilingual early childhood programs for deaf and hard of hearing children from birth to 5 years old. During this same time, the administration hosted Dr. Amanda Howerton-Fox, a deaf education researcher from a nearby college and co-author of this article, in a series of professional development sessions for teachers and speech-language professionals on the linguistic foundations of a bimodal bilingual approach. This approach, which is

*Photos courtesy of St. Joseph's School for the Deaf*





supported by current research in bilingual education, emphasizes the importance of developing both signed and spoken language (perhaps exclusively in its written form) so that children can use their knowledge of both languages to support their overall language and literacy acquisition. The word *bimodal* highlights the inherent linguistic differences between languages that use the manual-visual modality and those that use the auditory-oral modality, as well as the importance of developing the listening and spoken language skills of students for whom that is an appropriate goal. As a result of the knowledge gained in these professional development sessions, the teachers asked that Howerton-Fox continue working with them to integrate linguistic competencies in American Sign Language (ASL) and English into the school's English Language Arts curriculum.

### St. Joseph's A Place for Families

St. Joseph's has a long tradition of communicating closely with and offering

**Above:** Howerton-Fox leads a parent workshop, giving parents the opportunity to ask questions related to their child's language development.

ongoing support to the families of our students, and as we adopted a new bimodal bilingual approach to educating students, we invested time and resources in sharing our plans with our students' parents via parent-teacher conferences and Individualized Education Program (IEP) meetings.

Always an integral part of our school, families of our students can often be seen on campus, taking classes, meeting for parent groups, or volunteering at some of the school's many special events, such as World Read Aloud Day and plantings for our children's garden. The school hosts two weekly groups: one for the families of students in the Parent Infant

**Jodi L. Falk**, PhD, has been the upper school educational supervisor for St. Joseph's School for the Deaf in the Bronx, N.Y., since 2007. Prior to this position, she was St. Joseph's parent-infant teacher, an early intervention service provider in Westchester County, N.Y., and a high school teacher for the New York City Department of Education. Falk received her bachelor's degree in speech-language pathology from Hofstra University and both her master's degree and her doctorate in the education of the deaf from Teachers College, Columbia University. Falk wears two hats in the field of deaf education: As an educational supervisor, she oversees every aspect of school programming, including curriculum, instruction, personnel performance, and student behavior management; academically, she teaches as an adjunct professor at Iona College and presents at conferences. Commencing August 2019, Falk will be the executive director at St. Francis de Sales School for the Deaf in Brooklyn, N.Y.



**Right:** Howerton-Fox gives a TEDx presentation; some of her slides, “Why Bimodal Bilingual?” and “The Bilingual Brain.”



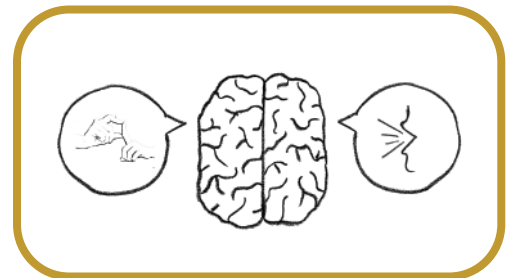
Program (birth to 3 years old) and the other for families of school-aged students (preschool to eighth grade). School social workers run the Parent Education programs. The programs are divided into sessions on education and sessions for social-emotional support. The educational sessions include classes in ASL and workshops on topics such as Deaf culture, the IEP process, behavior management, speech, language and literacy instruction, storytelling, and the use of technology. Guest presenters are invited as experts in their respective fields. Presenters have included local police officers, technology supervisors, educational supervisors, and members of the Deaf community. Mediated by social workers, the sessions offer families informational and social-emotional support as they explore topics related to raising their deaf or hard of hearing children.

As St. Joseph’s draws students from throughout the Bronx, a densely populated borough of New York City, distance and cost can present obstacles for attendance, so a taxi service is provided for those in the Parent Infant Program and a special bus service is available for parents to attend other meetings and activities. All sessions are multilingual—offered in English, ASL, and Spanish—and interpreters are provided for parents who speak other languages. St. Joseph’s also provides evening ASL classes for families and community members. Further, each family participates in a support group, and each family is assigned a social worker who advocates for them and helps them access community resources. An on-site food pantry and clothing collection is also available.



### A TEDx Talk A Need Exposed

Last spring, Howerton-Fox delivered a presentation on the importance of early exposure to sign language for all deaf and hard of hearing children—and the authors realized that our parents should be more aware of the rationale behind the changes taking place at St. Joseph’s. In “Language Beyond the Sound Barrier,” a TEDx presentation, Howerton-Fox covered the cognitive, linguistic, and social-emotional benefits of educating deaf and hard of hearing children bilingually in ASL and English as well as the importance of exposing the youngest deaf and hard of hearing children to visual language. Howerton-Fox and Jodi Falk, a St. Joseph’s educational supervisor who is also co-author of this article, began to plan workshops for parents that could be integrated into the already-scheduled parent support groups. We asked the question: *What is it that parents of deaf and hard of hearing children should know about language and literacy development—particularly bilingual ASL/English development—so that they can not only support their children at home but advocate for them at school and in society?* We reviewed materials we had previously gathered, including the content of Howerton-Fox’s TEDx talk, information from professional development sessions, and the survey responses of our faculty regarding their understanding of the



ASL/English approach. Instead of presenting this information in PowerPoint slides loaded with theoretical models and research citations, as it had been presented to the school’s faculty, we decided that the presentations should look more like a TEDx talk. We redesigned the slides so that they would be more meaningful to our audience of parents, the majority of whom speak English as a second language. We used fewer words, more visuals, and built in ample time for the parents to ask questions and engage in conversations that would allow them to connect the content of the presentation to their own firsthand experience.

We would use our first parent workshop from the fall to get a sense of what parents already understood about the differences between the Total Communication and bilingual approaches to deaf education and to introduce the following five arguments in support of the bimodal bilingual approach:

1. **Language supports language.** The ways in which bilingual learners use their knowledge of each language to



scaffold their learning of the other is well-documented in the literature (Garcia, 2009).

2. **Bilingualism is a gift.** Research in cognitive science has consistently shown that bilingual individuals have more cognitive flexibility and control in comparison to monolingual individuals (Costa & Sebastián-Gallés, 2015).
3. **Technology isn't perfect.** Cochlear implants have variable success rates, and the factors influencing success are not fully understood (Marschark, Sarchet, Rhoten, & Zupan, 2010).
4. **Early language is critical.** Decades of research indicate a critical period exists for human language development, after which language learning becomes much more difficult (Mayberry & Kluender, 2018).
5. **Membership in Deaf culture is empowering.** The benefits of participation in Deaf culture are not only linguistic but also psychological, social, and creative (Bauman & Murray, 2014).

We would focus a second parent workshop on the changes in the curriculum at St. Joseph's and discuss ways in which parents could support their children's learning at home. Thirteen parents attended the sessions. Ten parents spoke Spanish as a first language and communicated via a Spanish-English interpreter. One was bilingual in Spanish and English; one was bilingual in Arabic and English; and one was bilingual in English and Bembe, one of the languages of her native Zambia.

## The Dilemma of Early Language

### What Do We Tell Parents?

Overall, the workshops were very successful. Parents were grateful for the information and pleased to have access

to an expert to whom they could address their questions and concerns about their own children's language development. However, a moment of unexpected anxiety arose when the presentation turned to the critical importance of children developing language while they are still very young. As discomfort spread through the room, we thought about the parents who had children in middle school. For these parents, data that showed language delayed could mean language denied could not be helpful; it was too late for these parents. So strong was the reaction that we made an on-the-spot decision to stop talking about it; we cut short the discussion about how people's facility for language learning decreases with age and about the cognitive and social-emotional effects associated with the lack of early language in human development. Debra Arles, St. Joseph's executive director, who was observing the sessions, came to the front of the room to reassure the parents that they were doing the right things for their children, and that this new approach included a learning curve for everyone in the school, herself included. A few of the parents visibly relaxed upon hearing this.

## Send Us Your Thoughts

At St. Joseph's we remain committed to supporting parents, and we are conflicted about how to handle the data on the importance of early language learning. We believe strongly in the importance of giving parents accurate and complete information about language and literacy development, but we also understand that parents may interpret the data as a reflection on themselves and decisions they made long ago. Parents who feel negatively judged and deflated are not parents who are likely to become actively engaged in advocating for their children.

We would be grateful to hear the thoughts and experiences of the *Odyssey* readership on this critically important issue. Parents, teachers, and others involved in the education of deaf and hard of hearing children, please contact us via e-mail if you have a story or an insight to share. Help us to think about what we should tell parents, especially parents of older deaf children, about the importance of full language exposure during the earliest years of a child's life. Contact us most directly through e-mail: Howerton-Fox at [ahowertonfox@iona.edu](mailto:ahowertonfox@iona.edu) and Falk at [jodifalk@icloud.com](mailto:jodifalk@icloud.com).

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## OF SERPENTS AND DOVES:

# My Experience Learning to Work with the Educational System

*By Traci Penland*

**Traci Penland** is the mother of three children, two of whom are deaf. She earned her bachelor's degree in business administration from the University of North Georgia. Previously an advocate for Hands & Voices, the national parent advocacy organization, Penland recently started *Lead with Love*, a blog for parents of children born with hearing loss. She lives with her family in Atlanta, Ga., and welcomes questions and comments about this article at [tracipenland@gmail.com](mailto:tracipenland@gmail.com).

There were 10 of us at the table. We, the eight parents who had requested the meeting to talk about educating our children through American Sign Language (ASL), joined the director and the assistant director of special education and a researcher from a nearby research institute. The only person I felt was on our side was the researcher. The children represented in the room were either adopted, like mine, or from homes where the parents were not yet fluent in ASL. As a result, our children were already language delayed, and this added to the tension. We knew language was critical to our children's education, so we wanted them to begin intensive ASL instruction immediately. Every parent in the room had the same goal in mind—that our children graduate high school fully prepared for the rigor of college academics. The atmosphere was tense. In fact, I felt like it was a war ... two sides, each trying to outplay, outwit, and outlast—but I was ready. Rosalee, at 6 years old, was just beginning her educational journey. Nothing was more important to me than my daughter. Nothing was more important to my daughter than her education. If I had to fight for it, I would. War, as everyone knows, is hell. I was prepared to go through hell.

Thankfully, with Rosalee now in third grade, that's no longer how I feel. Rosalee has strong support in school. She has a teacher of deaf and hard of hearing students for English Language Arts, a language therapist fluent in ASL, a team of highly qualified interpreters, a daily ASL class, and a co-teacher in math. She is still behind in most areas due to her language delay, but she has made huge progress this year. We had our most recent Individualized Education Program (IEP) meeting last month. It lasted four hours. I brought food. We talked about her current reading level, tweaked the drafted goals, and laughed about how many people would be invited to her high school graduation party. The assistant

*Photos courtesy of Traci Penland*





**Left:** Rosalee (second from right) with two deaf friends, Fabrizio and Faith, and a hearing friend (far left) named Price. Price knew no ASL when they started kindergarten together. However, when the school identifies a child with a proficiency towards signing, they keep them in the same class with the deaf children every year. As a result, Price has become fluent at age 10. It's truly amazing to watch her sign.

what happens! Information overload! Click to click, site to site—it was too much. I couldn't process all the material.

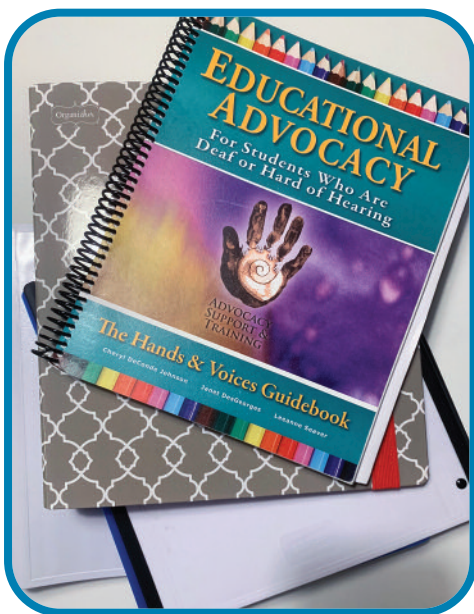
Fortunately, not long after that first meeting, I found something that changed my life. I was invited to attend a training given by the Georgia chapter of Hands & Voices, a parent-driven, nonprofit organization dedicated to providing support to families irrespective of the family's communication choice with their child. At the training, they presented the information in the *Hands & Voices Educational Advocacy Guidebook*. What a godsend! This was it—the map I had been looking for. Words and phrases I had been vaguely familiar with like “504 plan” and “IDEA” became comprehensible, even second nature to me. Finally, I felt knowledgeable enough to let my guard down. Eventually, I began working with Hands & Voices as an educational advocate, and I had the honor of meeting parents across the country facing challenges similar to my own.

As a result of my growing knowledge base, the next few meetings with the school officials went much better. I stopped talking so much and started listening. I learned about reading strategies that had worked for students in the past. Members of the school connected me with other parents of kids with hearing loss who I hadn't yet met. We started tossing around ideas for celebrating Deaf culture within the school. Together, we came up with a unique way for Rosalee to connect with

director of special education, who has attended all Rosalee's IEP meetings, said he would give a speech celebrating her accomplishment. The meeting felt supportive, friendly, as if we were all partners in devising the best possible education for Rosalee. So, this is the story of how I stopped thinking of “the school”—the combined presence of teachers, professionals, support staff, deaf education specialists, audiologists, and administrators—as my enemy. This is the story of how I realized that, like me, each person was an individual and, also like me, each cared about my daughter; they had her best educational

interests at heart.

Like most great changes, this one happened slowly. Diplomacy and forging partnerships do not come naturally for me. I was born in Central America in the middle of a civil war. Even though I was adopted and brought to the United States when I was an infant, conflict was in my blood—a fallback stance that always felt like the right thing to do. So, when I showed up at that first meeting and realized everyone at the table was more informed than I was, I immediately felt defensive. I had tried to get informed before the meeting, but just Google “IEP” and see



**Above:** These are just a few of my notebooks, featuring the *Hands & Voices Educational Advocacy Guidebook* referenced in this article.

her hearing peers by creating a class photo book showing each child's picture with his or her name sign (a special sign that is used to identify a person in ASL). The photo book was not my idea, but it came to life as I shared with the team how frustrating it was that Rosalee couldn't give me the name of any of her hearing peers; she just called everyone "my friend." Having the photo book this year has made a huge difference in the depth of our day-to-day discussions about what happened in school. In time,

the school officials and I truly became Rosalee's IEP team: a group of individuals each bringing his or her own insights, knowledge, and aspirations for Rosalee to share with each other. It didn't happen overnight; it happened slowly as I realized knowledge and grace together can be a powerful tool.

In Matthew 10:16 of the New Testament, we are cautioned to be as wise as serpents and as gentle as doves. Every mom I know goes into IEP meetings with a binder of material—usually ginormous—about their children and their children's education. It is our sword and shield. Knowledge

can be a powerful tool, I learned. However, if we are to make measurable and consistent progress across a school system, we must put down our binders, look across the table, and see the humanity sitting there. *Us* and *them* must become *we*. I can't do much on my own, but together we can change the world ... one child at a time.

When I picture the end of Rosalee's journey through public school, I see all of us there at her high school graduation, watching her walk across the stage, passing around the Kleenex—and getting ready for the biggest graduation party ever!



**Above:** The Deaf and Hard of Hearing Class invited Mr. and Mrs. Claus to read *The Night Before Christmas* and take Christmas requests from each child. (Mr. and Mrs. Claus were Mike and Sherrill Self, both deaf.)



**Left:** One of the outcomes of our meetings was that the school post signs throughout the building showing the ASL sign for each room/office—Art Room, Principal's Office, etc. The hearing students use this a ton!



# Parent to Parent: Tips for Advocacy

By Traci Penland

The following tips, many of them learned from my participation in Hands & Voices, may be helpful to parents. For more information, check out the Hands & Voices website, [www.handsandvoices.org](http://www.handsandvoices.org).

- 1. Get informed.** Without information, we cannot advocate effectively. We need to know what the law—the Individuals with Disabilities Education Act—promises our deaf and hard of hearing children. We need to understand the layout and language of an IEP and be able to craft and work with our child’s communication plan, and we need to know that the law is on our side. The best way to do this is through the *Hands & Voices Educational Advocacy Guidebook*, available on its website.
- 2. Involve Dad.** Most of the time, Mom does the research and works with teachers and officials from the school, but Dad’s participation is important, too. Okay, I know it’s frustrating for moms like me, but I’ve seen it again and again: when Dad shows up at the meeting, the school system takes note and ramps up its vigilance and responsiveness. Dad’s attendance at the IEP meeting is a signal to the school that this child’s education is important to everyone in the family. In my case, having Dad—my husband—was helpful not only because he is my daughter’s dad but because he is my trusted partner. My shins have been the recipient of what I call “a good kicking” (and what is actually a gentle nudge) from my husband. It’s his way of letting me know, “We get it; let’s move on now.” Further, a partner can share the role of asking for clarification when it’s needed and provide another person in the room to say, “So, by accommodations, you mean things you are going to do to help our daughter?”
- 3. Wear many hats.** Like most important relationships, the relationship with our school should be multifaceted. Sometimes we need to bring the latest research, and sometimes we need to bring brownies—a tip I learned from Lisa Kovacs, Hands & Voices director of programs. Sometimes our tone needs to convey the seriousness of our request, and sometimes we need to be silly and laugh. This doesn’t mean we should say one thing to the teacher and another to the director of special education; it means that every situation will require a thoughtful and appropriate response. Don’t go in guns blazing for the next request if the school has just given you something you asked for. This leads to the next tip.
- 4. Show gratitude.** It is important to not just feel but to show gratitude. There have been times when our school has agreed to our request, and it was only months later that I realized how big a deal it was, how many people and things had to move around to make it happen. Gratitude can be shown meaningfully in different ways: Etsy stars may want to spend a couple of nights in the garage fashioning leather engraved phone cases for the IEP team; photographers may want to take artful pictures of the school campus or (with permission) make a poster of the deaf and hard of hearing students to give to the teacher. For me, skilled only in shopping, a breakfast platter from Panera makes a great morning gift for the staff. The teachers and staff serve the students all year long, so don’t wait for the end of the year to treat; sprinkle gratitude throughout the year.
- 5. See the best in others.** We all know that teachers and administrators are overworked and underpaid. Their caseload keeps growing, but their support doesn’t. It is exhausting spending all day trying to balance the demands of parents and the school board. If something upsetting happens, go to the responsible person, give the person the benefit of the doubt, and get his or her side of the story. Don’t e-mail the principal. Ask the person for specific ways he or she can be supported, and then do it. Know that most individuals on the IEP team especially are likely going above and beyond, and they care about our children as much as we do. Walk in ready to collaborate. Of course, there is a time for due process, the legal recourse that the law gives parents. We must be grateful for this option, but recognize that it is the last option, and the *least good* option.

**Tawny Holmes**

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# Education Advocates: A New Frontier of Advocacy

*By Tawny Holmes Hlibok*

*I never had anyone understand my feelings [or] what my deaf daughter had gone through ... I so appreciate your putting all your knowledge and energy into changing the school situation and finally giving her a bright future. With your support, now we don't have to put up with the school assigning her menial tasks like sorting mayonnaise and mustard packets for two and a half hours every day. ~ Parent of a 19-year-old deaf daughter*

For parents and teachers, Individualized Education Program (IEP) meetings can be stressful. Worse, they can be ineffective—with parent, teacher, and student feeling that words were exchanged and passions ignited—without meaningful discussion, let alone effective development of or change in the student's educational program. One way to reduce the stress, expand the discussion, and perhaps improve the environment for a student is to bring to the meetings an Education Advocate, a person trained in federal law, familiar with IEP language and committed to working for the deaf or hard of hearing student. A trained Education Advocate can help teachers and parents understand important issues and support parents in understanding the IEP process.

As the need for such trained advocates became acute, the National Association of the Deaf (NAD), the civil rights organization of, by, and for deaf and hard of hearing individuals, stepped up and sent invitations to its state associations asking each to send a representative to be trained to the 2012 National Biennial Conference in Louisville, Ky. Twelve states sent individuals to this first training, and other states immediately joined the campaign. By 2018, all 50 states, plus D.C., Guam, and Puerto Rico, had joined, receiving an Education Advocate handbook with information about the role of the Education Advocate and the program itself.

Every NAD Education Advocate is deaf or hard of hearing, and most have a master's degree in deaf education and experience in teaching or working with deaf and hard of hearing students. They attend online trainings and at least one in-person training every year. Training sessions include everything from in-depth updates on

*Photos courtesy of Tawny Holmes Hlibok*





**Left:** Holmes Hlibok at one of her many education advocacy presentations with students, this one at the California School for the Deaf, Fremont.

**Below:** Felice Marcus, one of the Education Advocates in Florida, engages local deaf and hard of hearing children in a storytelling session at an education advocacy event.



relevant legislation—including provisions specific to deaf and hard of hearing children—to the role of deafblind intervenors, to ways to develop and apply negotiating skills. Education Advocates host events and workshops for families, advocate for legislative changes on the state or federal level, and meet with school administrators or government agency heads. In addition, they attend IEP meetings with parents and teachers.

In their role as IEP advocates, these trained individuals often sense the occurrence of imbalanced language dynamics and misunderstandings due to cultural issues. For example, at one IEP meeting, an Education Advocate met the student for whom she would advocate only a few minutes before the meeting began. As the meeting got underway, one of the student's teachers, who was a teacher of the deaf as well as a certified interpreter, announced she would function as both.

Immediately, the Education Advocate realized that she was in an ethically questionable situation. How could a student express herself freely about her experience in the classroom when she was dependent on her teacher for interpreting? When the meeting began, the ethical dilemma deepened. The student was asked to name her current goals, and the teacher/interpreter turned to the student and, instead of signing the words that had been spoken (i.e., "What is your current goal?"), asked a whole different question: "*You want to finish school and go work with your friend, Sheila\*, right?*" The student, smiling perhaps at the mention of her friend, nodded tentatively. Appalled at the twist in the question, the Education Advocate interrupted. She asked politely if she could take over the questioning, and once this permission was granted, she turned to face the student. Her questions were designed

to be neutral, to allow the student to be able to give a clear sense of who she was and what she wanted. "*What do you want to do?*" she asked the student. "*Do you like school? Do you want to finish school, or do you want more school, which? Do you want to learn more or go to work?*" The student said she did not want to work yet; she wanted to stay in school and learn more. The Education Advocate followed up by asking her in which subjects she wanted support, and the student responded, "Both English and math." This was what the student's mother had shared earlier with the advocate, so the advocate ended her questioning and the meeting continued. The IEP team members were unsure how to proceed, and later



**Left:** Members of the Education Strategy Team discuss education advocacy strategies. Pictured: Donna Valverde-Hummel, Dr. Melissa Herzig, Kim Bianco-Majeri, Onudeah Nicolarakis, and Susanne Scott.

it was learned that the school's administrators felt they had run out of classes to offer the student and wanted to see her graduate and leave the school. With the family's permission, the Education Advocate noted that the family was considering other schools and the tension in the room visibly reduced. She reminded the IEP team that placement (e.g., in which school) should not be discussed until goals and services were decided based on the individual student's needs (Individuals with Disabilities Education Act, 2004). The meeting ended with the IEP focused on what was best for the student, and after an independent evaluation and some paperwork, the student transferred to another school. She is now in a postsecondary educational program in which she is doing well, learning more English and math to assist with her dream of eventually working at a jewelry shop.

In another situation, the IEP team was skeptical of a deaf student's request to sit at a distance from an electronic speaker in the classroom. Sitting so near to the speaker gave her headaches, the student said, a claim that her teacher flatly did not believe. In fact, the teacher had accused the student of faking headaches and established her seat

permanently next to the speaker. With the support of an Education Advocate, the parents brought her audiogram to the IEP meeting and showed that the student had some hearing, was sensitive to vibrations, and, therefore, her request to put some distance between herself and the speaker should be honored.

In still other cases, Education Advocates have stopped situations in which students were misdiagnosed due to professionals who could not communicate with the student whom they were supposed to evaluate. In these cases, expectations were often placed lower than they should have been, which not only diminished the school's ability to serve the student but also the student's ability to learn grade-level information due to lack of exposure.

Low expectations are the bane of deaf and hard of hearing students, as too often hearing educators consider being deaf or hard of hearing a reason to expect low academic performance. When an Education Advocate was contacted by a mother concerned that her son's school was combining Total Communication and oral programs into one program without adequate planning or resources, the Education Advocate agreed to attend the upcoming IEP meeting by videophone. She was

surprised to see the IEP team discussing third-grade goals for a student in eighth grade. She asked the IEP team why the student, who had been exposed to language since birth and who had no other disability except Attention Deficit Hyperactive Disorder, was so far behind. When no one on the team could answer, she explained to the student's parent as well as the other IEP team members that being deaf should not warrant lower academic expectations. She further provided national resources on how they could adjust their programs and receive professional development and training to more effectively accommodate students who were deaf or hard of hearing. A recent Supreme Court case affirmed that services should be calculated to provide progress appropriate to the child's circumstances; for students who are deaf or hard of hearing, this includes the student making a year's progress in a year's time (Endrew, 2017).

NAD Education Advocates have also been effective in supporting students in private schools. In one private arts program, a student received a sign language interpreter only two days a week. The mother, a recent immigrant who was still mastering English, sought the assistance of an NAD Education Advocate. The advocate came to the meeting, explained the effective communication requirements of the Americans with Disabilities Act, and provided new guidance from the U.S. Department of Education and the U.S. Department of Justice on the appropriate protocol for ensuring deaf and hard of hearing students had language access (U.S. Department of Justice Civil Rights Division, 2014; U.S. Department of Education and U.S. Department of Justice, 2014). Upon



learning about those requirements and guidance, the private school immediately approved the student's request much to the happiness of the student and her mother.

Families have appreciated the assistance of Education Advocates as these advocates often assist not only at IEP meetings but also help families benefit from the advocates' experience and cultural knowledge as members of the Deaf community. Parents have reported that they are thrilled to finally have someone that understands their children's situation.

### **Now Available: A New Tool for Parents**

A wonderful new tool, the Parent Advocacy app, developed collaboratively by the Laurent Clerc National Deaf Education Center, NAD, the American Society for Deaf Children, and Hands & Voices, is now available both in Android and Apple versions. This free app includes videos, tips, resources, and checklists to prepare for school meetings, including IEP meetings, 504 plan meetings, and other related school meetings. Developed especially for parents of deaf and hard of hearing children, the app was released in May of this year.

Don't hesitate! Get ready to download

**Families have appreciated the assistance of Education Advocates as these advocates often assist not only at IEP meetings but also help families benefit from the advocates' experience and cultural knowledge as members of the Deaf community.**

**Below:** Hiwote Denu, one of the clients most impacted by NAD's direct IEP advocacy, and her family gave an award to Holmes Hlibok to thank her for making a difference.



the new app and seek an Education Advocate to provide you with information or support. For more information, including the qualifications of advocates and website contacts, visit [www.nad.org/educationadvocates](http://www.nad.org/educationadvocates). Also check out the annual National Deaf Education Conference ([www.deafeducation.us](http://www.deafeducation.us)), during which Education Advocates, teachers, other professionals, and families receive training.

*Note: Sheila\* is a pseudonym.*

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## CONSIDERATIONS WHEN DEVELOPING AN IEP FOR A DEAF OR HARD OF HEARING CHILD

**When developing a deaf or  
hard of hearing child's IEP,  
consider the child's:**

- Language and communication needs
- Opportunities for direct communications with peers
- Access to professional personnel who meet the child's language communication, academic, and social-emotional needs
- Access to direct instruction in his or her language and communication model
- Need for assistive technology

*Adapted from the Individuals with Disabilities Education Act, §300.324(a)(2)(i)-(v), at the Center for Parent Information and Resources.*

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## Tips for Education Advocacy

*By Tawny Holmes Hlibok*

✓ **Know what you and your child want and need.** Bring your notes and suggestions to the IEP meeting.

✓ **Check the state curriculum standards.** See if your child is on grade level or has age-appropriate expectations. For example, if your child is in third grade and has no additional disabilities, he or she should be learning third grade subject matter, and his or her IEP goals should be aligned with the Grade 3 standards in academic subjects.

✓ **Gather as much information as you can.** Talk to other parents, your child's teacher, and other service professionals who work with your child. Observe your child in the classroom after making arrangements in advance.

✓ **Be as calm and collected as possible.** If you are frustrated, seek an Education Advocate or other support—perhaps a counselor or other family member—to figure out the situation and what can be done to ensure the legal rights of the child.

✓ **Figure out a win-win situation.** As often as possible, look for ways the school itself can save money or benefit from your request. For example, if a school has difficulty finding an interpreter, offer school representatives assistance with networking or positioning advertisements or finding other students in the same category of grade or age who have similar interpreting needs.





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## LEARNING TO SELF-ADVOCATE:

# Why Active, Early Parental Involvement is Key

By Steven J. Wright

### Steven J. Wright,

PhD, is assistant professor of Deaf Studies and Deaf Education at Lamar University. He grew up in Buffalo, N.Y., where he attended mainstream public schools after becoming deaf at the age of 4. He learned American Sign Language at California State University at Northridge and graduated with a bachelor's degree in English from the University at Buffalo. Wright received his master's degree in organizational development from Medaille College, and in 2017, he received his doctorate in deaf education from Gallaudet University. His research interests focus on deaf critical theory, intersectionality in the Deaf community, and metacognition of deaf learners. Wright welcomes questions and comments about this article at [swright22@lamar.edu](mailto:swright22@lamar.edu).

Self-advocacy is not something that happens naturally. *Advocacy*, defined as “one who supports” (Merriam-Webster, n.d.), is an art form. Like many deaf or hard of hearing individuals, I learned the art of advocacy through a trial-by-fire process in which my parents and I struggled with the teachers and administrators of my public school. Together, we fought for and achieved programming that allowed me to experience more than we would have received had the educators and experts determined my programming alone.

I grew up in western New York, a hearing child born to hearing parents. I became deaf at age 4 from what my mother suspects was a high fever, though my audiological file lists the cause as an “unknown.” I was enrolled in an oral mainstream setting, learning and communicating with the use of residual hearing, FM systems, and hearing aids in keeping with the belief that deaf children should be able to produce measurably intelligible speech and recognize a measurable amount of spoken words; this would allow children like me to develop the skills to socially assimilate into hearing culture within postsecondary settings.

There are two problems with this approach:

1. Educators too often drive the educational ship, and parents are not empowered to make informed, educational choices.
2. Educators too often are immersed in a single educational ideology, often to the detriment of the deaf or hard of hearing child.

*Photos courtesy of Steven J. Wright*

**Right:** Wright with his mother.





This combination can lead to the conundrum of missed opportunities, language deprivation, and inappropriate programming that puts an undue burden on the deaf or hard of hearing child. Further, it stifles deaf or hard of hearing students' development of a skill they will require throughout their lifetime: the skill of self-advocacy.

### **A Lesson from Life** **Teaming up with Parents**

During the winter of fifth grade, my classmates—all hearing students in the school in which I, equipped with an FM system and speech therapy, was mainstreamed—began preparing for a spring concert in honor of St. Patrick's Day. As the concert took shape, a tangible excitement permeated the classroom during each rehearsal. I would watch as the other students performed. There were

various skits and songs and a rudimentary version of the Irish jig, but what fascinated me most was the limerick competition.

Although *limerick* is defined as “a structured five-line verse” (with aabba rhyme), we used the term in accordance with its earliest definition (i.e., poetry that originated in gatherings of partygoers in a certain region of Ireland (Oxford English Dictionary, [www.oed.com](http://www.oed.com)). In the limerick competition, students practiced reciting a poem again and again, seeing who could repeat the words with the most speed and precision. What fascinated me was how the students would face off against each other, each exclaiming faster and faster, until a winner was announced. Lunch immediately preceded rehearsals, and as we gathered in the cafeteria students would “slam limericks” at each other

until they were out of breath. I so wanted to participate, but rehearsals were scheduled during chorus, and chorus was scheduled during my speech therapy. Finally, I went to my teachers to ask that the schedule be changed, but they were resolute. Speech therapy was required. More important, they pointed out, “There is no point in you attending chorus ... you cannot sing.” I was crestfallen. During the long bus ride back to my house, I fought back tears. When I arrived home, I ran inside, found my mother in the kitchen, buried my head against her chest, and sobbed. She got down on her knee, clasped my head between her hands, and asked, “What is wrong?” My father, hearing the commotion, appeared. Through tears, I explained what happened. My parents told me that if being in the spring concert was something I really wanted to do, we



**Left:** Wright as a young child.

would make it happen.

This must not have been easy for my parents. They faced an educational system replete with confusing laws and a maelstrom of complex information to be parsed. Like so many parents, they tended to defer to educators and to acquiesce in what the school's experts told them was the best educational plan for their deaf son. Perhaps they also accepted the implicit message of the school and the surrounding culture—that the most important aspect of my education was learning speech and assimilating into hearing society.

The principal and speech teacher had not wanted me involved in the spring concert, but my parents insisted. The following week, we met with teachers and school administrators. Although I did not entirely understand the discussion, I felt the tension in the room, the friction between the adults. I also felt a sense of empowerment and solidarity. For the first time, somebody seemed concerned about what I wanted to do, not what the professionals thought. For the first time, I felt that

my needs were important, too. My parents and I were a team of three, and we were standing up against a slew of hearing educators who simply believed that people like me did not belong in school activities in which singing and dancing took place. My parents asserted that if a child wanted to sing, a child should be allowed to sing. The skill of the singing was not the issue. After all, it was unreasonable to expect that every hearing child in music or chorus classes would sing well. The issue was the opportunity to participate in the least restrictive environment to the extent allowed. Further, my parents wanted to know why spitting out words at rapid-fire pace could not be a natural part of my speech therapy.

In the face of our joint advocacy, school experts and bureaucrats backed down. I practiced the limerick slam with my speech therapist three times a week while attending chorus twice weekly. I sang badly, I'm quite positive, but nobody seemed to care. Spring rolled around, and it was time for the competition. I was a ball of nerves, but

when my turn on stage came, I caught sight of my parents among the audience beneath the blinding spotlight and the butterflies quickly abated. I went to the microphone and spat out what I had been practicing. I spoke rapidly, firing the words as if from a machine gun. I still remember what I said:

*Shake hands with your Uncle Mike,  
me boy  
And here is your sister, Kate  
And there's the girl you used to swing  
Down by the garden gate  
Shake hands with all of the neighbors  
And kiss the colleens all  
You're as welcome as the flowers in  
May  
To dear old Donegal*

*Meet Branigan, Fannigan, Milligan,  
Gilligan, Duffy, McCuffy, Malachy,  
Mahone, Rafferty, Lafferty, Donnelly,  
Connelly, Dooley, O'Hooly,  
Muldowney, Malone, Madigan,  
Cadigan, Lanihan, Flanigan, Fagan,  
O'Hagan, O'Hoolihan, Flynn,  
Shanahan, Manihan, Fogarty,  
Hogarty, Kelly, O'Kelly, McGuinness,  
McGuinn*

As I finished, the audience cheered. I did not win, but even today I remember the sense of accomplishment I felt. The meaning of participating in such an event with my peers was monumental—so monumental that I am able to detail it richly here nearly 30 years later. They say hindsight is 20/20 and in my adult years, I look back on this moment with the bittersweet sensation of pride.

I was proud to engage in an activity from which I would have been excluded had it not been for the joint advocacy of myself and my parents. Part of me admires the bravery I had at such a young age to defy school administrators and speak before an audience in an auditorium. Perhaps I did not perform perfectly, but the payoff was worth its weight in gold for confidence and the knowledge it gave me. After that, I felt



that young deaf children could participate in whatever their hearts desire.

### **From Student to Professor Advocacy Remains Critical**

Looking back, I see that this experience—my parents respecting me and coming to my defense, and the teachers, administrators, and deaf education specialists eventually supporting our decision—taught me the importance of advocating for what I knew was best for myself. It was a critical moment in my education. I learned the importance of advocacy, and I began to learn how to advocate. From that moment forward, my parents and I realized the importance of our involvement in my education. We came to consider our involvement especially important at meetings to discuss my IEP. The IEP can be a source of great benefit if and only if parents and their children are involved. After what we considered a victory, my parents encouraged my continual involvement in the IEP process, not just as a student, although that was important, but as a member of our family team.

Yet advocacy for me did not advance in a smoothly rising curve. Some decisions continued to occur without our input. For example, as a restless child, I longed to go outside every day for recess with my peers. I wanted to be in the sun. I wanted to exercise. I wanted to get my hands dirty. Instead, often I was pulled out of recess. I would be sent to speech therapy or another resource room meeting with an itinerant teacher. This led to unhappiness at home. I was lucky that my parents encouraged me to speak openly about what was working for me, what was not working for me, and what struggles I experienced at school. Since my parents encouraged me to engage in continuous dialogue with them, they were able to garner a more complete picture of what I needed and what I did not need.

In high school, I would engage in self-advocacy again, this time when I

convinced my parents that I did not need more speech therapy. Although they initially resisted—claiming that I was simply being a rebellious teenager—our discussions led to their realizing that I had passed the point where the rote work of repeated pronunciation was beneficial and, in fact, would conflict with other opportunities I wanted to pursue—like Advanced English Composition, Writing, and Literary Studies. Again, my parents and I made our position known, and speech therapy was removed from my IEP as a freshman in high school. This allowed me time to take classes that reflected my love of literature. As I progressed, my own desires were increasingly considered—both in conjugation with



**Above:** Today, Wright is a professor of Deaf Studies and Deaf Education.

my day-to-day programming and in alignment with my transition goals.

I ended up graduating with a Regents diploma, the college preparation degree for which New York is known and sometimes envied throughout the nation, with a concentration in English. In my case, succeeding in removing the supports that the experts initially recommended allowed me the necessary time to pursue the appropriate credits that led to a Regents diploma. It was

not until I matriculated at California State University, Northridge, however, that I was introduced to American Sign Language (ASL) and Deaf culture. From that day forward, I accepted myself as a Deaf person. Once I finally embraced who I was truly meant to be, I fell in love with my community, the language, and the shared experiences of other Deaf people—and I incorporated this love into my own sense of self. While I maintained my love of English literature, I adopted ASL as my language of preference. As an undergraduate, I learned to believe that a deaf or hard of hearing child can have the best of both worlds. Spoken English, speech therapy, and the ideals of the days of my childhood have a place, but they are only part of a successful approach, and one size does not fit all deaf children. In hindsight, I wish that a bilingual environment, in which deaf and hard of hearing children had access to ASL and English, had been available to my parents when I was enrolled in school.

Today, I have a bachelor's degree in English literature, a master's degree in organizational development, and a doctoral degree in critical studies. I am a professor of Deaf Studies and Deaf Education at Lamar University, where I teach research design, statistics, and methodology on the doctorate level and law and advocacy and ASL literature on the undergraduate level, a dual focus that fuels the passions I developed as I navigated public school while a child. I tell my deaf and hard of hearing students—young undergraduates who are coming into their own just as I did all those years go—that “being your own staunch advocate is the key to success.” I encourage them to recognize that neither teachers nor parents are always correct about what is right for the child in their classroom. Parents need to have meaningful dialogue with their children, and teachers need to engage in meaningful dialogue with parents. The risk parents take when accepting without question the advice of school personnel is that they may rob

their deaf or hard of hearing children of other ever-present opportunities. Especially in high school, discovering and putting together the best educational experience should be done together—with family, the child, and school personnel.

Every deaf and hard of hearing child deserves to be protected, allowed to participate in events with their peers and able to make their needs known. They rely on us—parents, caretakers, and educators—to be their advocates. As children navigate the K-12 years, watching and assisting in IEP meetings and other discussions, experiencing their parents' advocacy, they are empowered to become their own advocates. The young adults who are my deaf and hard of hearing students will go on to become advocates, counselors, IEP team leaders, and teachers of deaf and hard of hearing students all over the United States. Most have already found that the

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world too often discriminates against deaf and hard of hearing individuals, inhibiting access to education, employment, and recreation, and that the art of self-advocacy remains critical even as they move through their adult years and their professional lives.

Self-advocacy is an art. It requires diligent, unwavering knowledge of law and policy and the tempering finesse of soft skills in social graces. If they are fortunate, the first place children begin to learn this art is in school—and their first teachers are their parents.

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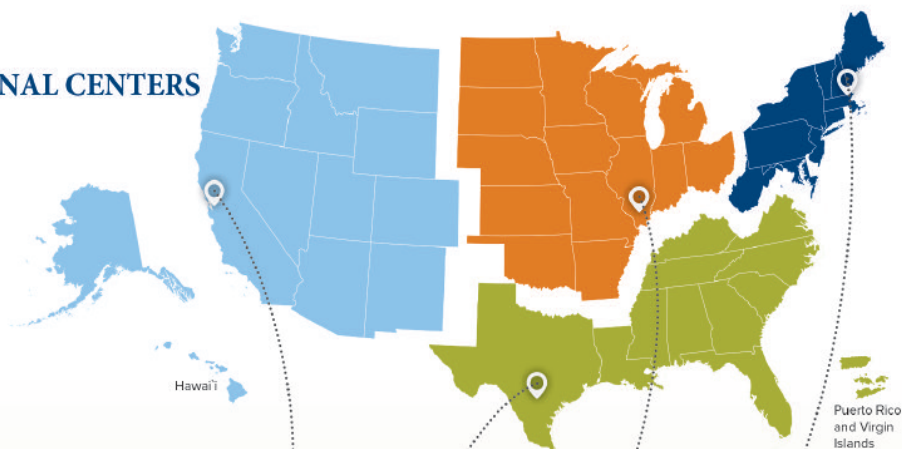
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## REGIONAL CENTERS

*Through partnerships with their host institutions, the Gallaudet University Regional Centers (GURCs) share Gallaudet's undergraduate and graduate programs and the Laurent Clerc National Deaf Education Center's resources and expertise through training programs, workshops and conferences, youth programs, technical assistance, and consultation.*

*For more information, contact us at [national.outreach@gallaudet.edu](mailto:national.outreach@gallaudet.edu).*



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# Assistance for Child Advocates: A Few Clicks Away

By Steven J. Wright

Research indicates that deaf and hard of hearing children are not present for their IEP meetings (Calderon, 2000; Luft, 2014), a troubling finding that confirms my own professional experience. Too often, I find that parents view the IEP solely as a way for determining the academics of their deaf or hard of hearing children. Yet the IEP affects life in the home as well as in school. If a child is organically integrated within a mainstream program, it has a dramatic effect on life at home and on the child's social and emotional development.

Younger students may have a difficult time articulating their needs; however, this does not mean that they cannot express desires, dislikes, and dreams. Parents can help their children simply by supporting them. They can buttress their children's expression and perhaps help them overcome shyness while serving as a communication intermediary to members of a professional IEP team.

Parent attendance and advocacy are critical to the child's well-being. Becoming an advocate for deaf and hard of hearing children may seem daunting to you as parents, but you are not alone. Advocacy is a skill that is supported by a wealth of online resources. Information necessary for advocating has never been easier to find. In this digital age, it may be just a few clicks away.

Here are places to start:

- **National Association of the Deaf** ([www.nad.org](http://www.nad.org))—NAD has a website that spells out key components necessary for advocacy, including the laws that relate to specific accommodations in educational settings for deaf and hard of hearing children. The website explains and offers guidance on the use of Section 504 of the Rehabilitation Act, which concerns employment rights, and the Individuals with Disabilities Education Act, which concerns educational rights, including how to establish an IEP team for your child. Further, NAD trains Education Advocates who can assist parents and families.
- **Laurent Clerc National Deaf Education Center** (<http://clerccenter.gallaudet.edu>)—The Clerc Center, located on the campus of Gallaudet University, offers valuable information and resources on its website. For example, *Odyssey*, in which this very article is printed, is published annually and offered free online as well as in print. Further, valuable resources for parents can be found under the New to Deaf Education tab, which offers resources on literacy strategies, early intervention resources, and includes a helpful guide on classroom interpreters for students in mainstream settings. Parents and paraprofessionals may also want to check out the 2019 Education and Advocacy Summit: Deaf Education that was held in February.
- **Lamar University** ([www.lamar.edu](http://www.lamar.edu))—Lamar offers a bachelor's degree through an advocacy track in education with some online options. Students from all backgrounds are welcome to take or audit courses. Parents, educators, and paraprofessionals are encouraged to explore programs and contact faculty or instructors for resources in their specialized areas.
- **Online collaboration** ([www.redefiningacademiccollaboration.com](http://www.redefiningacademiccollaboration.com))—Lamar University, Gallaudet University, Western Oregon University, and Towson University have developed a free website for parents, professionals, and paraprofessionals that explores a range of topics concerning individuals who are deaf, deafblind, or hard of hearing.

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**Ashley N. Greene-Woods**, MS, is a deaf education teacher in a public high school who has a decade of experience working in the field of deaf education in various roles. She obtained both her bachelor's and master's degrees in education of the deaf from Texas Woman's University and is currently a second-year doctoral student at Lamar University. A deaf ASL user born to hearing parents, Greene-Woods has two young children.

# Parents and Appropriate Assessment:

## Critical to the Education of Deaf and Hard of Hearing Children

*By Ashley N. Greene-Woods and Natalie J. Delgado*

It was 2010 and Jose, a 17-year-old deaf student in a western state, was earning A's and B's when his mother learned that he would not graduate. Jose's mother did not speak English. She had not attended any school meetings, and no one at the school had sought her out. Instead, the school had put her son, a boy of average intelligence, into special education. From kindergarten through high school, Jose had been in class with students who had intellectual disabilities, some of them severe. Only when it was time for graduation did his mother realize he was reading at the second- or third-grade level (Koehler & Whelan, 2015).

Professionals in deaf education can take heart that it was the Yakima Hearing and Speech Clinic that referred Jose's mother to a parent advocate, and it was the parent advocate who finally arranged a meeting with Jose's teachers. At the meeting, one of the teachers—who earlier had humiliated Jose by tearing up his paper before the class—admitted she had not known Jose was deaf (Koehler & Whelan, 2015). With graduation looming, a lawyer took Jose's case, a hearing was held, and a judge issued a scathing opinion: The school district had failed to provide Jose with a free and

**Right:** Greene-Woods teaches an ELA lesson and provides feedback on her deaf student's work.

*Photos courtesy of Ashley N. Greene-Woods and Natalie J. Delgado*





**Natalie J. Delgado,** MS, is a first grade teacher at the Louisiana School for the Deaf with nine years of experience in deaf education in various roles. She obtained her bachelor's degree in psychology from Gallaudet University, her master's degree in deaf education from Lamar University, and she is currently a second-year doctoral student at Lamar University. A Latinx deaf ASL user and a speaker of English and Spanish, Delgado was born to hearing parents.

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appropriate education and, therefore, the school district would pay the family \$1 million and agree to teach Jose for an additional six years at a cost of \$250,000 a year (Koehler & Whelan, 2015). The judge noted that the school had given Jose work below his grade level rather than adequately address his deafness (Ferolito, 2015). When the school district refused to accept the verdict, a Yakima county superior court judge lowered the six-year educational extension to four years but kept the \$1 million award to Jose and his mother (Ferolito, 2015).

As those involved in the education of deaf and hard of hearing children, we can only respond to Jose's case with sadness and anger. We know that when deaf and hard of hearing children are isolated in classes with only students who are intellectually disabled, the result can be a tragedy. Such classrooms are not always suitable for deaf and hard of hearing children and their unique needs. We know that hearing aids alone do not guarantee deaf and hard of hearing children full access to communication, and amplification does not guarantee deaf and hard

of hearing children full participation in academic life. We know that despite the financial award and four extra years of private teaching, Jose will never be compensated for the priceless early years of his education that are now lost forever.

There were so many missteps in Jose's case, according to news accounts: the director of special education had signed off on Jose's Individualized Education Program (IEP) when she had not been present during its development. Jose's hearing loss was never addressed by the school; in fact, the school attempted to blame Jose for his lack of accommodation by saying he was "at fault for not using effective hearing aids" (Koehler & Whelan, 2015). Jose had been situated—"warehoused," the newspaper headline said—with less than effective hearing aids in classes for intellectually disabled children (Ferolito, 2015). We may never know the specifics of why Jose was failed by his school system. Was it the evaluation? Was it the implementation? Was it indifference? We do know that sometimes evaluations are inaccurate for deaf and hard of



**Above:** A deaf high school student works on an autobiographical piece.

**Below right:** Each deaf or hard of hearing child is at the center of controversial discussions, such as which classroom placements are appropriate, which language is appropriate, and how amplification should be encouraged.

hearing children, and we do know that Jose's mother had not been part of the process that determined her son's education.

### Evaluators and Parents Critical for Deaf Children

Jose's situation presents an extreme example of what can happen to deaf and hard of hearing children in our nation's schools when assessment data is either inaccurate or ignored and parental input is absent. Presenting a unique challenge to the educational system, each deaf or hard of hearing child is at the center of controversial discussions, such as which classroom placements are appropriate, which language is appropriate, and how amplification should be encouraged. As Jose's situation illustrates, these decisions are some of the most important in a child's life.

Evaluations of students' placement, language, and use of technology decisions require the work of specialized professionals who administer evaluations developed by other specialized professionals. Each should have certification in his or her field, and certification should be evidence of qualification. Those who are involved in assessment impact the results. If an evaluator cannot communicate with the child he or she is evaluating, the resulting evaluation may be suspect. Even if the evaluator uses a sign language interpreter, information can get lost. In fact, only 25 states have minimum requirements for public school interpreters (Registry of Interpreters for the Deaf, n.d.). This lack of nationwide standards means that a wide range of skills exists among educational interpreters. In fact, so few educational interpreters are qualified and certified that they are often referred to as "unicorns" among deaf educators.

Compounding the difficulty is the unique relationship of

deaf and hard of hearing children to the English language. Many of these children achieve ongoing access to English for the first time when they arrive at school. This linguistic barrier is exacerbated when tests are administered by evaluators who are unfamiliar with deaf and hard of hearing students and their unique linguistic and cultural needs. Then these assessments are documented in the child's IEP, a legal document that is used for decision making about the child's school, classroom placement, goals, communication, and experience. In order to ensure the information in the IEP is an accurate reflection of the child's abilities, it is critical that deaf and hard of hearing students are served by skilled evaluators who are familiar with their linguistic and educational needs.

A Bill of Rights published by the National Association of the Deaf stresses the importance of having professionals who are knowledgeable about language acquisition for deaf and hard of hearing children present on the evaluation teams (National Association of the Deaf, 2016). When the assessor is unfamiliar with sign language and thus cannot assess the qualifications of the interpreter, there is no way to be certain that communication occurs and that the resulting evaluation is valid.

Parents need to be involved in every aspect of their child's education not only because they bring important information to the process but also because they can question and even provide insight into the assessments, and they provide oversight to the assessors. Often the most important members of the IEP team, in which evaluation results are discussed and a course of learning is decided, are the child's parents. Parents have the right to participate in developing their child's IEP. They have the right to question or suggest changes in placement, services, interpreters, and assistive technology. They have the right to request further evaluation. If parents disagree with an IEP team or its decisions, they have the right to appeal. School

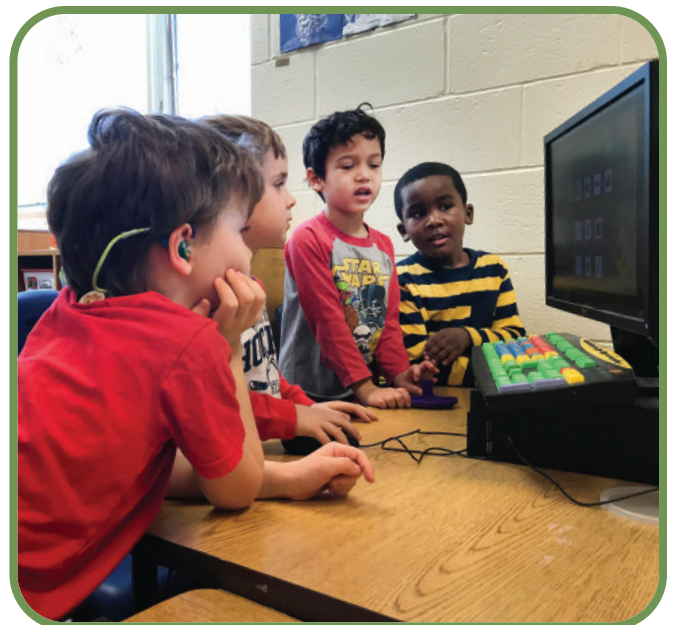


PHOTO CREDIT: CAT VALCOURT-PEARCE



professionals only get so much time with each child, whereas parents are with their children throughout their first years and, therefore, can be more aware of their emotional and mental needs.

The presence of parents can mitigate against the sort of costly mistake that occurred with Jose. In Jose's case, the price of the school's failure to accommodate a deaf child was excruciating in terms of the financial obligations of the district and, even more important, in terms of the child and his academic and emotional well-being. According to his attorneys, Jose's intensive tutoring brought his reading, writing, and math skills to a high school level. He has learned sign language, and he hoped to enter postsecondary education (Koehler & Whelan, 2015). However, there is no way to know how many "Josés" are still in our schools or to measure how many of the nation's deaf and hard of hearing children have been affected by minor misplacements or even misdiagnoses. Still, accurate assessment, rooted in cultural as well as in academic understanding of the deaf or hard of hearing child, and parental involvement in every child's education can mitigate a situation like Jose's from ever occurring again.

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## Resource

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## ASSESSING THE DEAF OR HARD OF HEARING CHILD:

### Four Key Points

By Ashley N. Greene-Woods and Natalie J. Delgado

.....

*Imagine yourself a 6-year-old in elementary school, pencil tapping on a strange table in a small room with a person you haven't met before. Your interpreter is sitting by this strange person, but your interpreter is acting more formal than usual and saying, "You can do this yourself." The strange person pulls out books and flashcards, then asks you to answer questions about pictures. You begin to feel anxious because you're not a great signer, and you're not great with English either. In fact, you have just begun to acquire formal language.*

.....

Access to language is perhaps the most important aspect of the education of students who are deaf or hard of hearing. Nevertheless, parents must remember that these students, unless they have other disabilities, should be working on grade level with their hearing peers. Assessment can make a big difference. As they discuss assessment for deaf and hard of hearing students, parents should consider the following:

- 1 Deaf and hard of hearing children should be assessed in each of the languages they use.** Ideally, the assessor would be qualified to provide the assessments in each of the child's languages—English, American Sign Language, Spanish, or whatever language is used in the child's home. If an interpreter is used, the interpreter should understand how the assessment process works and the role of the interpreter.
- 2 Deaf and hard of hearing children should be administered more than one language assessment.** Sometimes it is hard to tell if language deprivation, developmental delay, or even just cultural difference has rendered the assessment invalid. A variety of language assessments can help narrow this issue.
- 3 Deaf and hard of hearing children's language assessment should be considered in tandem with their language background.** If the child uses home signs, gestures, or pointing, the evaluator needs to be mindful of the fact that their assessments may look different from a child who was raised with full language access from birth and, therefore, speaks or signs fluently. Language is not only the primary tool of a child's expression but impacts the way that child understands the world. Evaluators need to be sure that they can understand the child and his or her frame of reference.
- 4 Deaf and hard of hearing children's parents should be important advocates on the assessment team.** In many cases, the professionals who assess children are not afforded the luxury of spending quality one-on-one time with the child to learn his or her individual needs. Parents alone may know these. At times, evaluators may miss something that the parent thinks is important. Parents must be there to disagree or raise questions.

**Oscar Ocuto**, MA, a doctoral candidate in the Deaf Studies and Deaf Education program at Lamar University, owns 512 Terps, a sign language interpreting agency in Austin, Tex. He earned his bachelor's degree in secondary English and education and his master's degree in deaf education from Gallaudet University. Ocuto's work focuses on the role of sign language in the home and how sign language benefits deaf children's critical thinking skills. Ocuto lives in Austin with his family, including two children (Cameo, 6, and Rocco, 2). He welcomes questions and comments about this article at [ooocuto@lamar.edu](mailto:ooocuto@lamar.edu).

# A Family's Advocacy:

## Reflections of a Deaf Son

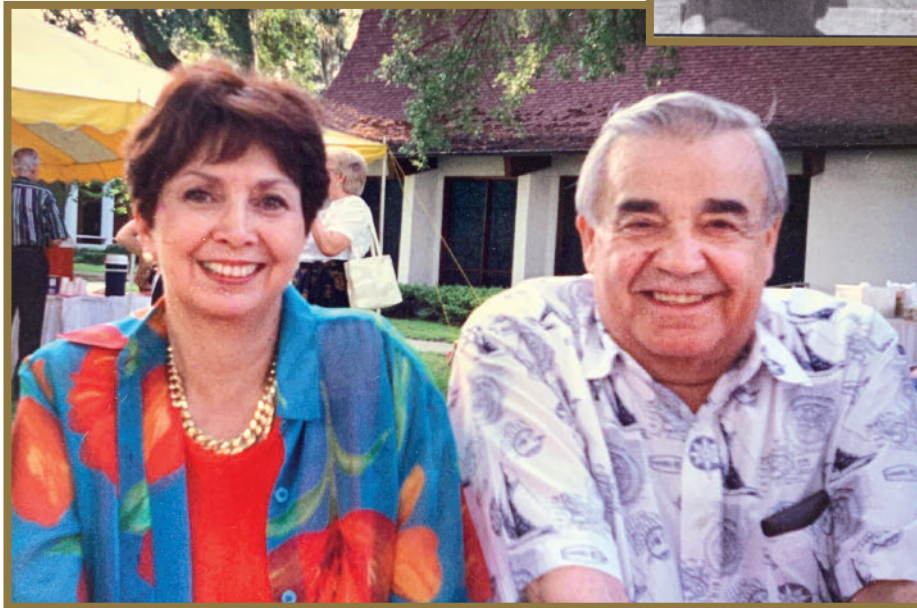
*By Oscar Ocuto*

I remember asking my mother at different points in my life why I could read better—generally handle English better—than my friends. Mama would always consider the unusual depth and speed of my language and literacy development and respond with a variation of the following: *“I refused to accept what the doctors were telling me. I refused to accept that you, my son, could not learn constructively and would not amount to more than a forever dependent individual in society just because you ended up being deaf.”* This—her refusal to accept the negative opinions of some professionals and her determination to make sure that her son succeeded academically and socially—is perhaps what began my mother's advocacy. While my father's advocacy was less focused on my schooling, I have developed a sense of appreciation for the advocacy of both my parents. This meant that as an independent and self-sufficient adult, I have come to appreciate my parents' stories.

My mother, Elaine Fasquelle, was born in Tela, Honduras, in 1938. Her father, Oscar, who is my namesake, worked for the United Fruit Company (now Chiquita), the international banana exporter. Mama eventually found herself working for Taca, a small airline that flew between the United States and Central America. She later transitioned to Pan American Airways, a job that allowed her to travel the world through the 1960s and 1970s. My father, Arthur Ocuto, was

*Photos courtesy of Oscar Ocuto*





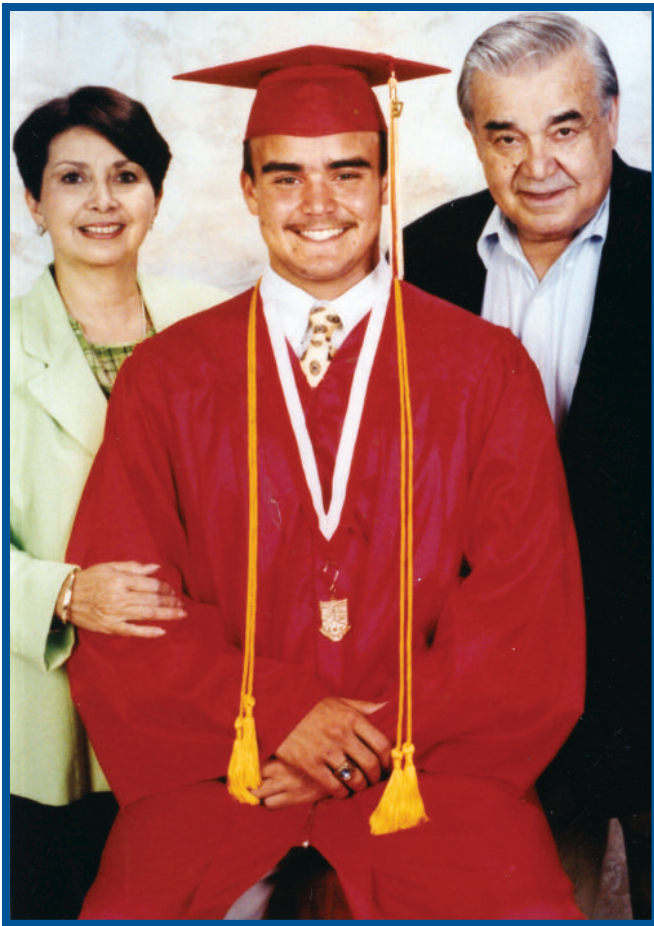
**Above, clockwise from left:** Ocuto with his father, Arthur; with his mother, Elaine, in 1988 as she spoke at a rally to support keeping FSDB open; supportive, involved parents.

born in Somerville, Mass. His parents, Giuseppe and Anna Ocuto, immigrated to the United States from Sicily, passing through Ellis Island in the early 1920s. Daddy would eventually do a stint in the Navy, working as part of the crew assigned to clean up in the aftermath of the Pearl Harbor attack. He came back home to New York City and then worked for the Ford Motor Company, a job that required a significant amount of travel. At one point, Daddy was a passenger on a Pan Am flight on which my mother was a flight attendant. She must have made an indelible impression! After the plane landed, he asked her out to dinner. It was November 1961, and, as they say, the rest is history.

For the first 13 months of my life, I was hearing. I learned to walk and to talk, following the normal timetable for developing toddlers and speaking Spanish, the language of my parents and my own first language. Then I contracted meningitis. The bacterial infection rendered me completely paralyzed on my right side and critically ill. My mother slept by my bed at the Sacred Heart Hospital in

Philadelphia, Pa. She prayed every moment of the day and every night, but I continued to get worse. One night, as the realization of her son's impending death set in, she would always say she only felt divinely grateful. She thanked the Lord for bestowing on her the opportunity to experience motherhood, and she asked that God take her only son home with Him if that was how He saw fit. Not long after, she fell asleep. The next morning when she woke up, the doctors told her that her son had experienced a remarkable anomaly; the fever had finally broken and the paralysis had disappeared. I was recovering.

Days later we went home, and my family's life returned to normal except for one small detail. Mama noticed that when she called my name—Oscar most of the time, but *Oscar Lucanus!* when I was doing something I should not be doing—I showed no response, not even an acknowledgment of her voice. Mama tried the well-known pots and pans test, dropping them behind me with their attendant thud; I did not respond. We went back to the hospital for confirmation. The doctors said what Mama



**Left:** Ocuto with his parents at his high school graduation.

already knew: I had survived meningitis but at the expense of my hearing. I was deaf.

### **Guidance Leads to Knowledge Knowledge to Advocacy**

Fortunately, Sacred Heart, the hospital where I had undergone treatment for meningitis and had my deafness measured, had a relationship with the Parent Infant Program at the Pennsylvania School for the Deaf (PSD). My mother was referred there. Mama said that the first day she visited PSD and saw people moving their hands, she had no idea what the movements meant but she felt that using them made sense. Since my aural world was closed off, my visual world needed to be heightened. Sign language made sense to her.

Not long afterwards I was enrolled at PSD and Mama, having procured *The Joy of Signing*, was learning signs. She would thumb through the book for the signs she needed to make sentences to talk with me. She began volunteering at school. As she opened up communication with me at home and reinforced her learning in the halls and classrooms of PSD, she was already on her journey to advocacy.

I was in the Parent Infant Program when PSD announced the closing of its high school. My father was figuring out a way

to start his own automotive export/import business. He had a group of clients from Central America and began thinking about relocating the family. With the upcoming changes at PSD and in his work, a family move made sense. Like so many parents of deaf and hard of hearing children, my parents prioritized my education as they considered moving. They looked for states with deaf programs and settled at first on a move to Miami, where they planned to enroll me at the Florida School for the Deaf and Blind (FSDB) because of its Total Communication policy. Total Communication, which later became known as Sign Supported Speech, was what we used at home. When Mama found out that Miami was a five-hour drive from FSDB, we instead decided to make our home in Jacksonville, about 35 miles north of the school, and we eventually settled in St. Augustine Beach, only a few minutes away. Mama took an early retirement from Pan Am so that she could stay home with me full time.

By now I was 7 years old, and Mama's sign skills had reached the point where she and I had meaningful conversations. Her signing enabled me to access language at home and to appreciate from a young age her interest in my education and, therefore, its importance. Daddy traveled extensively so our communication was a mix of rudimentary signs, spoken English, fingerspelling, and hand gestures, and our relationship became complicated because of our inability to converse without difficulty. Actions can, and do, speak louder than words, however, and I never doubted his love.

Daddy would bring back souvenirs from his work in Mexico, *luchadores*, tiny action figures, and recount as best as he could the experiences of enjoying *antojitos* that he bought from vendors on the way to the wrestling matches. He taught me to fish, filet my catch, cook it, and prepare meals on camping trips. As I grew older and became more involved in sports, my father was there for the vast majority of my games whether they were home games at FSDB or on the road against other schools. Daddy even traveled behind the football team bus by himself, driving 10+ hours from Florida to North Carolina to see me play football against the Eastern North Carolina School for the Deaf.

### **Mama's Advocacy Grows From Teacher Meetings to Conferences**

My mother became a certified interpreter and, with three languages at her command, she interpreted part time and was eventually hired at the school. Working at FSDB allowed Mama to build her knowledge of the special education laws and regulations through her relationships with administrators. She attended parent-teacher meetings, including my Individualized Education Program meetings. She would arrive with her confidence, her signs, and her high expectations but as



I grew older, she would not speak for me. My mother would make sure I answered the educators for myself. She felt it was important that I actively be involved in shaping my own long-term goals.

Mama participated in parent advocacy groups (i.e., Florida Concerned Parents of the Deaf, American Society for Deaf Children), and she cultivated relationships with officials both at FSDB and at the mainstream schools I attended through FSDB. She also went to the biannual conferences of the Convention of American Instructors of the Deaf as well as the Conference of Educational Administrators of Schools and Programs for the Deaf to further expand her network of advocacy. As I progressed through school, she continued developing her understanding of how special education laws could benefit my educational needs.

Mama's personal involvement enabled her to communicate to my teachers her high expectations for my academics both at school and at home. She would meet with each of my teachers to ensure she understood what support was needed at home to bolster academic performance at school. Often I kept a journal, recording events as they transpired and facilitating communication between home and school. We were fortunate that the school responded well to Mama's expectations. In a sense, Mama was the quintessential networker—she knew the value of taking the initiative in communicating expectations, understanding how these expectations could be met, and then

applying the process at home to ensure my academic development.

In fifth grade, a threat to the FSDB budget led to a rally in the state capital of Tallahassee. My mother took the opportunity to explain to me PL 94-142, the original federal law that mandated free and appropriate public education for deaf children, and I began to understand my rights as a deaf child. I addressed the rally, too, explaining how my education—attending some classes within FSDB and other classes in nearby mainstream environments—conformed to the parameters of the law and were essential to me as a young deaf individual.

### **Not Limited to School Hours** **Ongoing Advocacy**

Mama used her sign skills to continuously interpret and explain things to me. Her constant signing showed me so much about the world, including the fact that it continued moving on regardless of whether or not I was attuned to it.

I have fond memories of the summers we spent with my cousins in Honduras. Although I knew rudimentary Spanish, my mother was ever present, always interpreting and making sure that I knew what was going on around me. Whenever possible, Mama insisted that I chronicle these trips via journaling and brought artifacts back to school so that my teachers could integrate my experiences into formal educational



## **CONNECT WITH LEADERS. DISCOVER A PASSION. INFLUENCE LIVES.**

### **DEAF AND HARD OF HEARING INFANTS, TODDLERS AND FAMILIES: COLLABORATION AND LEADERSHIP INTERDISCIPLINARY GRADUATE CERTIFICATE**

The Infants, Toddlers, and their Families certificate program is an 18-credit program offering courses online and on-campus.

The program offers a range of disciplines with current evidence-based knowledge and skills for working with families and their very young children who are deaf or hard of hearing.

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**Left and below:**

Ocuto with his mother on Gallaudet's football field; a recent family photo.

activities. Sometimes I felt Mama—in her continuous interaction with the school staff, her fluent communication skills, and her determination that I learn about the world and how to navigate through it—could be overbearing. In

fact, she was a “helicopter parent” at a time before the term was invented. When I asked her about this, she would respond, “One day you will understand why my fight now will benefit you as an adult.”

Daddy died while I was still in graduate school, and I so regret that he never had the opportunity to see me become a man, start a family, and be a father. Mama, who had risen to become executive assistant to the superintendent at FSDB before she retired, lived to see me

progress through graduate school, get married, and welcome her first grandchild. She died in 2014, but I see the effect of her work and that of my father every day in our lives. As I try to pass on their values to my children, I realize that my mother was unusual in the skill, depth, and persistence of her advocacy. Her determination to communicate with me, her advocacy within the schools and in my personal life, as well as her love, made me the man I am today.



## Resources for Parents and Educators

The following resources may be helpful for parents and educators who seek more information about working together to benefit deaf and hard of hearing students.

### Websites

- American Society for Deaf Children (see Parents & Families), [www.deafchildren.org](http://www.deafchildren.org)
- Hands and Voices, [www.handsandvoices.org](http://www.handsandvoices.org)
- Laurent Clerc National Deaf Education Center, <http://clerccenter.gallaudet.edu>
- LEAD-K, [www.lead-k.org](http://www.lead-k.org)
- National Association of the Deaf, [www.nad.org](http://www.nad.org)
- Parents of Deaf Kids: Sign Language, Community, Culture, [www.facebook.com/groups/ParentsofDeafKids](https://www.facebook.com/groups/ParentsofDeafKids) [SignLanguageCommunityCulture/permalink/612005225816289/](https://www.facebook.com/groups/ParentsofDeafKids/permalink/612005225816289/)
- Visual Language & Visual Learning (VL2) Parent Package, <http://vl2parentpackage.org>

### Books

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# How to Best Support Families and Caregivers

## Who Are Disconnected, Alienated, and Underserved

### SO THEY CAN BECOME INVOLVED AND EFFECTIVE ADVOCATES

*By Mary Ann Kinsella-Meier*

In educational settings, where decisions must regularly be made related to what type and focus of services to provide, having a parent/caregiver advocate in their corner can be very important to children who are deaf or hard of hearing. In fact, when the Clerc Center reviewed public input from families, caregivers, and professionals in deaf education (2010-2012), strengthening the partnership between a family and their child's school or agency became a priority area (Szymanski, Lutz, Shahan, & Gala, 2013).

As a result, a major focus of the Clerc Center Strategic Plan 2020, or CCSP 2020, is to support all groups to recognize the importance of parental advocacy and involvement, and to do that by strengthening both sides:

1. Increase parent/caregiver knowledge about special education law and their children's specific needs so that they may advocate effectively for them, including at team meetings.
2. Increase awareness among school and agency educational professionals about the needs of deaf and hard of hearing children, and about the value of a parent or caregiver advocate (Gallaudet University, 2015).

As challenging as it may be for family members to advocate for what they believe is best for their child, the task can be far more difficult for families who may be disconnected,

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*Photos courtesy of Ruth Reed*





PHOTO CREDIT: MATTHEW VITA

alienated, or underserved. Therefore, it has become a goal of the Clerc Center to figure out how to better support those families. Who exactly are these families?

The **disconnected** do not view themselves as included with others but as a burden to others (Bryan, Morrow, Anestis, & Joiner, 2010).

Families described as **alienated** experience uneasiness due to their “exclusion, or self-exclusion, from social and cultural participation” (Hajda, 1961), particularly when it involves the special education process (Jung, 2011). For example, culturally and linguistically diverse individuals experience strong feelings of isolation, powerlessness, and alienation during the Individualized Education Program (IEP) process, which can become too overwhelming for them to defend their opinions (Jung, 2011). This can become true for anybody; it is “not affected by an individual’s background, social stature, or age” (Dean 1961). Personal experience has shown some of us that anyone can become alienated sometimes. Some parents have two roles: as a parent of deaf or hard of hearing children or children with learning needs and as a professional who works with deaf or hard of hearing students. In this situation, we as parents can find ourselves joining a meeting with our



**Above and below:** The more families can be advocates for their children and support their progress, the better their children do and the longer they stay in school (Henderson et al., 2007).

coworkers about our deaf or hard of hearing child and still experience worry that we may not be able to express ourselves well enough to get what we feel our child needs. Although this may be an uncomfortable feeling, it gives us a special perspective of what other families experience.

The **underserved**, by definition, are “not getting enough help or services” (MacMillan Dictionary, n.d.). This group includes those who grew up in poverty and attended resource-poor schools (Rendon, 2006). Also included are families newly arrived from other countries, even if their children were born here or arrived at young ages. Included, too, are families on the other end who may have lived here for generations but have maintained cultural customs. Unlike newly arrived families, they may also have stayed in cultural communities that are different from the predominant Anglo European beliefs of the United States. Still others among the underserved are children or families who are significantly more mobile than families in general. The parents may be migrant workers, or the children may be in foster families or in the juvenile justice system.





**Left and below:** Parent-to-parent advice is invaluable in helping parents learn to advocate for their children.

## Defining “Parent Advocacy” or “Family Advocacy”

As we seek ways to encourage advocacy among those not of the predominant Anglo American culture, we should first ask whether the value given to advocacy is itself culturally based. Some cultures, and thus some immigrants and first generations, expect the school to control the planning of their child’s education (Trainor, 2010). The “culture” of teachers and educational administrators may sometimes agree with them.

Kalyanpur, Harry, & Skrtic (2000) noted that decisions made during IEP meetings are influenced more by assessments provided by the educators involved than by the anecdotal reports of parents. Lake and Billingsley (2000) listed further circumstances that can frustrate any family’s ability to advocate. Some of those situations seem especially relevant to the disconnected, alienated, or underserved. They include an imbalance of knowledge between school and the parent/family advocate, financial or time constraints, and communication breakdowns.

According to Scheetz (2004), the dominant Anglo American culture values “independence, freedom, assertiveness, equality, self-help skills, and self-directedness.” The key parts of advocacy—self-reliance, direct communication, and individualism—are encouraged, if not expected. These values may not be the same values shared by families from other cultures. Therefore, these families may reject, or have difficulty accepting, these Anglo American norms, values, and beliefs. Interestingly, the Individuals with Disabilities Education Act (IDEA) never mentions the term *advocacy*. Instead, it uses the word *participation*. As Trainor (2010) observes, that term can “invoke a range of involvement comportment, from passivity to adversarial, which may or may not include advocacy.” How can parents (or others who are temporarily or permanently taking on parental roles) be supported as they seek productive ways to participate in their child’s case?

## Possible Actions

It’s one thing to know that research shows parental involvement improves student achievement and school attendance while dropout rates also decrease. Research also shows that this is true for families of all socio-economic backgrounds, races, and ethnicities. However, it’s another thing to encourage that involvement from parents who feel and/or are disconnected, alienated, or underserved.

When we see family members hold back from speaking out about their children’s needs and strengths, we want to show them how valuable they are and stress the importance of sharing their insights with the educational team. An observation by Wright and Wright (2014) might be helpful here. They noticed that a child’s parent or guardian has the most detailed knowledge of a child’s interests, strengths, and challenges, and the greatest interest in what’s best for their child. As Henderson, Mapp, Johnson, & Davies (2007) stated, “The more families can be advocates for children and support their progress, the better their children do and the longer they stay in school.” In a PowerPoint presentation based on their book, Henderson et al. listed suggestions of what makes a family member a successful advocate for a child:

- An awareness of how the system works
- A willingness to work with school personnel to plan the child’s future
- A motivation to steer their child to higher-level classes or programs
- Knowing how to get help if needed, and to speak out for their own child and for other students and families, if problems develop





**Left:** Recruiting families as volunteers is one way to involve them in their child's school community.

- Provide language classes for families. These classes could include sign language classes.
- Publish reports about school board meetings and lists of coming events in multiple languages.

One of the most cited models of parental involvement was discussed by Epstein & Sanders (2006). It consists of six primary areas for schools to consider when attempting to keep families informed and to involve them and their communities in their children's educational activities:

1. **Parenting**—Assist families with parenting and childrearing skills, creating opportunities at home that support learning.
2. **Communication**—Through two-way communication, keep families informed about school programs and the student's progress.
3. **Volunteering**—Recruit families as volunteers.
4. **Learning at home**—Involve families with educational activities that support classroom learning.
5. **Decision making**—Include families in the discussion and decision-making process.

Henderson et al. also offered suggestions for advocating for a child with special needs in general, but these suggestions may also apply to families with deaf or hard of hearing children. These include:

- Building positive relationships with teachers
- Having a clear understanding of the IDEA and the educational process
- Planning for the long term, not just the current school year

### Parent Experiences and Priorities

Parent-to-parent advice can be some of the most trusted by the disconnected, alienated, or underserved. The Clerc Center recently completed a survey in which parents identified important strengths for successful advocacy. These included a knowledge of a child's strengths, weaknesses, academic performance, and legal rights. The parents offered the reassuring reminder that learning to advocate is an ongoing process, and that others can sometimes assist with advocacy efforts, including audiologists, friends, and parent support groups (Jackson & Lutz, 2016).

The variety of cultural norms among a school's families should not be viewed as a problem but a way in. Visiting new families in their homes can be one way of learning about, and committing to, those cultures, and recognizing and supporting differences in the forms of parental involvement:

- For instance, Hispanic/Latino families value the strength of family ties. Talk with families to learn how to integrate home activities with learning activities encouraged by schools to use at home.
- Work with human resources personnel at family members' work places to coordinate shifts and work schedules with school calendars to allow for parental involvement with the child's homework and attendance at meetings at school.



PHOTO CREDIT: CAT VALCOURT-PEARCE

6. **Collaboration**—Work with the families as well as with their communities to enhance student success.

The fifth category, decision making, brings us full circle. Supporting a family in its advocacy efforts can nurture their natural tendency to stand up for their child into an expertise in identifying what will work and an ability to express that to school personnel. In the words of DesGeorges, Johnson, and Seaver (2013), “A parent becomes an effective advocate when she blends her expertise in special education law with an ability

to skillfully turn theoretical knowledge into practical applications that work on an IEP for her child.”

Wright and Wright (2006) presented an equally positive conclusion for all groups. They pointed out that when informed parents present information on their child’s educational needs and legal rights, that can lead to “a healthy working relationship with the school”—and, in this case, to better educational outcomes for deaf and hard of hearing children.

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# Parent Advocacy App: Assisting Families of Deaf and Hard of Hearing Children in Grades K-12

*By Mary Henry Lightfoot*

*How can I better participate in my child's Individualized Education Program (IEP) meeting? I really don't even understand what this "IEP meeting" means! What's the difference between a 504 meeting and an IEP meeting? Does my child need an IEP or a 504 plan? Why doesn't my child have any of these things?*

Advocating for your deaf or hard of hearing child can be a daunting task ... and intimidating. So many professionals around a table ... and you as the parent. What can you do as a parent to advocate for your deaf or hard of hearing child? Why is advocating for your child at school meetings important?

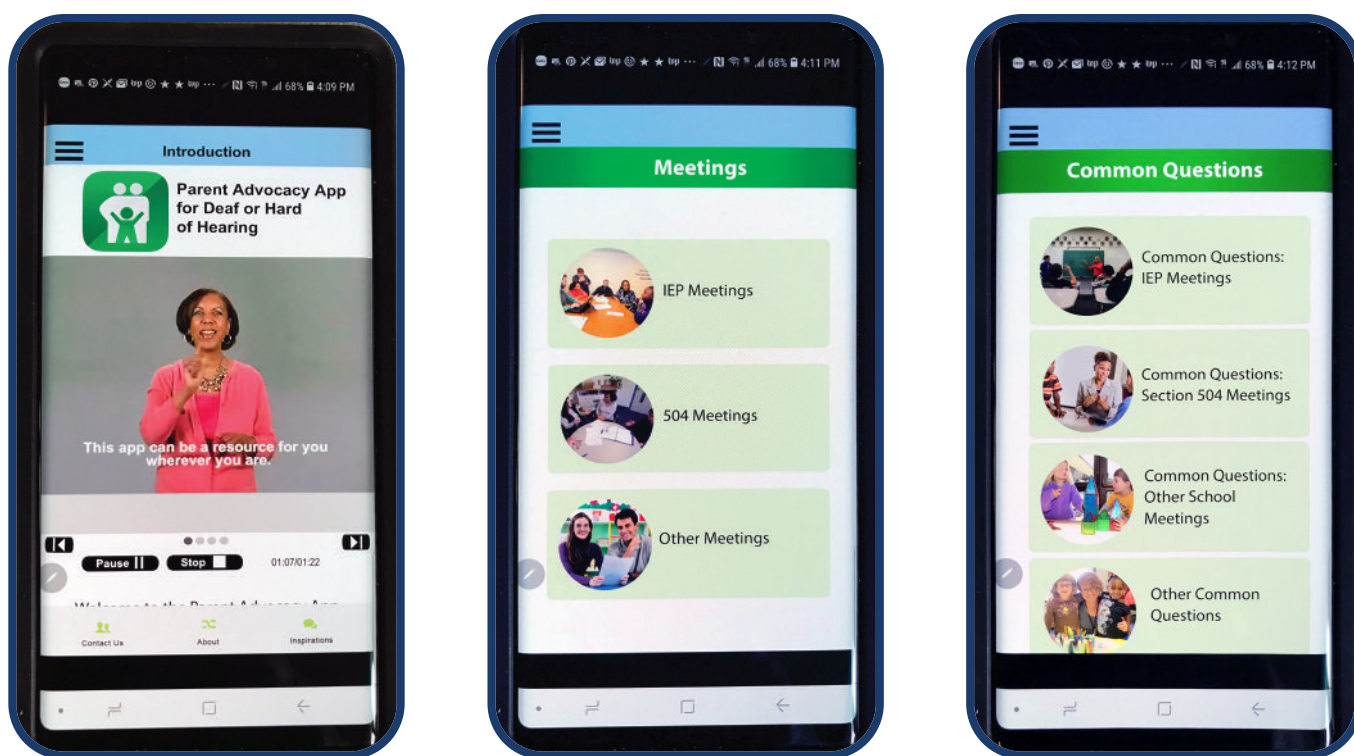
There is help at your fingertips. As Apple says (2009), "There's an app for that!" The Laurent Clerc National Deaf Education Center, in collaboration with the American Society for Deaf Children (ASDC), Hand & Voices, and the National Association of the Deaf (NAD), has created an app to assist you with understanding how to advocate for your child (kindergarten to twelfth grade) during educational planning meetings. The app details aspects of the IEP law and IEP meetings and the law regarding 504 plans and 504 plan meetings, and how to tell if your child may be eligible for one of these legal protections.

## **What Does Advocacy Mean?**

What do we mean by "advocacy"? Trainor (2010) states, "Early disability rights literature described advocacy as the act of speaking and acting on behalf of another person or group of people to help address their preferences, strengths,

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*Photos courtesy of Mary Henry Lightfoot*



and needs (Wolfensberger, 1977).” This definition reflects the important role of families to speak up for their children and to advocate for their educational needs. Parent advocacy works toward your child receiving an appropriate education (Turnbull & Turnbull, 2001, as reported by Trainer, 2010).

### Is MY Child Included Under the Topic of Advocacy for Deaf and Hard of Hearing Children?

Perhaps you are wondering if advocacy is needed if your child has a cochlear implant or if your child uses spoken English to communicate. Or perhaps you are wondering if advocacy is needed if your child is already working on grade level or, conversely, is behind cognitively. The answer is yes! Marschark and Hauser (2012) discuss the great diversity among deaf and hard of hearing children, stating, “Not only do we have to find the most effective way to support learning in deaf and hard of hearing children as a group, but each child may learn differently and at a different rate.” This underscores the importance of advocating for your child’s individual learning and social needs.

A foundational concept was stated by Hauser, clinical neuropsychologist and researcher: “... deaf children are not just hearing children who can’t hear” (Marschark & Hauser, 2012). Regardless of whether your child uses visual communication, uses auditory communication, or has a cochlear implant, how they learn may be different from their typical counterparts

**Above and bottom right:** The Parent Advocacy app assists you in understanding how to advocate for your deaf or hard of hearing child.

(Marschark & Hauser, 2012). Deaf and hard of hearing children can learn, grow, and progress on grade level and excel. However, simply removing communication barriers does not always equal satisfactory learning (Marschark & Hauser, 2012). As parents, part of our job is to advocate for accessible education that meets our child’s individual needs. While this can be a challenge, there are tools available. The Parent Advocacy app is one such tool.

### Let’s Take a Closer Look at the App

The app provides information and explores common questions, strategies, and resources for three types of meetings: IEP meetings, 504 plan meetings, and other school meetings. It allows you to use a series of checklists to determine if you’ve adequately prepared for the meeting, determine what should be considered during the meeting, and determine how you might follow up after the meeting. It has a place for you to take notes as well.

The Common Questions section answers questions such as: *What special considerations should teachers be giving my deaf or hard of hearing child? How can I be the best advocate for my child at a meeting? What is a Section 504 meeting? Is my child eligible for 504 support? What happens at an IEP meeting? How can I*

*participate in the IEP process?* Perhaps you have had these same questions.

The Strategies section provides six strategies to help you advocate for your deaf or hard of hearing child, such as “soft skills for advocacy” and “get outside help.”

The Checklists section emphasizes the multipart role that you play in advocating for your child. Your role starts before you arrive at the school meeting and continues beyond attending the meeting. While this process may initially feel overwhelming, the checklists give you concrete ways to prepare for the meeting, participate in the meeting, and follow up after the meeting. This section is interactive and provides checkboxes that can be used to show completed items as you progress through the advocacy process.

The Resources section provides information to connect you with people, organizations, and information, helping you in your journey of advocating for your deaf or hard of hearing child. It takes you to the laws that are the foundation of the IEP and 504 meetings

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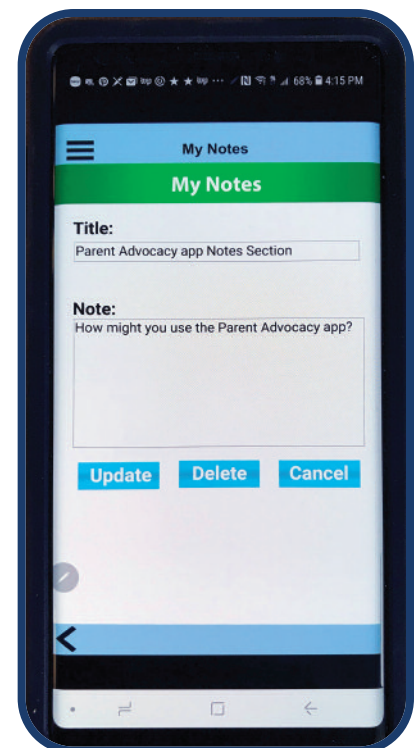
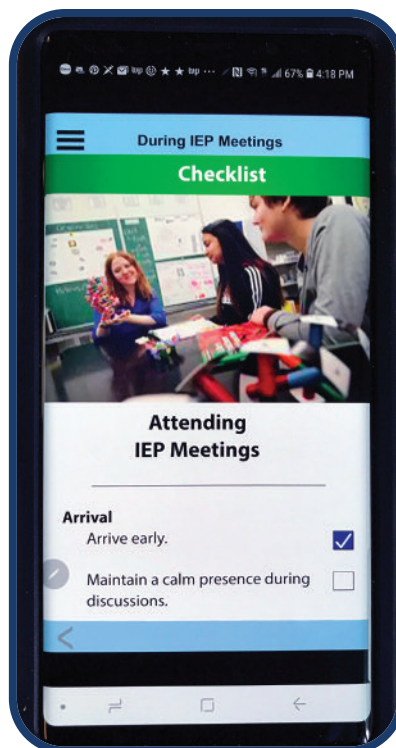
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**The Parent  
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and connects you with people and organizations in your state. There’s help with resources and assistance at the state level from ASDC, Hands & Voices, and NAD. The resource area has free information from the Clerc Center and the collaborating organizations.

### Why an App?

Now that we have explored the Parent Advocacy app, you might wonder why we decided on creating an app instead of a website or other publication. The app is designed to provide flexibility for your individual needs and use. Pew Research Center states that as of 2017, “about three-quarters of U.S. adults (77 percent) say they own a smartphone, up from 35 percent in 2011, making the smartphone one of the most quickly adopted consumer technologies in recent history” (Perrin, 2017). The cellphone is closely held and used. It’s often the first thing people look at in the morning, it’s carried throughout the day, and it’s the last thing viewed in the evening. You can use your cellphone while on the go or sitting quietly at home. The smartphone is





accessible across income ranges. In fact, “One-in-five adults whose annual household income falls below \$30,000 are smartphone-only Internet users” (Perrin, 2017).

In terms of using the Parent Advocacy app, you can briefly look at one section or extensively explore the app and links. While the app has full usability with an Internet connection, you can use portions of the app even when not connected. The app is available to use while waiting in line at the grocery store, while in a school meeting, or while at home. You can view information to help while advocating and get what you need in real-time. The app format provides you with access to parent advocacy information in any place and at any time. This is quite a useful feature!

### How the App Can Help You

Information provided from the organizations collaborating with the Clerc Center can help you on your journey to increased advocacy for your deaf or hard of hearing child. For example:

- ASDC offers a Knowledge Center of resources to parents/families and professionals. They (n.d.) state, “There is no one right way. Every child and family is different. Values, experiences, opinions, and resources vary from family to family. What works in one situation may not work in another. There are a number of ways to be successful raising a deaf or hard of hearing child. No one plan or formula will work for everyone.” The app shows how you can advocate for solutions that are tailored to your child’s individual needs instead of simply proceeding with one standard or popular approach.
- Hands & Voices’ *Educational Advocacy Guidebook* (DesGeorges, Johnson, & Seaver, 2013) discusses how advocacy for our children includes considering our child’s social and emotional health and development. They show that even when our child appears to be “fine” educationally, it may be appropriate to advocate for addressing social and emotional aspects. Within the app, an example of looking beyond a student doing “fine” educationally is the 504 meeting Common Questions section. The app specifies that children cannot be excluded from a 504 plan just because they are performing at grade level.
- In their publication *Legal Rights: The Guide for Deaf and Hard of Hearing People*, NAD (2015) discusses current laws supporting deaf and hard of hearing students and states that every child has “the right to qualified teachers, accessible classrooms, and appropriate materials and programs.” The app delineates the applicable laws and provides links for more detailed information.

### Finally ...

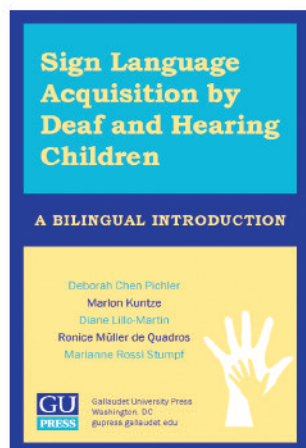
Wright (n.d.) states, “In your advocacy journey, you need two things—accurate information and support. This journey is more difficult if undertaken alone.” We hope that the Parent Advocacy app will provide both information and support as you take the journey to becoming a knowledgeable, self-assured, and loving advocate for your deaf or hard of hearing child.

The app is available from the Google Play Store and Apple’s App Store; it is free for your use. You can do a search under “Parent Advocacy” or “Gallaudet University Mobile Apps” to find it. For questions about the app, contact [onlinehelp.clerccenter@gallaudet.edu](mailto:onlinehelp.clerccenter@gallaudet.edu).

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# RESOURCES FOR EDUCATORS



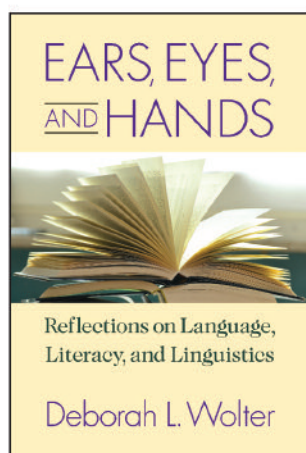
## **Sign Language Acquisition by Deaf and Hearing Children**

A Bilingual Introduction

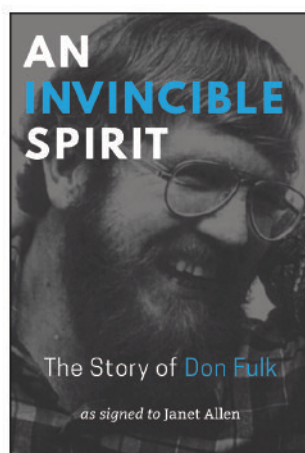
Deborah Chen Pichler, Marlon Kuntze, Diane Lillo-Martin, Ronice Müller de Quadros, and Marianne Rossi Stumpf

This video text offers an accessible introduction to first, second, and bilingual language acquisition, focusing on sign languages as the primary frame of reference. The content is signed entirely in American Sign Language with accompanying slides and an optional English voice-over.

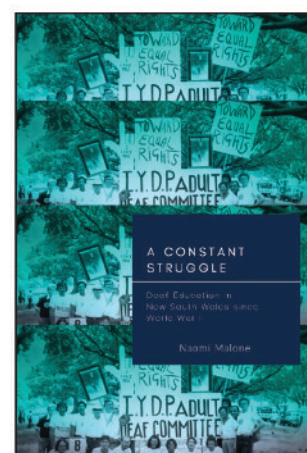
Available at [signlanguageacquisition.com](http://signlanguageacquisition.com)



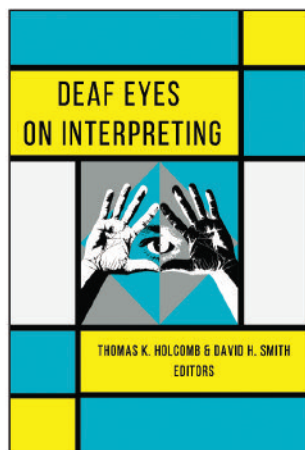
*An examination of language privilege from a seasoned educator*



*The story of a deaf quadriplegic who fought for an independent life*



*A historical assessment of deaf education in Australia*



## **Deaf Eyes on Interpreting**

Thomas K. Holcomb and David H. Smith, Editors

Written entirely by Deaf authors, this volume brings Deaf people to the forefront of the discussions about what constitutes quality interpreting services. A variety of settings and experiences are examined, including educational settings.

View chapter summaries in ASL at [youtube.com/c/GallaudetUniversityPress](https://youtube.com/c/GallaudetUniversityPress)

**Ukawia Johnson,** BSW, BBA, is a child protective service worker and volunteers as a youth counselor for teenagers who are deaf or hard of hearing. A resident of Mobile, Ala., she has two sons, Lajaren and James. Johnson obtained her bachelor's degree in business administration from Faulkner University and later earned a bachelor's degree in social work, for which she always had a passion, from Troy University. She welcomes questions and comments about this article at [ukawia@gmail.com](mailto:ukawia@gmail.com).

# Deaf Plus: A Mother Reflects on Her Son's Experience

*By Ukawia Johnson*

The day that we both fought so hard for was here. He did it! We did it! After 12 years of ups and downs, uncertainties, hard work, determination, and tears, my son James graduated from high school with a regular diploma.

James's accomplishment was a truly special milestone on a journey that has certainly not been smooth. He was born with cerebral palsy and has scoliosis along with a number of other health concerns, some of which have necessitated four surgeries between the time he was born and the time he entered high school, with more surgery still to come. When James was a newborn—only 3 months old—he was diagnosed with auditory neuropathy, a condition in which the inner ear successfully detects sound but has a problem sending sound from the ear to the brain (National Institute on Deafness and Other Communication Disorders, [www.nidcd.nih.gov](http://www.nidcd.nih.gov)). As a parent, I had all the emotions that I now know are common: I was scared, upset, and in doubt. *How could he be deaf? I am not deaf; my family has no history of deafness. What if the test were wrong?* I knew my child heard me; he responded to my voice. The first few years were learning years for us both. I did not know what to expect, and I did not know what to do. It turned out that James had a moderate hearing loss in both ears that later progressed to a severe loss. Most of the medical focus was on James's physical disability resulting from the cerebral palsy; the doctors seemed less focused on his hearing loss.

When James was about 3 years old, I was informed that there was a preschool for deaf children in our city of Mobile in Alabama. Prior to my learning about the preschool, James had only attended mainstream daycare. I toured the school and James began shortly after, attending the preschool for about two years. He started kindergarten at the Regional School for the Deaf, and a year later he transitioned into the mainstream public school system. It was recommended that James repeat

*Photos courtesy of Ukawia Johnson*





# ALABAMA SCHOOL FOR THE DEAF

*Founded 1858*

**Left, clockwise:** James as a toddler and young child; leaving James (age 14) at ASD to embark on a new school journey; James pictured with Representative Napoleon Bracy, Jr., after receiving the 2017 Youth Leadership Award; James's senior year at ASD.

kindergarten because, they said, he wasn't as mature as the other kindergarteners. Not really sure what that meant, I accepted the recommendation. We embarked on another year of kindergarten, and James received his first hearing aids.

James's Individualized Education Program (IEP) stipulated that he have a paraprofessional aide to help with daily school activities. As a result of cerebral palsy, he needed assistance holding his lunch tray, using scissors, and writing along with other motor tasks. First grade passed smoothly. His teacher was sensitive and helpful; his speech pathologist was great. In second grade, however, everything changed—and I boldly became an advocate for my child.

In speaking with James and his paraprofessional, I learned that James was not receiving the services that we had been promised. These included a reading coach and some one-on-one class time. Worse, he was made to sit in the back of the classroom, and he was not called on when he raised his hand. Further, while the other students moved from discussion to discussion, he remained isolated. Instead of participating, the

teacher allowed him to color. When I asked the teacher how she could so deliberately isolate a student within her classroom, she said she did not call on him because she could not understand his speech. She also refused to wear the FM microphone that was connected to his hearing aid and would have provided him with clearer hearing. This was not what I expected when I sent him to school, and this was not what I was going to allow. After that first talk, I thought things would improve, but daily conversations with James revealed nothing had changed. I attempted to speak with his teacher again, but she refused to meet with me. I asked to talk with the principal. There was no reply. I sent letters to the school board, and again there was no reply. It wasn't until I retained an attorney that I received a response. Still, it was not what I had hoped for. In fact, I, who had never considered myself

anything more than a concerned mother who wanted a good education for her son, now found the school board considered me an adversary. Some members of the IEP team accused me of “wanting special treatment.” I did not want special treatment; I wanted my son to have the reasonable accommodations promised by the law. Faced with the threat of legal action, the school board allowed James to have reasonable accommodations and a chance to participate in class activities. Unfortunately, this decision came at the end of the school year. James’s entire second grade year was spent fighting for fair classroom treatment.

Things finally improved slightly and James continued with his education, moving through the elementary grades in mainstream classes. He was somewhat of a loner. James is normally very social. In fact, he is “Mr. Personality,” excited to engage others in laughter and conversation. Sadly, many people, most important the other students, only saw

**I did not want  
special treatment;  
I wanted my son to  
have the reasonable  
accommodations  
promised by  
the law.**

his disability. The way he felt and the way he was treated presented a constant struggle for him—and in some ways a constant defeat. He was unable to participate in sports due to physical limitations. My son, so wanting companionship, wasn’t happy.

ASD is in Talladega, over 270 miles away. We ultimately decided to allow James to attend the school, and he began eighth grade at ASD.

Although the first month was a hard adjustment for our family, we eventually got used to the change. At our nearby public school, James had been accompanied by an adult throughout his school day, and after school he was often alone. This all changed when he went to ASD. James, who had learned signs in preschool but refused to use them, began signing again. He made friends. He became very involved in school activities and organizations. In fact, he was dorm president, vice president of his class, a member of the Student Body Government, and a member of the leadership council. He participated in various leadership camps,

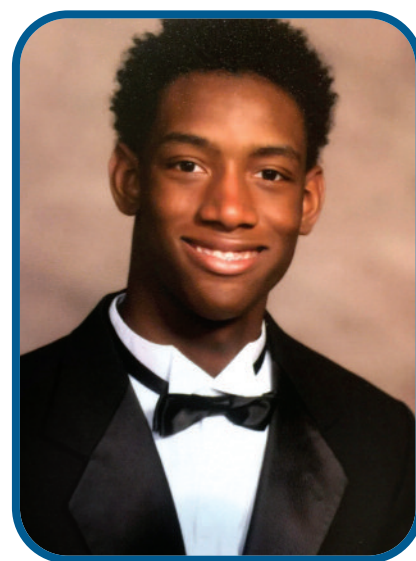


### **A Life-Changing Decision**

We knew that an alternative to public school was available. We toured the Alabama School for the Deaf (ASD), part of the Alabama Institute for Deaf and Blind, when James was in seventh grade. He had attended summer camp there. After rejecting the decision for many years, we began to reconsider. Should we allow James to go to ASD, where his peers would be more like him? We live in Mobile and

**Left and right:** James’s senior photos at ASD.

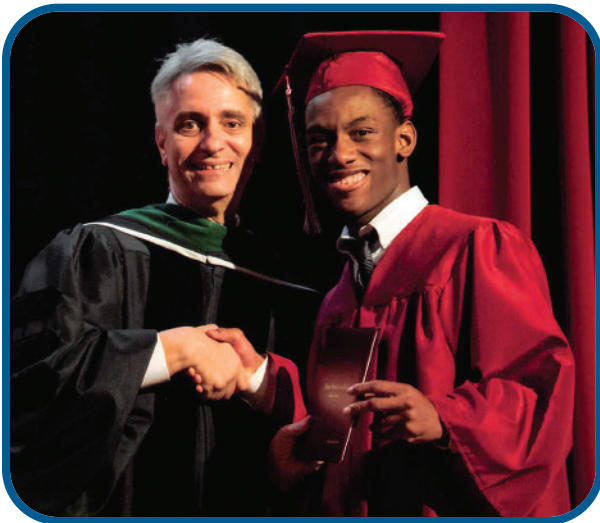
**Far right:** James on graduation day with Dr. John Mascia, president of the Alabama Institute for Deaf and Blind; a proud mother, a successful son.



and in 2017 he received the Youth Leadership Award from the Mobile Area Governor’s Committee on Employment of People with Disabilities.

At ASD, James was evaluated on his strengths and needs, and the school individualized a plan for him. He participated in work experience activities, and we attended yearly career fairs at his school, where we met representatives from various colleges and businesses. Each provided valuable information as well as described the





program in which he would learn to self-advocate, become ready for a full-time job, live independently, and continue his academic work. His goal: to attend Troy University, in Troy Ala., and major in counseling.

### Looking Back, Looking Ahead

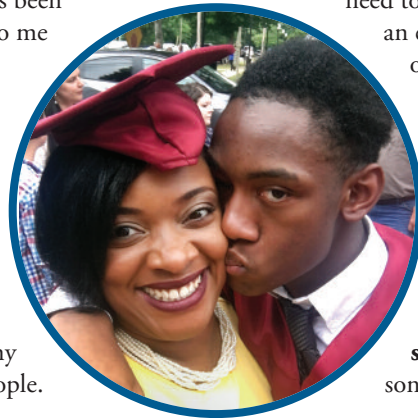
It has always been important to me that James received a

quality education and an opportunity to be involved in social and academic life. I was determined that he understand that his hearing loss and health needs did not make him any less valuable than other people.

I wanted James to believe in himself and not let his disabilities define his future. Instead, his future should be determined by his skills and determination.

Asked how he feels about having a disability, James responded, "I feel my disability has been a blessing. I have been able to participate in and experience things I may not have had the chance to if I didn't have a disability." He once told me, "I could feel sad, I could be angry, but I am still going to have a disability. I just

need to accept it and be an example ... to help others deal with their disabilities as well." As James's mother, his advocate, and his biggest supporter, I am grateful to ASD—and I am **so proud** of my son.



steps to complete the application process. At our final gathering—the IEP exit meeting—James, his teachers, counselors, administrative staff, and I discussed his future. James wanted to attend college, but his ACT scores were not high enough for the college he chose. We discussed alternatives, and James decided to attend a transitional



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## LEARNING ABOUT ADVOCACY EXPERIENCES OF FAMILIES OF COLOR:

# Multiple Perspectives Guiding the Research Process

By Susan J. Schatz and Lori Lutz

**Susan J. Schatz,** PhD, is a research project manager in the Laurent Clerc National Deaf Education Center's Planning, Development, and Dissemination office on the campus of Gallaudet University in Washington, D.C. She manages internal and external research requests and conducts research projects related to the Clerc Center's priorities and initiatives, with emphasis on the implementation of evidenced-based practices and educationally related practices for use with deaf and hard of hearing students. Previously, Schatz taught for several years in an American Sign Language/English bilingual classroom in various educational settings. She was also a teacher-supervisor and coordinator of instructional support at the Clerc Center's Kendall Demonstration Elementary School for several years before joining the Clerc Center's Monitoring, Evaluation, and Research team.

Parents and caregivers have hopes and dreams for their deaf and hard of hearing children and have aspirations for their success whether it is at school, home, and/or in the community. Advocating for their deaf or hard of hearing children's needs, education, and/or access is one of the different ways families are involved. Research provides examples of key parent advocacy strategies and activities (e.g., Henderson, Mapp, Johnson, & Davies, 2007); however, some of these suggestions may reflect Anglo American cultural values (Scheetz, 2004; Trainor, 2010), which raises the following question: *"What are some of the advocacy strategies and/or resources parents/caregivers of color have used to advocate for their children's educational needs?"*

This question is important because factors impacting families' abilities to advocate include financial or time limitations, imbalance of knowledge between schools and families, and issues with school-family communications (Lake & Billingsley, 2000), differing perspectives regarding school and family responsibilities (Scheetz, 2004; Trainor, 2010), and experiences of barriers related to ethnicity, race, and socioeconomic class (Ramsey, 2000; Lo, 2008; Stanley, 2015) as well as language barriers for families using a language other than English (Hughes, Valle-Riestra, & Arguelles, 2002; Lo, 2008).

### Understanding the Meaning of Parent Advocacy

A review of parent advocacy literature (Kinsella-Meier, 2019) suggests that successful parent-advocates: 1) know how the education system works; 2) build

*Illustrations courtesy of the Laurent Clerc National Deaf Education Center*



## Are you a parent or caregiver of color who has a deaf or hard of hearing child?

The Clerc Center is conducting a nationwide study to understand the experiences of families of color in supporting their deaf or hard of hearing child's educational needs.

### We want to know:

- What resources (e.g., community or church members, videos, apps, organizations) and strategies (e.g., communication, school involvement, technology, parent-school meetings) have you used to ensure your child's educational needs are being met?
- What experiences and challenges have you faced while advocating for your child's education?

Join us for a small 60- to 90-minute focus group discussion on this topic. Your contribution will be valuable in determining the next steps for supporting deaf and hard of hearing children's education.



**Dr. Sandra Jowers-Barber** researches and writes about the history of the African American Deaf community in Washington, D.C. She is the stepmother of an adult deaf daughter who is the mother of three hearing children.

### Interested?

positive relationships and work with teachers and school personnel; 3) support their child's education throughout the years; 4) know how to get support; 5) know how to speak out for their child's needs; 6) know and understand the special education laws and their (as well as their child's) legal rights; 7) know their child's strengths, weaknesses, and academic performance; and 8) plan for the long term (Henderson et al., 2007; Jackson & Lutz, 2016). An educational advocacy guidebook is also available for parents seeking resources to advocate for their deaf or hard of hearing children (DesGeorges, Johnson, & Seaver, 2013).

However, Kinsella-Meier (2019) points out

that the general understanding of parent advocacy may reflect the Anglo American cultural values more than we realize and suggests that we should learn more about perspectives and meanings of parent advocacy held by other ethnic, racial, and/or culturally diverse communities (Lo, 2008; Stanley, 2015; Trainor, 2010). Understanding meanings of parent advocacy from other communities' views may help schools and parents with different perspectives regarding parent advocacy to work together for a common goal—to ensure their deaf or hard of hearing children have the supports they need to achieve their potential in school.

**Lori Lutz**, PhD, is the director of Monitoring, Evaluation, and Research at the Laurent Clerc National Deaf Education Center at Gallaudet University in Washington, D.C. Her work involves oversight and monitoring of federal reporting requirements, public input processes, performance and evaluation components of the Clerc Center's strategic plan projects, and research management and collaboration activities. In her 18 years in this field, Lutz has conducted evaluations of training and products, program implementation processes, and dissemination activities designed for parents of deaf and hard of hearing children from birth through high school as well as educators and professionals who work with them.

The authors welcome questions and comments about this article at [Susan.Schatz@gallaudet.edu](mailto:Susan.Schatz@gallaudet.edu) and [Lori.Lutz@gallaudet.edu](mailto:Lori.Lutz@gallaudet.edu).

## Families of Color Advocacy Research Team



**Dr. Valerie Borum** *Research Team Consultant*

Dr. Valerie Borum's research agenda includes a focus on the role of ethnic culture in health, mental health, and disability and hearing families with deaf or hard of hearing children, with special attention to African Americans. She is a graduate of Gallaudet University (MSW) and Howard University (PhD).



**Dr. Sandra Jowers-Barber** *Focus Group Facilitator*

Dr. Sandra Jowers-Barber researches and writes about the history of the African American Deaf community in Washington, D.C. She is the stepmother of an adult deaf daughter who is the mother of three hearing children.



**Darrius Doe** *Research Assistant*

Darrius is a research assistant. He also works in Gallaudet University's Communications office as the social media copywriter. Doe has a small deaf family, and is from Maryland. He is a graduate of Gallaudet University with a sociology degree.



**Dr. Lori Lutz** *Co-Researcher*

Dr. Lori Lutz has more than 20 years of experience with evaluation, focusing on training and programs, and research about hearing families' experiences with their deaf and hard of hearing children. Currently in Washington, D.C., Lutz, who is deaf, is the child of hearing parents from a rural midwestern state.



**Zoe Rodriguez** *Research Assistant*

Zoe Rodriguez is a research assistant. She previously worked as an assistant director for Youth Leadership Camp under the National Association of the Deaf. Rodriguez is from Puerto Rico, and she is fluent in Puerto Rican Sign Language and Spanish as well as American Sign Language and English. She is a graduate of Gallaudet University with a psychology degree.



**Dr. Susan J. Schatz** *Co-Researcher*

Dr. Susan J. Schatz is a research project manager at the Clerc Center. She previously worked in deaf education as a teacher and administrator for more than 20 years. Schatz is a graduate of Gallaudet University with both linguistics and education degrees.

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result, the research study is based on three principles: 1) openness to multiple meanings of parent advocacy, 2) inclusion of multiple perspectives, and 3) involvement of community members throughout the research process.

**1. Openness to multiple meanings of parent advocacy**—Special education advocacy strategies often require a specialized knowledge and understanding of special education laws, legal rights, and navigation of educational systems (Lo, 2008; Stanley, 2015; Trainor, 2010)—knowledge that may not be available to many parents. Trainor (2010) has suggested that there are different ways parents advocate for their children's special education needs. Also, parent advocacy may be understood differently based on cultural beliefs and values (Trainor, 2010). Kinsella-Meier broadly defines a parent advocate as one "who represents the needs of the child and is a constant presence in the child's life, who knows the child intimately and thereby knows the child's needs" (2017). Using this definition for the research study allows us to be open to different approaches, strategies, and resources families of color use to advocate for their deaf or hard of hearing children.

**2. Inclusion of multiple perspectives**—To learn about parent advocacy experiences from

parents/caregivers of color, the research study was designed and implemented based on the belief that the process should be as inclusive as possible to ensure cultural relevance and transparency. Focus groups, rather than one-on-one interviews, were selected for the study because this format allowed people to share their own perspectives and stories with others (Hennick, 2014). This opportunity for parents/caregivers of color to respond to others makes it possible for them to think about, explain, or clarify their comments with each other, leading to a clearer and possibly a deeper understanding of their advocacy efforts (Carey & Asbury, 2012; Hennick, 2014). Parents, educators, and school professionals of color reviewed focus group questions and some participated in a mock focus group. Their feedback was used to revise materials and procedures so that the study process, from learning about the

### Families of Color Advocacy Research Study

The Laurent Clerc National Deaf Education Center has begun a research project, Families of Color Advocacy, to learn about parents/caregivers of color's advocacy efforts and experiences to ensure their deaf or hard of hearing children's educational needs are met. The undertaking of this research project is based on key principles so that individuals involved with the project learn about perspectives, knowledge, and experiences that are not a part of their culture, language, and/or identity.

#### PRINCIPLES GUIDING THE FAMILIES OF COLOR RESEARCH STUDY

Knowledge about experiences of parents/caregivers of color advocating for their deaf or hard of hearing children (Borum, 2007; Ramsey, 2000; Steinberg, Davila, Collazo, Loew, & Fischgrund, 1997; Struxness, 2000) is still developing. As a



study to the study's completion, would be clear, relevant, and supportive for Black/African American or Hispanic/Latino parents who want to participate in focus groups to share their parent advocacy experiences.

**3. Involvement of community members throughout the research process**—Learning about advocacy experiences shared by parents/caregivers of color is best accomplished when Black/African American and Hispanic/Latino individuals are involved with the study processes to the development and dissemination of parent advocacy resources for educators working with families of color. Their involvement helps us to glimpse understandings through their perspective and to provide insights into the experiences of parents/caregivers of color that may be missed otherwise. The process to include community members for all parts of the research project involves developing and building trust among community members and research team members.

### Lessons Learned So Far

We have learned many important lessons from people of color who have provided assistance with and feedback for the research study before we began setting up focus groups with parents/caregivers of color. Their feedback regarding language included:

- **Language needs to be clear and to the point.** Even though we worked hard to ensure language in parent letters and consent forms was easy to read, culturally relevant, and jargon-free, some words may be intimidating to or misinterpreted by parents. For example, some parents may view research as an experiment. Also, focus group reviewers suggested avoiding the use of vague terms such as *greatest* and *helpful*.
- **Use language with which parents are familiar.** Black/African American professionals who reviewed the focus group processes suggested changes to a focus group question about educational planning meetings by first checking with parents to learn whether they have participated in an educational planning meeting before specifically asking about Individualized Education Program (IEP), Individualized Family Service Plan, and 504 meetings.
- **Clarify meaning of terms by providing examples.** Some terms, such as *resources* and *types of support*, were not clear to focus group reviewers. They suggested adding examples

for these terms so that parents would have a better idea of their meaning.

- **Keep questions brief and to the point.** Feedback suggested that some of the focus group questions were too long, and that questions needed to be short, specific, and straightforward.
- **Include community members in all aspects of the research design and process.** The involvement of Black/African American professionals in a pilot focus group, role playing as Black/African American hearing parents of deaf and hard of hearing children, provided

critical feedback regarding the flow and setup of the focus group discussion. As a result of their feedback, we changed the process of introductions, the order of focus group questions (starting with general questions and ending with more specific ones), and revised some questions to improve clarity. We are especially grateful to this group of professionals for their honesty, straightforward commentary, interest, and investment in this process because their involvement led to improved focus group processes for Black/African American parents participating in the research study. We plan on continuing to seek feedback from committee members throughout the entire study. Along with lessons learned, the three principles guiding our research project will continue to its completion.

### Focus Groups for Families of Color: Sharing Stories About Their Advocacy

The Clerc Center is hosting five focus groups with Black/African American parents/caregivers and Hispanic/Latino parents/caregivers in different parts of the United States. The groups include:

#### Residential or Day Schools for the Deaf

Site 1 – Black/African American parents

Site 2 – Hispanic/Latino parents

#### Public Schools

Site 3 – Black/African American parents

Site 4 – Hispanic/Latino parents

A fifth site will be identified within the next year.

As a result of these families' sharing their experiences with us, information about successful strategies used by

**To learn about parent advocacy experiences from parents/caregivers of color, the research study was designed and implemented based on the belief that the process should be as inclusive as possible to ensure cultural relevance and transparency.**

parents/caregivers and schools to support their advocacy efforts, barriers these parents/caregivers encountered, and resources they used to advocate for their deaf or hard of hearing children's education will be used by the Clerc Center to develop resources to meet this need.

### Our Work: Looking Within and Outward

Learning from parents/caregivers of color about their experiences advocating for their deaf or hard of hearing children means first looking within ourselves and through other people's eyes to discover what parent advocacy means to

us. It also means understanding that each one of us as individuals and as members of specific groups have experiences and identities that influence how we see, learn from, and open up to each other as we work together to learn about the meanings of parent advocacy, advocacy strategies, and resources used by these parents/caregivers, successes and/or barriers to their advocacy efforts, and other insights critical to understanding these families' experiences. It is a rich, complex journey that will involve many lessons about what it means to be a parent or caregiver of color advocating for their deaf or hard of hearing children's education in our society.

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# Seeking Submissions for the 2020 Issue of Odyssey

**THEME: Diversity and Fostering Inclusive Learning**



The 2020 issue of *Odyssey* will focus on how schools, professionals, and families are working together to create and foster inclusive environments for all deaf and hard of hearing children and students.

Commitment to inclusive practices has become a mainstay of American education in response to rapidly changing demographics. Schools and programs are rising to the challenge of meeting the needs of diverse populations of students who may come from homes and families that vary by race, ethnicity, culture, sexual orientation, gender identity, socioeconomic status, locality, age, level of education, disability, and language use. How are families and professionals in deaf education programs responding to those needs? How do we ensure the inclusion of social justice and social-emotional growth along with high academic expectations for deaf and hard of hearing children? We want to know:

- How do schools and programs recruit and train personnel who reflect the students they serve? And what do schools and programs do when the personnel do not reflect those they serve?
- What strategies and practices are being developed to close the achievement gap for students of color as well as for deaf and hard of hearing students with disabilities?
- How do we ensure a supportive educational environment for students who are LGBTQIA (or whose families may be) or who come from multiracial, blended, or adoptive families?
- How do deaf education programs and schools prepare students to respond to issues of social justice for themselves and for others?
- How do families work with teachers and professionals to foster inclusive learning? What types of communication, activities, and programming do families find ideal for supporting inclusivity with schools and programs? How do families support their children's needs, making sure they are included not only at home but also in their school and community?

The Clerc Center seeks articles from families and professionals sharing their stories and experiences—the strategies they used, the challenges they faced, and the outcomes they achieved in their quest to enhance inclusion and equity for their children or students.

Please e-mail your ideas to [Odyssey@gallaudet.edu](mailto:Odyssey@gallaudet.edu). We will begin accepting submissions on June 1, 2019, and continue until October 4, 2019, or until the magazine reaches capacity. Contact us via e-mail at any time with questions or to discuss your ideas.





**Sitara Sheikh**, MS, is a vocational rehabilitation counselor for the Maine Bureau of Rehabilitation Services, where she has worked for over eight years. She was born deaf and grew up bilingual using American Sign Language and English. Sheikh earned a bachelor's degree in social work and a master's degree in human resources development from the Rochester Institute of Technology as well as a master's degree in rehabilitation counseling from Virginia Commonwealth University. Formerly a Peace Corps volunteer, she worked as a teacher in Kenya for three years. After returning to the United States, she worked as a training specialist and case manager at different agencies. Sheikh welcomes questions and comments about this article at [sitaranasim@gmail.com](mailto:sitaranasim@gmail.com).

# Reflections of a VR Counselor: There's a Job for Everyone!

*By Sitara Sheikh*

The transition from school to work is wonderful and exciting, but the process can also be scary. Each of us goes through it—turning 18, opening a bank account, applying for a first job, and the myriad of activities entailed in legally becoming an adult. While some students, in accordance with the law, remain in school until they are 21, at whatever age school-to-work transition is experienced, young adults must acquire new information, get access to resources, and adjust to new environments.

As a vocational rehabilitation (VR) counselor who is deaf in the Bureau of Rehabilitation Services in the beautiful state of Maine, I often work with families of deaf and hard of hearing children who have autism or cognitive challenges. I listen as families talk about their children's transition from school to work. They express love and fear in their questions: *Can my child be independent? Will he or she be able to ask questions, share concerns, triumphs, and fears? Will my child be happy?* I reassure parents that everyone can work! This—the motto of our agency—applies, of course, to everyone, including those deaf and hard of hearing individuals who have autism or other challenges. At VR, we focus on finding meaningful employment for individuals with disabilities. Employment First Maine ([www.EmploymentFirstMaine.org](http://www.EmploymentFirstMaine.org)), legislation passed in 2013, provides integrated community services for individuals with disabilities and has resulted in VR being part of a broad-based coalition of individuals with disabilities, families, advocates, providers, and state agency representatives committed to improving and customizing employment for Maine citizens with disabilities.

Transitioning from school to the workplace is challenging for any individual, but it can be even more challenging for a deaf or hard of hearing young adult who has autism or an intellectual disability. Families can help.

*Photos courtesy of Sitara Sheikh and Tyese Wright*



Here are some tips:

- **Start early.** The transition process often takes longer for deaf and hard of hearing students who have additional disabilities and involves more exploration. Those concerned in a child's transition to the workplace should connect with VR when the child is 14. A relatively new law—the Workforce Innovation and Opportunity Act, passed in 2014—emphasizes starting transition services early to allow a student's transition team the time to work creatively, collaboratively, and consistently with businesses, schools, and other community providers.

Pre-employment transition services include job exploration, self-advocacy, work-readiness training, work-based learning, and future training opportunities. These services allow transitioning students to acquire workplace skills while in high school. Parents also participate as part of the transition team as they

**Above:** Sheikh gives a transition workshop to deaf and hard of hearing young adults at a high school in Southern Maine, during which ASL interpreters and CART services were provided.

enable their children to explore their interests, abilities, strengths, and challenges, especially through supporting placement in different work environments.

The law requires VR to support individuals with disabilities and remove barriers to employment. VR counselors educate employers about the Americans with Disabilities Act, discuss tools and accommodations, and purchase devices to support individuals with maintaining employment. This means that we can use those precious summer months for work experiences. Summer jobs empower young individuals to understand work etiquette, learn how to advocate for themselves, explore their goals, and develop problem-

**Right:** A student with an interest in animals interns at a dog and cat grooming business to gain work experience.

solving skills. Work is not just about getting a job; it is about the whole person.

- **Involve the individual.** Unlike many other children, deaf and hard of hearing children with additional challenges may not be exposed to the idea of employment or career. They may need more time to understand what transition to a work environment means and to discuss job and career options.

Parents and educators can take the initiative and introduce them to people who do different kinds of work. For example, they can encourage these young adults to shadow someone who works in their area of interest. This gives the young person an understanding of what it means to be in the workplace and prepares him or her for the transition. Once the transition is underway, deaf and hard of hearing students with additional disabilities may need more time to learn what college, vocational training, or the workplace is like.

- **Learn about resources.** As a rehabilitation counselor, I have noticed that navigating the system is complicated, and it can be overwhelming. Perhaps as a result, many families either are not aware of the resources available or they do not know how to access them effectively. At VR, our goal is to work with parents, families, school



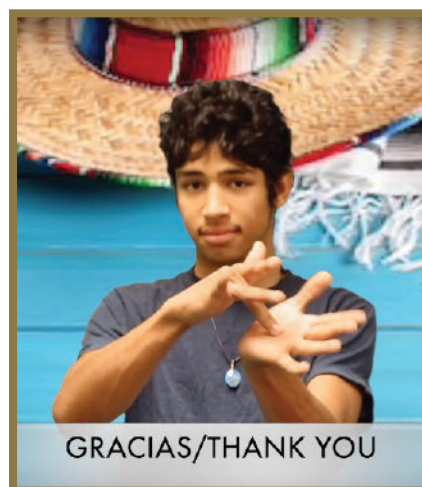
representatives, and the young person's support system to find resources and provide advocacy when needed. For students who are deaf or hard of hearing with additional challenges, resources can come from many places, including VR agencies, social service agencies, mental health agencies, disability rights or deaf advocacy programs, and other organizations. In Maine, for example, Maine Hands & Voices, the parent advocacy group, can provide guidance to parents to connect to resources, and the state Office of Aging and Disability Services can provide services for individuals with intellectual disabilities, including those who are deaf or hard of hearing.

While every state has different criteria for eligibility, VR professionals are there to help families navigate what can be a daunting complex of services. Never hesitate to ask for assistance—

whether from VR, social services, or your local advocacy agency for deaf and hard of hearing people. In each agency are people who want to work together to make the transition of a deaf or hard of hearing individual a success.

- **Participate in transition meetings.** Having regular transition meetings will enable the team to consistently support the student in developing work goals. Additionally, the student will be able to start learning skills in self-advocacy and problem solving and to apply coping skills in their lives. Transition is a process, and students need time to get information, apply it, and express themselves. Each representative in the transition meeting listens, shows patience, and empowers students to process each step critically.
- **Explore VR.** Located in every state, VR services can assist individuals in having real-life work experiences. Training individuals in different workplace environments in which they learn new skills can be exciting; different experiences

**Below:** A student interning with a school's ASL and Deaf Studies Program signs LSM (Mexican Sign Language) for a vlog during Hispanic/Latino Heritage Month.





enable individuals to grow. For deaf and hard of hearing individuals with additional challenges, direct communication is important. It is also important that they work with those with a cultural understanding of what it means to be deaf or hard of hearing.

In Maine, VR supports clients by educating employers about hiring individuals with disabilities. We strive to understand the needs of the businesses and then connect the business with potential candidates who can do the work with or without accommodations. Sometimes we work with employers to figure out specific tasks that can be successfully performed by people with very significant disabilities. On-the-job training, work assessment, and other services are also provided to enable the student to get hands-on experience; team collaboration is vital.

- **Seek allies and support.** Don't be afraid to approach a teacher, social worker, case manager, VR counselor, or another parent for support. Different perspectives help parents and young people make well-informed, balanced decisions. Therefore, individuals getting ready to seek employment should be encouraged to socialize with their peers. In Maine, a peer support group for those who are deaf or hard of hearing with cognitive challenges meets every month; these meetings enhance each individual's emotional support.

As in all states, Maine struggles with having too few employment providers with fluency in American Sign Language or visual gestural communication. We are working to solve this problem by training deaf people in the specialized communication and work support skills needed to become employment specialists.

**On-the-job training, work assessment, and other services are also provided to enable the student to get hands-on experience; team collaboration is vital.**

Empowering individuals to express their work-related needs and abilities to employers directly and to engage in everyday work conversations is a critical part of helping people be successful.

### **Everyone Can Work!**

In the right job and with proper support, everyone can work. For

students who are deaf or hard of hearing and have an intellectual disability or autism, the search for a successful job should begin early. This means contacting VR when a child is 14 years old, forming teams to help explore work options, learning about services, and connecting with adults who have already successfully transitioned into the workplace. Ask questions and follow through to get the information.

If, for whatever reason, families are not satisfied with the VR experience, they should feel free to request assistance from a state's Client Assistance Program. Every state has a link to its Client Assistance Program on its VR website. (For example, the website for residents in Maine is [www.maine.gov/rehab/cap.shtml](http://www.maine.gov/rehab/cap.shtml).) Professionals there can help with clarification and follow-ups—even nudges—to the VR system. Whether in need of pre-employment training, work experience, or job seeking, be persistent. Everyone can be ready to work!

**Below:** Students interested in teaching physical education intern at an elementary school.



**Carl Wayne**

**Denney** graduated from Gallaudet University in 2000, where he was a dedicated intramurals participant and a past president of the Student Body Government. He has explored the continental United States, working at various state schools for the deaf as a teacher, dormitory supervisor, and public relations specialist. Denney and his wife, Tuesday, are the parents of five children, two of whom are deaf. He lives in West Virginia, where he enjoys reading, working out, and spending time with his family. Denney welcomes questions and comments about this article at [indyhawks@gmail.com](mailto:indyhawks@gmail.com).

# Advocating for a Child Who Identifies as Transgender: A Parent's Journey

*Q&A with Carl Wayne Denney*

Every day Carl Wayne Denney or his wife, Tuesday, becomes a teacher for Livia, their 13-year-old daughter. Livia is one of five children and the second deaf child of Carl and Tuesday, both of whom are also deaf. They have enrolled their daughter in schools and programs around the country, but they have not been able to find a program that can provide the support they need. It is the Denneys' desire to protect their daughter. In their search for the appropriate school, they have experienced objections to Livia's enrollment in the school and ostracism from the community and other parents. Parents have told their children not to socialize with her. Then there was the man who threatened to shoot her via an online forum following a news article detailing her daily struggles. This is because Livia is a transgender female. While the sex that she appeared to be at birth was male, she never felt male; instead, she identifies as female. Below, in a Q&A that *Odyssey* did with Denney via e-mail, he reflects on schooling his daughter academically and in life.

**ODYSSEY:** How did you feel when you realized that your daughter was transgender?

**DENNEY:** My wife was the first to realize it. She was watching "The Oprah Winfrey Show," and Oprah had a mom, the author of the book *My Princess Boy*, as a guest. The way the author described her child described our child, too—exactly. My wife decided to initiate a conversation. She asked Livia—who was living, of course, as a boy—if he liked dresses, and he said, "Mommy, I am a girl."

As for me, I am a man who is very much into athletics, fitness, competition, and the jocular culture of brotherhood and fellowship. When my child was born, I saw a son and I saw myself coaching him. He would play football, and he would be a tight end. He was going to be a basketball center. A baseball catcher. I have three other sons, and I coached them in community basketball and football. I also coached the prolific Indy Hawks, who captured three

*Photos courtesy of Carl Wayne Denney*



**Left:** Livia, age 13.

PHOTO CREDIT: CAROLYN ROCKOW

national club championships in the mid-2000s. It is rare for a Deaf father to have a Deaf son and be in an environment in which they can be on teams together, and I had been looking forward to sharing those father-son moments.

**ODYSSEY:** How did you and your wife initially respond?

**DENNEY:** First, we tried to negotiate ... be a girl at home, be a boy at school. It didn't work. It was too complicated and, basically, what we wanted as opposed to what she wanted. We were letting society dictate us instead of what our child's heart was desiring, so we chose our child and never looked back. Now we have a daughter, and we are all in. We support her all the way.

**ODYSSEY:** What happened then?

**DENNEY:** We allowed our child to be who she wanted to be. As simple as that. My wife took Livia to the store and let her buy dresses. Our son became our daughter. The difference in behavior was night and day. She was a brand new person. My wife says she was like a butterfly coming out of her cocoon. She started talking—signing with us—constantly, and she hasn't stopped since. She is so full of life!

**ODYSSEY:** Was the transition easy?

**DENNEY:** Perhaps it was easier than the alternative—accepting a thoroughly miserable child, knowing the suicide rate is high among the LGBTQ community with those who are or were repressed. We had not been able to understand Livia's behavior. It was okay with us that our child played with dolls, but when she was a boy she was so unhappy. She hated school. She would take off her clothes in the car—and once she threw her shoes at me while I was at the wheel. I was driving down the road dodging flying shoes. She wouldn't sign to us at all. We had three sons prior to her, and I had never experienced anything like this before.

Was it a struggle at first? Yes. At first, I didn't understand. I questioned myself. I wondered if, after three healthy and rambunctious sons, I had made a mistake somewhere along the way or maybe our child was just feminine (which is perfectly fine). The struggle was not about Livia's sexuality but over why she was having those terrible temper tantrums, those angry fits. Those scared me immensely. Only later after we watched and researched into this online—where very little information was available, combined with our first-ever visit by a Child Protective Services (CPS) representative who came to investigate why our biologically male child was



going to school sometimes wearing feminine clothing—did we begin to understand. The CPS representative explained that it was burgeoning, and that many people—children, teens, and adults—were becoming more and more “themselves,” shedding societal expectations of them and simply being themselves. Livia was one of them, and the CPS representative was very supportive, leading us to further information and exposure. With that knowledge, we realized her fits of anger were all over having to wear male clothes to school. Happiness was having her wear the clothes she wanted to school. Man, I will forever cherish the memory of her beaming when she walked to the school bus wearing her dress and shoes. I was apprehensive but decided if this is what she wants, she’s got it.

**ODYSSEY:** You realized Livia was transgender when she was around 3 to 4 years old. Since then, you have moved often, and Livia has been in several different schools. Would you talk about your experience with this? Did you advocate for her?

**DENNEY:** Yes, we’ve had Livia in a hearing school and schools for the deaf. It hasn’t always been easy, but it hasn’t always been hard either. We have had a variety of experiences in different schools for the deaf. Some schools were wonderful and accommodating but we couldn’t afford the cost of living in that area. Other schools struggled to understand what she was and what we were experiencing as parents of someone very different than your normal everyday child. With time, the reception everywhere was very much more accepting. Within a three-year period, society had evolved; people everywhere were outwardly fine with the transgender image. (We do not advertise our child—this is an important thing to understand; we accept her for who she is, but we do study society at large.) Still, there were some ongoing unfortunate incidents in the community. I once had my driver’s license withheld at a local hospital where I took her for a suspected severe ankle sprain because they were suspicious as to why my son (as named under the insurance card) was wearing female clothes so they called CPS, as I mentioned earlier. Lucky for us, I had notes detailing who she was when we arrived to register, and the interpreter assigned

**Make sure your child’s rights are protected, that your child is not ostracized, that your child has the same opportunities as everyone else.**



PHOTO CREDIT: CAROLYN ROCKOW

had previously interpreted for us at academic and community events. This was an example of an isolated incident based on suspicion and fear. Needless to say, we never returned to that hospital.

When life took us to a different state, we once again explored local schools. In one school, the reception was lukewarm—not just because Livia was transgender but because we were from the “big city” and we were “outsiders.” Livia didn’t face adversity, but there was some reluctance as to her enrollment. There were some brief spots of turbulence that caused us to step up and advocate for our daughter. For example, she was recommended to be suspended for 10 days for using the girls’ restroom. We had to step up then and advocate—and the discussions were forceful; I mentioned “lawsuit” and then school officials checked with their higher-ups and finally agreed to allow her to go to whichever restroom she wanted. This is the most common-sensical solution to a very nerve-wracking issue, symbolic of a national struggle. In another school, she excelled academically and earned high honors but was continually lonely and alone. We have also experienced ongoing accommodation issues, mistrust, and a lack of fluent signers. It took an emotional toll on all of us and still does to this day. Sometimes standing up for your daughter means accepting advocacy must be done in another environment. Homeschooling seemed to be the solution. We pulled her out and put her into a homebound program via the deaf school.

**ODYSSEY:** How is the homeschooling progressing?

**DENNEY:** Her mother and I do our best. A nearby school for the deaf is in the process of hiring a teacher who will videophone/teach her four hours a week. Livia is intelligent. She keeps up with her schoolwork and is just about on grade level. She gets great language exposure at home. Still, nothing beats being part of a school with its full offerings—academics, social life, sports. I earn a good salary, but I am always exhausted due to the long commute round trip and overnight workload. Livia is also struggling with loneliness; she needs socialization. Our future is up in the air; we are looking at relocating. In the meantime, we’ve set up a small personal home business so Livia can be self-sustaining and maybe have

some funds set aside for the future surgery she will need because the job market isn't great, especially for those unique like herself. It's growing little by little as home businesses do, but Livia's helping with it and doing a heady job for someone only 13.

**ODYSSEY: Are you close as a family?**

**DENNEY:** We used to do a lot of stuff together as a family. Now, our two oldest boys (24 and 20) are on their own. Massimo (16), Livia, and Noelle (10) are still at home. Everyone signs; our deaf children are fluent in English as well as ASL, and our hearing children are fluent in ASL as well as English. Since moving to our current home state, we've gone on hikes, checked out some beautiful overlooks, and we love going to the beach. We are close-knit but everybody also has their own interests. I encourage independence. I've been everywhere and am still curious about other locales. I encourage the kids to do the same.

**ODYSSEY: How did Livia's siblings adjust to the change?**

**DENNEY:** They struggled at first. Massimo struggled because they were close in age. Noelle has always seen Livia as who she is—her sister. Everybody has long accepted her for who she is since she was 3 or 4; that's a decade now. She's a great kid, a great sister, a fun conversationalist with a wicked sense of humor (just like her dad), and a very loving and caring person. She's close to her mom, and she looks up to her.

**ODYSSEY: What is the biggest issue facing Livia right now?**

**DENNEY:** The biggest issue? It is society. I think in some areas of the country, yes, society and many individuals accept transgender people. However, there are people who still freak out when they see the word *transgender*. We don't advertise Livia's gender identity, but it always comes up in school conferences. Professionals will sign to us: "DO-DO bathroom?" The answer is always simple: Let her use her preferred restroom, which is the girls' restroom, and leave her be. Other than that, schools are the least of her problems. Today, many people are supportive. After what we've been through—accepting our daughter and then advocating for her both educationally and socially—we have been asked for advice, and we give it the best we can. Neither of us is a licensed professional in whatever field, but we have the best knowledge of our own daughter's persona, which is: Let the kid be.

**ODYSSEY: Having experienced so many different educational situations, do you think of yourselves as experienced parent advocates now? Do you have any advice that would help other parents?**

**DENNEY:** Our advocacy centers on Livia, and we give people who ask for help the same advice we gave ourselves. Make sure your child's rights are protected, that your child is not

ostracized, that your child has the same opportunities as everyone else. We don't lecture or give workshops because that's not our thing. We go for a common-sense approach and leave it at that. Don't go insane when people don't automatically accept your child—give them time to adapt and overcome set prejudices. Often, kids don't want who they are discussed or advertised; they just want to be left alone to do their thing like a normal kid ... but this means parents of children like Livia must work with the school to ensure their rights and get the education to which they are entitled.

## TIPS FOR FAMILIES ON Supporting Their Transgender Child

By Larissa Clapp

*Larissa Clapp, MA, is a counselor at the Laurent Clerc National Deaf Education Center's Kendall Demonstration Elementary School. She is also the co-creator, with KDES psychologist Blake Culley, of the Clerc Center's new LGBTQIA training (see p. 86 for more information).*

- **Seek support** if possible (e.g., online chat groups, informative links, organizations, other parents of transgender children, experts).
- **Familiarize yourself** with the latest laws and legal rights that impact your transgender child so you understand to what they are legally entitled.
- **Recognize** that your child has their own unique personality, mind, and journey.
- **Become comfortable** with advocating for the well-being of your family, including your transgender child, and teach your child self-advocacy skills as well.
- **Remind yourself** that positive family support can literally save the life of a transgender child.
- **Realize and embrace** the fact that there will be some challenges and difficult moments, but there will also be many beautiful milestones and memories.

# To Advocate or Not to Advocate? There is No Question:

## WHY PARENTS MUST ADVOCATE FOR THEIR CHILD'S EDUCATIONAL NEEDS

*By Christopher Hayes*

*If you buy a toaster that doesn't work as it's supposed to, you take action ... You don't wring your hands and wait for the company to find you. It's the same with IDEA [Individuals with Disabilities Education Act, the law that protects the rights of deaf and hard of hearing children in the classroom] ... The full implementation depends on parents. ~ Cutler (1993)*

According to the University of Notre Dame's online dictionary (n.d.), the word *advocacy* comes partly from the Latin word *advocare*, which means "to summon or call to one's aid." This definition provides an interesting look into what advocacy means when looking at the special needs of a child. Advocacy is a summoning of support, a call for resources to address the child's particular needs.

In rural schools, itinerant teachers deal in situations in which the number of deaf and hard of hearing students is high, and the number of trained teachers of deaf and hard of hearing students is low. For example, I am the only teacher for all 40 deaf and hard of hearing students in our county. I work in a mainstream environment with students whose hearing loss varies from mild to profound. For all these students, parents represent vital members of their educational teams. It is our responsibility to encourage and support these parents as advocates and to recognize parents as the critical element in their children's education. Knowledge of their child's disability or challenges does not automatically place a parent in an advocate's role. Sometimes educators assume that because parents are involved, the parents understand their rights and responsibilities surrounding the needs of their child. This may not be the case. Attendance at teacher conferences and school meetings does not constitute advocacy.

A parent's understanding that their child has an exceptionality does not mean that a

*Photos courtesy of Christopher Hayes*

### **Christopher**

**Hayes**, MA, CED, has been an itinerant teacher for deaf and hard of hearing students in Highlands County, Fla., for the past 14 years. Hayes earned his bachelor's degree in deaf studies from the University of Arizona. He also completed his master's degree in deaf education from the University of Arizona, where his final project centered on streamlining and improving itinerant services through the use of technology and handheld devices. Shortly thereafter, Hayes received professional certification from the Council on the Education of the Deaf. He is currently serving as past president on the executive board of the Florida Educators for the Deaf/Hard of Hearing. Hayes lives in Sebring, Fla., with his wife and three children. He welcomes questions and comments about this article at [hayesc@highlands.k12.fl.us](mailto:hayesc@highlands.k12.fl.us).





**Left:** Hayes meets with a parent to discuss resources available to deaf and hard of hearing children.

parent understands the educational impact of their child's exceptionality. In my experience, parents with whom I work—all of whom live in rural districts—are not exposed to the means or the resources to become advocates for their children. There are several reasons for this:

- **Parents too often believe that their opinion is not valued or that it does not matter.** According to a study by researcher David Engel from 1988-1990, “parents feel inadequate and unqualified in special education situations across socioeconomic and other demographic classes” (Phillips, 2007). This study demonstrates that it doesn't matter whether rich, poor, highly or minimally educated, parents report that they feel unqualified to direct the education of their children.
- **Parents believe that they don't know as much as the professionals do.** Although parents are the caregivers and have raised the child, there is a feeling that they have little to offer the educational process. Engel reported that “parents feel that their own observations or requests are given little weight and that decisions are based primarily on the recommendations of the professionals” (Phillips, 2007). Whether it is because of the professionals'

unfamiliar language or the extent of their education, parents seldom speak up at meetings and rarely question educators' decisions. This reaction may be even more pronounced in meetings that involve deaf or hard of hearing children because hearing loss is a low incidence event and the chances that parents would have a deep understanding of it or the educational alternatives it entails are slim.

- **Parents are unsure how to navigate the process of addressing concerns.** Parents are naturally concerned about their children's performance. They want to know how their children are doing; they want to know if it is advantageous to change their children's educational program. They also want to know how their children are doing in relation to hearing children and in relation to their deaf and hard of hearing peers. Therefore, we need to explore why parents are so often silent in our educational meetings. Perhaps they are given too much information; or what they are hearing is extremely difficult to internalize and process; or they feel a sense of self-doubt and fear that if they disagree with the experts, the experts will retaliate.



**Left:** Hayes works with a student on a literacy activity.

**Below:** Sharing information and resources with families involves and empowers them in their child's education.

- **Parents fear retaliation.** Parents report feeling that if they talk to teachers or staff about needed services or resources, their requests will frustrate or anger the professionals, who will thus take out these feelings on their children.

### Reaching Out and Supporting Parents

With over 15 years of experience as an itinerant teacher, I have found it helpful to take deliberate steps to support and foster advocacy from parents. Others may find these steps useful as well. They include:

- **Maintain open lines of communication.** Maintaining an “open door” and allowing face-to-face communication as well as communication through phone and e-mail permit parents to reach out and test ideas, express concerns, talk about their children’s successes or needs, and seek help in finding resources. Setting limitations is necessary, of course, but teachers should try to be available and set aside time when parents can come in to discuss their children.
- **Value parents’ input.** Pay attention when parents talk; observe the ways they interact with and advocate for their children. Parental input is valuable, even when it is subjective. Challenges at home are not necessarily challenges at school and vice versa. This is important information and must be included as input within reports and Individualized Education Programs. Bottom line: Parents know their child, too, but in a different way.
- **Empower parents.** Knowledge is power. Share resources and information, and support parents in their own search for information and ways to advocate. The more you put them in charge, the more they will feel confident and

comfortable with advocacy. People love to know that they can make choices, too, and that they are doing the right thing.

- **Remain professional and unbiased.** We are in a field in which professionals disagree adamantly. In a mainstream itinerant setting, children come from different backgrounds, cultures, socioeconomic backgrounds, language exposures, and communication modalities. Our job is to be conversant with all sides of the issues, to focus on the best educational programming, and to remember that we do this for the child and not for ourselves. Also, teachers are professionals and our conduct reflects on our schools and districts, and especially on our field. Seek to understand, then to be understood.
- **Thank parents and praise them.** Parents are important members of every educational team. They often advocate for their children in ways that may seem small, but we need to notice this and praise their effort. Having a child with hearing loss is a multidimensional condition; parents have a lot to learn, and sometimes not a lot of time in which to make decisions. So, when they act on behalf of their child, it is important to recognize and support their actions.

This places a lot of the cheerleading and pep talking in the hands of the itinerant teacher. However, when I can do this, I see parents become more informed and more actively participate in the advocacy process.



PHOTO CREDIT: CAT VALCOURT-PEARCE

**Knowledge is power.  
Share resources and  
information, and  
support parents in  
their own search for  
information and  
ways to advocate.**

connotation sometimes changes—and the parents' actions may be viewed by the school staff as adversarial. This can cause a breakdown in the process of advocacy for parents, and it may change the atmosphere of cooperation between parents and schools.

As educators, we must understand the role of parent advocacy and make recognition of its importance visible. If teachers, counselors, and support staff can help parents see

### In My Experience

In my experience, advocacy—adding a voice to support children in their education—has a different connotation depending on who is doing it. We teach our students to advocate for themselves because skills in advocacy will help them throughout their lives. Educators and staff advocate for students, providing information and support. Both forms of advocacy tend to be viewed positively, but when a parent steps in to advocate for his or her child, the

their own importance, they may go a long way to fostering and encouraging parent advocacy. Parents need to be recognized for what they understand and what they do. The more they feel that they are doing the right thing for their child, and the more they see that their input is valued, the better they feel and the less likely they are to feel detached and divorced from the decision making that determines their child's education. We need to actively encourage their involvement and advocacy.

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# The Importance of Quantity and Quality of ASL

## with Young Deaf and Hard of Hearing Children

*By Todd LaMarr and Lisalee D. Egbert*

*A critical part of parental advocacy is being informed. Sometimes this means educators must stay on top of research and share what they learn with parents. This may be especially important in the case of research on early language exposure.*

Exposing our youngest children to language—whether it is English, American Sign Language (ASL), or any other fully developed language—is essential. Early language experience leads to stronger kindergarten language ability, which is one of the best predictors of later academic success (Pace et al., 2019). This is the reason that educators advocate using ASL with deaf and hard of hearing children. Through use of ASL, deaf and hard of hearing children are ensured full access to a full language. Research indicates, however, that it is not only the use of a language but also the amount of the language and the way adults use that language that is critical to the child's development. In fact, studies done with hearing children indicate that it is the quantity and quality of the language that children receive that affects their cognitive and academic outcomes (Gilkerson et al., 2018; Marchman & Fernald, 2008).

### Language Quantity, and Quality

#### What the Science Shows

Studies with hearing children showed that the quantity of language—the sheer number of words that a child experiences—varied greatly among families. In a day's time, 2- to 4-month-old infants heard an average of 15,071 words from adults, but there was a difference of almost 6,000 words between the infant who heard the greatest and the infant who heard

*Photos by Matthew Vita*



**Above:** One unique strategy Deaf parents use with their deaf or hard of hearing child is to make the signs on the book itself or on the child.

the fewest number of words (Gilkerson et al., 2017). These day-to-day differences in the quantity of language exposure added up and compounded over time, leading to a difference of potentially 30 million words received by a child's fourth birthday (Hart & Risley, 1995). This difference had early and long-lasting effects. Parents who exposed their children to a larger quantity of language at 18 months had children with larger vocabularies and faster language processing six months later (Hurtado, Marchman, & Fernald, 2008). Children who heard more words in the first two years of life demonstrated better language and cognitive abilities eight years later (Gilkerson et al., 2018).

While quantity is important, so, too, is the quality of language to which children are exposed. Researchers have found that quality of language—the way parents use language with children—also differs among families, and these differences also impact later abilities. One measure of language quality concerns how children experience language. Hearing children can experience language when their parents talk directly to them and when they overhear it being used in their environment. Hearing children who more frequently experienced language through being talked to directly had larger vocabularies and faster language

processing abilities than other children (Weisleder & Fernald, 2013). Another way to measure the quality of language is through the amount of turn-taking that a child experiences. Turn-taking is the intimate exchange of communication between the adult and the child that occurs in conversation. For the first year of life, infants and parents engage in about 200-300 back-and-forth interactions per day (Gilkerson et al., 2017). Hearing children who experienced more conversational turn-taking with their parents gained more vocabulary (Cabell et al., 2015) and exhibited greater activation in language areas of the brain (Romeo et al., 2018).

### **Research with Hearing Children Implications for Deaf and Hard of Hearing Children**

The lessons learned from research with hearing children can easily be applied to deaf and hard of hearing children. While educators have long advocated early use of ASL for deaf and hard of hearing children in order for them to experience the benefit of full language access,

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PhD, is a two-term member of the Maryland Governor's Office for the Deaf and Hard of Hearing Advisory Council and sits on the Maryland Cultural and Linguistic Competence Committee related to mental health services for deaf and hard of hearing individuals. Egbert received a Civic Engagement Award for service in social justice, diversity, and equality. She also serves in the Early Hearing Detection and Intervention (EHDI) Program for the Maryland Department of Health and for the Parents' Place of Maryland as well as the EHDI Screening and Beyond Advisory Committee. She and her husband are deaf, and they have two hard of hearing and two hearing children.

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we should also advise parents and educators of young deaf and hard of hearing children to increase the quantity and improve the quality of the sign language to which their children are exposed. This means taking advantage of opportunities when together and signing more. It also means signing to the child directly and engaging in turn-taking that encourages children's participation in conversation.

The discussion of ASL quantity and quality can seem very intimidating, especially for parents who are still learning ASL, but parents do not need to be fluent signers to do this. Research has shown that even for parents who are still learning ASL, the quantity and quality of their sign language interactions with their deaf or hard of hearing child can make a substantial positive difference in their child's development (Allen, 2015; Allen & Enns, 2013). Furthermore, we can encourage parents to turn their daily routines and chores into rich language experiences. For example, before going to the grocery store, they can help their child create the grocery list, learning the signs for each item of food they expect to buy. Once in the store, parents and children can discuss the color, size, shape, weight, and texture of each product as well as their differences and similarities.

Further, resources exist to help both parent and child learn new signs and see ASL used by skilled native signers. These resources can help increase the quantity of signs and the quality of signing to which a child is exposed as well as allow parents to enjoy materials with their children. For example:

- A free library of ASL signs, including an ASL/English dictionary ([www.lifeprint.com](http://www.lifeprint.com))
- Children's stories produced in ASL ([www.dawnsign.com](http://www.dawnsign.com))
- Bilingual English/ASL story apps developed for children (<http://Vl2storybookapps.com>)

**By increasing the amount of ASL deaf and hard of hearing children experience and ensuring we engage our children directly with visual strategies, we have the potential to impact their early language and cognitive abilities and, later, academic achievement.**



### **The Visual Difference Mentors and Reading**

One of the reasons that hearing parents may be hesitant to sign more and engage in quality interactions with their deaf or hard of hearing child is that this requires visual and language strategies with which hearing parents are often not familiar (Lieberman, Hatrak, & Mayberry, 2014; Spencer, Bodner-Johnson, & Gutfreund, 1992). A way to improve quality language interactions is to elicit the support of Deaf individuals to serve as mentors to hearing family members.

A Deaf Mentor can model strategies for engaging young deaf or hard of hearing children, such as getting and keeping their attention. They can also provide Deaf cultural knowledge and strategies for signing. In one study, after Deaf Mentors visited their homes, hearing parents learned important strategies, such as getting a child's attention, and strategies to improve quality language interactions. Families who were visited by a Deaf Mentor had deaf children who demonstrated larger vocabularies and more advanced English skills compared to deaf children whose families did not work with a mentor (Watkins, Pittman, & Walden, 1998).

Reading is a great way to increase the number of signs a child is exposed to and offers opportunities to practice high-quality strategies unique to reading with deaf and hard of hearing children (Swanwick & Watson, 2005). To increase sign exposure, parents can learn the signs beforehand to introduce new signs to the child. A few unique strategies Deaf parents use are to make the signs on the book itself or on the child and to sit across from the child so the child can easily see both the book and the parent signing.

Resources exist to help parents learn visual strategies for interacting with and reading to their deaf or hard of hearing children and help them increase the language quality that they provide. These include:

- A collection of research-based briefs for families and educators, from Gallaudet University's Science of Learning Center on Visual Language and Visual Learning (<https://vl2parentspackage.org>), that includes topics such as "Visual Attention and Deafness" and "Family Involvement in ASL Acquisition"
- A free webcast, "Language Learning Through the Eye and Ear," from the Laurent Clerc National Deaf Education Center (<http://clerccenter.gallaudet.edu>), for parents about



how deaf and hard of hearing children acquire language and supportive strategies

### Advocating for Language Quantity and Quality Matter

As both educators and parents, we believe that as we advocate for the value of sign language in the lives of deaf and hard of hearing children, we must also explain and advocate for the importance of increasing the quantity and

improving the quality of the sign language that our deaf and hard of hearing children receive. It is essential that we support parents as they learn new visual strategies for interacting with their deaf or hard of hearing children. We must make parents aware not only of the importance of learning and using ASL but also of the importance of using it more often and more effectively. This means understanding the significance of “quantity” and “quality” of language

exposure and explaining it to parents.

As simple as it may seem, the science is clear: By increasing the amount of ASL deaf and hard of hearing children experience and ensuring we engage our children directly with visual strategies, we have the potential to impact their early language and cognitive abilities and, later, academic achievement. We owe this information to parents so that they can more effectively advocate for their children.

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# Educators Empowering Families

*By Christy M. Neria, Stephanie M. Young, and Delcina M. Colantuono*

*When an education department brought students who communicate through American Sign Language (ASL) and students who communicate through spoken language onto the same campus, educators focused on empowering families to advocate—whatever their choice of communication.*

Recently, our district reconfigured our program for deaf and hard of hearing students, combining the Total Communication (TC) and Listening and Spoken Language (LSL) programs for elementary students and relocating students and staff into a single school. This prompted staff to reflect on and discuss the pedagogy unique to each program. We analyzed approaches to language, education, and advocacy for our students and families. We realized that while our programs reflected diverse principles and approaches, extensive commonalities exist. The primary commonality was the need for families in both programs to receive support for working with their children in language, whether the language was signed or spoken. We needed to help families learn how to provide and incorporate language into their daily routines, and we needed to advocate and teach our families how to advocate for themselves and for their children to maximize learning for everyone.

*Advocacy* means speaking out and taking action in pursuit of a cause (LaRocco & Bruns, 2000; Turnbull et al., 2011). In our program, the approach to advocacy is the same whether families choose to communicate with their children through speech and signs or through speech alone. Family involvement has always been valued. We included families in all stages of their students' educational journeys in order to equip them to advocate for their children. We realized that both programs had the same goals: *Teach,*

*Photos courtesy of Christy M. Neria*



**Left, above, and below:** Families enjoy a Dr. Seuss Read-A-Thon and family picnic.



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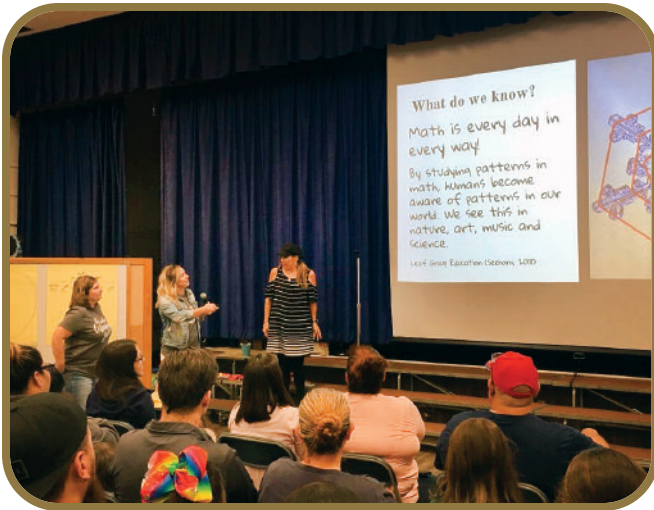
*Empower, (Actively) involve, and Make innovative projects.* This gave us an acronym for our approach: TEAM. Here is a closer look:

- **T** stands for *teaching*. We teach all families, whatever their communication choice, to work to improve communication with their deaf or hard of hearing child.
- **E** stands for *empowering*. We want to empower our families through providing resources and materials that are specific to their situation and communication modality.
- **A** stands for *actively involve*. We want to be proactive in gleaning the participation of families in the educational environment for their children.
- **M** stands for *making innovative projects*. We want these projects to inspire family participation in their child's education.

## **T-TEACHING Begins with Parents**

Literacy and learning begin at home as children naturally interact with their families (Adams, 1990; Anderson, Hiebert, Scott, & Wilkinson, 1985; Neuman, 1999). Therefore, teaching—parents as well as students—is essential. We are trying to reach all parents, including those from different ethnic communities, those of low economic status, those who may be cognitively or socially disadvantaged, and those who are simply unaware of how to support their children through their education. We must explain to families the importance of communicating and sometimes coach parents and care providers on how to communicate effectively and work with their children in order to enhance their language development. Multitudes of teaching opportunities exist in the home, and both programs point these out to promote our





**Left:** Teachers give an introduction at Family Math Night.

**Below:** Families measure and cook during Family Math Night.

students' language development. Here are a few examples.

#### **FOR ALL FAMILIES—TC AND LSL**

The following strategies have been useful for both TC and LSL families:

- Setting up informal meetings with our support staff to answer parents' questions regarding their children's hearing loss and equipment
- Inviting families and parents into the classroom to participate in and observe specific language strategy opportunities
- Inviting parents onto campus to observe and participate in schoolwide activities (e.g., Read Across America, Poetry Night, Parent Literacy/Math Nights) during which teachers model language-learning strategies
- Using Individualized Education Program meetings and parent conferences to share tips for communicating, reading, and writing with children
- Providing opportunities for home-to-school connections (e.g., making shopping lists, cooking, writing letters to each other, hiding something and writing directions on where the child can find it, labeling the house with the names of things, watching a movie and having the child discuss his or her favorite part)
- Exploring hands-on science or math topics with families in the classroom, conducting experiments with materials that families may have at home (e.g., making baking soda volcanoes, building model rockets, creating geometric shapes with toothpicks and marshmallows)
- Sharing resources on advocacy so that parents and children can advocate for accommodations and their individual needs

#### **FOR TC FAMILIES**

Our TC program encourages parents to establish their children's language as ASL in order to support their learning and literacy, and to communicate with their children through signs—and for some children through signs and speech—to incorporate language into daily routines. Some of the ways we support parents in learning how to communicate include:

- Offering weekly classes in ASL to the entire family
- Sending home weekly videotexts of ASL vocabulary
- Responding to inquiries about ASL
- Exchanging photos through texting so teachers can see what experiences students have at home and use these experiences in the classroom to build literacy
- Encouraging parents to use ASL with their children during all waking hours to ensure full access to communication

#### **FOR LSL FAMILIES**

Our LSL program optimizes learning and academics through listening. One way to achieve this is through maximizing



inclusion in the mainstream environment in response to the child's individual needs as well as incorporating language-learning opportunities into daily routines. We include families through:

- Encouraging parents to have their child wear amplification during all waking hours to create an open line of communication
- Encouraging parents to talk to their child as if the child has typical hearing
- Teaching families to narrate daily happenings with their children
- Meeting families before and after school to coach and guide caregivers through the hierarchies of a child's development in the areas of listening, speech and language, auditory skills, cognitive skills, and social skills
- Inviting parents to Listening and Language Nights, during which tips are shared on how to facilitate listening, spoken language, and literacy through hands-on activities in which parents can meet and encourage each other and learn to assist their children in developing both academic and everyday vocabulary

## **E-MPOWERMENT**

### **Helping Parents Know Their Impact**

"Knowledge is power, and shared power ... is central to every partnership" (Turnbull et al., 2011). Sometimes families may not be aware of the information needed to help them support their children. Thus, it is important to ask them questions about their needs at home and offer them suggestions and resources. Resources are suggested that are unique to each child's needs, and both our TC and LSL programs emphasize the importance of sharing resources that align with the curriculum and support families in helping their children.

#### **FOR ALL FAMILIES—TC AND LSL**

Teaching and providing resources are important; however, involving families in events and in class activities is also critical in promoting advocacy. Giving the family opportunities to experience the content being learned in class, as well as providing opportunities for the students to show what they have mastered, supports family advocacy. These opportunities allow the student and the family to be a part of the school community. At each event, the importance of language—

whether visual or oral—is highlighted, and teachers model strategies in working with deaf and hard of hearing students.

Through both the TC and LSL programs, we encourage involvement with families through the following:

- Looking actively for opportunities to answer questions, support families, and listen to concerns
- Encouraging parents to attend special events (e.g., events demonstrating coding and robotic projects students create in class, showing classroom-made movies, field trips)
- Creating opportunities for families to interact at school (e.g., through the library, potlucks, music performances, talent shows, holiday programs, PTA, literacy/math/poetry nights)
- Creating opportunities for active involvement with students' hearing peers during inverse mainstreaming, art, and/or coding

#### **FOR TC FAMILIES**

Some of the resources our TC program has developed and uses include:

- Teacher-made ASL DVDs and suggested ASL YouTube links for families unable to attend ASL classes
- ASL apps and websites, and the ASLnook on YouTube

**Giving the family opportunities to experience the content being learned in class, as well as providing opportunities for the students to show what they have mastered, supports family advocacy.**

**Below:** Families build geometric shapes with toothpicks and marshmallows at Family Math Night.







**Above:** Families use pumpkins to promote descriptive language during Family Literacy Night.

**Bottom right:** During Epic Build/Open House, students share their projects.

- ASL/English and ASL/Spanish dictionaries provided to the students' homes
- Information concerning Deaf community events (e.g., ASL Expo, interpreted events)
- Games that help students practice skills with their families (e.g., memory game with vocabulary words/signs, links to software programs such as [www.reflexmath.com](http://www.reflexmath.com))
- Recipes from cooking done at school (e.g., we print the recipes, send them home, and encourage families to replicate the process of preparation and cooking with their children)

#### FOR LSL FAMILIES

Some of the resources our LSL program has developed and uses include:

- Daily/weekly newsletters and classroom apps to reinforce the language and listening taught in the classroom and with exciting activities to do at home to support their child's listening and speaking skills and academics through active play (e.g., making slime, games, storytelling, cooking activities)
- Websites that families can use to support their child's

listening and speaking skills (e.g., Med-El, Cochlear, Advanced Bionics, Supporting Success for Students with Hearing Loss, AG Bell, Learning and Listening)

- Events and activities (e.g., Cochlear, AG Bell, student fundraising, Starky Hearing Foundation)
- Participation in the After School Program so families can see how they can help their child with their homework to meet their reading goals

### (A-CTIVELY) INVOLVE AND M-AKE INNOVATIVE PROJECTS

#### ... and Inspire Parents

Authentic engagement (Schlechty, 2002) is essential in order not only to help students solve problems and make meaning but also to encourage connections between school and family. By engaging students and families, all members of the TEAM may feel more invested in education and want to become more involved. One way to do this is by facilitating and developing curriculum that showcases student innovation while peaking families' interests enough so that they want to participate in the learning process.

#### FOR ALL FAMILIES—TC AND LSL

Here are some of our successful projects:

- Students create videos about themselves and their hearing loss to advocate for their needs (e.g., to introduce themselves to a new mainstream teacher)
- Students use coding software and create robotics projects
- Students make and perform in classroom movies based on what they learned in class (movies are sent home with





students, or showings occur at school)

- Students use and create QR codes and websites
- Students create videos based on vocabulary they are learning to practice at home
- Students participate in cumulative projects (e.g., dances, performances, plays) with their hearing peers
- Students make books about their study trips, daily routines, and home events
- Teachers share classwork, innovative learning activities, and pictures through group texts and/or communication applications (e.g., Class Dojo) so parents can communicate with their children more effectively

### When Families Seem to Hesitate Strategies for Involvement

In both our TC and LSL programs, some families seem to hesitate to participate in their children's school life. Many reasons exist for this hesitation. Low participation sometimes correlates with a family's socioeconomic status or difference in the culture and language from that experienced at school. Some families may want to participate; however, they may feel intimidated or they may not have the resources or time to support their children in language and learning. When this happens, we actively seek out these families and prompt them to become involved in their children's learning community. As we approach these families, our team is careful not to simply take charge. We know that when the parents feel involved in the learning process, they are more likely to follow through. When they help develop learning strategies, they are more likely to use them with their children.

In order to include all families on our educational TEAM, teachers need to build trusting relationships. This means respecting, honoring, and being sensitive to family needs

(Turnbull et al., 2011). In order to demonstrate how we hold in high esteem the families with which we work, we try to do the following:

- Initiate additional meetings with families at times convenient to them
- Visit the homes (e.g., check on families at home, attend family events if invited, bring materials to provide support and explain the content)
- Make phone calls (e.g., explain content or events, provide updates, figure out transportation)
- Use FaceTime, Skype, or the Video Relay Service (e.g., to teach signs)
- Provide resources in multiple languages to help families follow daily routines, classroom newsletters (e.g., Spanish/English/ASL dictionaries, resource books from Cochlear, Oticon: Plugged In, MedEL: Will Wonder, We Learned to Listen, Neither Nor, El Deafo)
- Communicate with families through classroom apps and other messaging services that include translation (e.g., Class Dojo)
- Work with other professionals or individuals personally involved with the family (e.g., other family members or social workers) if given permission

As educators in our TC and LSL program work with families, we continue to look for new ways to advocate and support advocacy. We want to include all families—no matter their choice of communication—so as teachers and parents we can collectively support our students' language and learning as well as better the lives of all our deaf and hard of hearing students. After all, as Helen Keller so poignantly said, "Alone we can do so little, together we can do so much."

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# Deaf Students with Disabilities:

## A Functional Approach for Parents and Teachers

*By Sara Schley and Jessica Trussell*

Already a widely diverse group, deaf and hard of hearing students have different communication preferences, physical and academic abilities, and personality traits. When a deaf or hard of hearing individual also has one or more disabilities, the diversity increases exponentially. A deaf or hard of hearing child's already complex needs are compounded when additional disabilities are present. In this article, we summarize an approach we have used for the last five years teaching graduate classes and working with future teachers of deaf and hard of hearing children. Parents may also want to consider this approach as they work with educators and the Individualized Education Program (IEP) process to advocate for their children.

Each disability changes programming needs dramatically, and decisions for any child with disabilities in addition to deafness must be highly customized. Meeting the child's needs by focusing on functional demands in the educational environment—rather than discussing compliance with special education law—allows all parties to maintain collaborative interactions and the child to learn more effectively. This mindset (focusing on the functional impact of disabilities in the classroom rather than on legal definitions that qualify a student for special education services) assists teachers, service providers, and parents to collaboratively develop effective interventions.

When planning special educational services, a multidisciplinary team, including parents, considers 13 disability categories codified in the Individuals with Disabilities Education Act (IDEA) to determine the disability or disabilities for the child's IEP. These categories are meant to capture large differences in physical, perceptual, health, behavior, and learning factors and provide legal justification for qualifying the child for an IEP. Parents and

*Photos courtesy of Sara Schley and Jessica Trussell*



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educators understand that these categories do not inform the multidisciplinary team about how to best educate the child, but instead they provide legal justification for the provision of individualized educational services. While “deafness” and “hearing impairment” are identified as disability categories in IDEA, they may not be identified in the IEP of a child with multiple disabilities, including deafness. For example, one student’s IEP might say that he or she has “multiple disabilities,” and another student’s IEP might say he or she has “hearing impairment” and “specific learning disability.” It is worth noting that attention deficit disorder (ADD)/attention deficit hyperactivity disorder (ADHD), cerebral palsy, and dyslexia, so often seen in the classroom, are not listed in the IDEA structure of disability definitions.

Developing the IEP is designed to be a collaborative process among regular education

**Above: 1.** Academic disabilities impact access to academic learning but occur without below-average intellectual functioning. **2.** Cognitive disabilities include those where intellectual functioning limits learning of either academic skills or adaptive functioning. **3.** Social disabilities impact the social interaction and behavior management of the classroom. **4.** Physical and sensory disabilities impact students’ access to the educational environment and materials.

teachers, special education teachers, parents, and service providers to ensure specific educational goals are outlined at least annually. We propose a functional classification system to layer on top of the IEP process, focusing on the functional impact on the classroom of a child’s specific disabilities. This functional classification system could be for regular and special education teachers (including teachers of the deaf and hard of hearing) to use throughout the year when planning classroom

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interventions and when collaborating with school personnel, service providers, parents, and families.

We propose four broad disability classifications that impact the deaf or hard of hearing child in the classroom: *academic, cognitive, social, and physical and sensory*. Each of these should be addressed separately, providing additional insight in instruction and collaboration with family and service providers—everyone who has a stake in the child’s educational plan. While the IEP still guides the process, parents and educators can use these functional categories to plan and implement the IEP in the classroom. Below is a closer look at the categories.

### Academic Disabilities

Academic disabilities are those that impact academic learning but occur without below average intellectual functioning. These include learning disabilities, such as dyslexia, dyscalculia, dyspraxia, memory disorders, executive functioning, problem solving, sequencing, ADD/ADHD, and challenges with producing or comprehending language.

Once this set of disabilities is

identified, teachers can provide accommodations and adaptations to improve access to academic learning. Strategies that have been successful with hearing students with disabilities (Swanson & Hoskyn, 1998; Archer & Hughes, 2011) include a combination of:

- Explicit or direct instruction, or instruction with purposeful statements about the rationale for learning the new skill, clear explanations and demonstrations, and supported practice with feedback
- Strategy instruction, in which teachers provide direct learning strategies such as sequencing, segmentation, strategy cues, and controlling task difficulty
- Modeling and instructing students in small interactive groups

When using these strategies with deaf or hard of hearing students, teachers add supports, such as graphic organizers, that provide visual supports. Further, teachers model their thinking process during instruction by signing or speaking their thoughts as if thinking

aloud to show students how an adult uses language to think through a process. This type of intervention can be done at home as well, with parents using language to show their own thinking processes about decisions being made in the family.

### Cognitive Disabilities

Cognitive disabilities limit intellectual functioning. When students—deaf, hard of hearing, or hearing—have cognitive disabilities, learning goals may be modified. More common cognitive disabilities in the classroom may be Down syndrome and traumatic brain injury. Sometimes these conditions limit adaptive behavior, including self-care skills such as putting on and taking off jackets and using the toilet.

For this population, simultaneous prompting can be an effective teaching strategy. In simultaneous prompting, the teacher gets the student’s attention and then asks a question or delivers a prompt followed by the correct answer. The student repeats the answer and the teacher restates the answer as reinforcement (Neitzel & Woolery, 2009). Another effective strategy is error correction—stopping the student when he or she is completing a task incorrectly, modeling the correct way to complete the task, and then setting up the task again for the student to complete in the correct manner. Parents can incorporate these strategies into daily living activities at home, such as dressing oneself, teeth brushing, or hand washing.

For deaf or hard of hearing students, teachers may need to rehearse implementing these strategies while using sign language. More time may be needed to sign, and the questions may need to be modified in response to the students’ visual attention. Teachers of the deaf and hard of hearing also need to ensure they have student eye contact and their lessons are appropriate for students whose primary mode of learning is visual. At home, the same is true. Parents should ensure they have

eye contact before beginning any instruction.

## **Social Disabilities**

Social disabilities include autism spectrum disorder, oppositional defiant disorder, depression, anxiety, bipolar disorder, and ADD/ADHD. When students have social disabilities, classroom personnel may need to add accommodations and modifications that ameliorate social interaction and behavior in the classroom. Children who are deafblind may also experience social disability.

For these children, the Picture Exchange Communication System (PECS), a functional communication system that is self-initiated and can be learned quickly, may be an option (Bondy & Frost, 2011). PECS starts with instruction on using single pictures to communicate, then using multiple pictures to make sentences, and lastly using pictures for a multitude of communication functions (e.g., requesting, commenting). For students who are deaf or hard of hearing, PECS may be paired with sign language and speechreading. In fact, several educational interventions have been devised for deaf and hard of hearing students with social disabilities. These include:

- Discreet Trial Training, a one-to-one highly structured intervention with clear, concise directions and planned prompts that are faded over time (Cohen, Amerine-Dickens, & Smith, 2006).
- Pivotal Response Training, a play-based intervention that occurs in natural settings and encourages parental involvement. This intervention targets particular skills or behaviors in pivotal areas of development, such as motivation, self-initiations, responsivity to multiple cues, and self-management (Koegel, Koegel, Harrower, & Carter, 1999).

- Video modeling and self-modeling, in which a skill is targeted through providing video examples. The teacher determines what skill to target and then makes a video modeling the skill in a natural or contrived context. The video can be made from a first-person or a third-person point of view. The student watches the video a predetermined number of times and then attempts to carry out the skill. The teacher will prompt throughout the video to maintain the student's attention (Bellini & Akullian, 2014). With the ubiquitous use of smartphones with recording capabilities, it is easy for parents to make video models for home and community routines, such as washing dishes or ordering at a restaurant.

Each of these tools can be used in the home, and close collaboration between parents and teachers will help the child's educational development.

## **Physical and Sensory Disabilities**

Deaf and hard of hearing children with physical and sensory disabilities include those who have cerebral palsy; orthopedic or mobility impairments; vision impairment; and health challenges, including epilepsy, asthma, hemophilia, and traumatic brain injuries. They also include children with complex genetic conditions, such as CHARGE syndrome, Usher syndrome, Treacher-Collins syndrome, and Waardenburg syndrome. When students have physical and sensory disabilities, the educational environment and some parts of the learning experience may need to be modified. This may require attention to the physical layout of the classroom as well as to educational activities. Students with these conditions may need changes to curriculum and help in physically navigating the educational environment.

In addition to modifying the environment and activities, these

students also need a teacher with a flexible teaching style who is able to integrate them as fully as possible into their classrooms. Traditionally, problem areas for integration have been recess, physical education, transportation and field trips (Pivik, McComas, & Laflamme, 2002). A collaborative approach among general education teachers, teachers of the deaf and hard of hearing, specially trained specialists in other disabilities, (e.g., orientation and mobility specialists for students who are visually impaired), and parents and families is crucial. The teacher's and parents' motivation, attitude, and teaching style are equally important: Those who have a flexible instruction style tend to adapt or equalize the curriculum or environment instead of assigning assistance to the student (Egilson & Traustadottir, 2009).

Assistive technology options might also be helpful for some of these students. Voice recognition and speech-to-text systems can help in situations where students do not have dexterity to write efficiently; eye-tracking devices are useful in situations in which there is limited hand mobility; alternative input devices are available for computer use, such as head wands, mouth sticks, mice with oversized trackballs, sticky keys, and adaptive keyboards. Screen magnification, resizing text, and changing font color can be useful for some students with visual impairments. Technology can help students with various gross motor impediments, too. Teachers can find devices that help hold materials for transport, and students can participate in sports with adaptations for physical needs. These devices can also be used at home and in the community.

## **Helping Teachers Teach and Children Learn**

Teachers of deaf and hard of hearing students report that they do not feel prepared to meet the various needs presented by their students with multiple disabilities (Guardino, 2015). Looking at the functional impact of

these disabilities in the classroom and grouping students together with similar instructional needs may be an effective way to address these students' needs. Exploiting these students' similarities rather than focusing on their differences fosters effective instruction. Parents can advocate with teachers to focus on their child's instructional needs, rather than on a disability category or label.

Estimates range from about 30 percent to over 50 percent of deaf and hard of hearing students have more than one diagnosed disability (Guardino & Cannon, 2015). Environments, curricula, and even teaching style, for parents or teachers, are amenable to change—whereas most disabilities are not amenable to change and require accommodation. In classes in which we teach about deaf and hard of hearing students with additional disabilities, this functional impact classification system has helped students plan appropriate interventions for diverse classrooms.

Special education law requires an IEP, and this includes deaf and hard of hearing students. Elaborate customization for these students may be difficult given constraints on time, budget, staff, and resources. Using a functional impact classification—meeting students needs based on academic disabilities, cognitive disabilities, social disabilities, and physical and sensory disabilities—may help consolidate intervention within a teacher's or service provider's caseload and make teaching and learning an easier process. In the home, parents can use this system to help them choose interventions that will work for their children to be successful at daily living tasks and decisions.

The functional classification system frames how disabilities are most likely to affect the classroom and instruction (with the understanding that the impact can apply to more than a single functional area) as well as learning that happens in the home. Educators and parents can use these categories for thinking through and planning

appropriate instruction and supports on an ongoing basis throughout the year, working together to find the best system and the best balance for the child. This framework benefits new and pre-service teachers, by providing an explicit link between specific disabilities and the

functional impact on the classroom and instruction. It also benefits parents as they advocate for their children with a framework that focuses on abilities and needs rather than on satisfying legal requirements.

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# Hands & Voices' Family/Professional Model for Effective Advocacy: Reflections on Training

*By Janet DesGeorges*

I was surprised by the call. It came from someone I knew, a high-powered attorney, who was raising a deaf child. He wanted me to come with him to advocate for his son's Individualized Education Program (IEP) at their upcoming meeting. As a trainer and educational advocate, I am often requested to attend such meetings. Still, his desire for my presence surprised me. Who better than a lawyer to advocate for the IEP goals? Who better than a lawyer to explain the needs of his son to the school's teachers and professional support staff? However, this dad told me that he had not felt his input was respected at the meetings. In fact, he said, he had never felt his input so discounted as in the IEP meetings he had recently attended.

Whether as an educational advocate sitting through scores of IEP meetings with families who feel like they have to fight the system for basic access for their deaf or hard of hearing child or as part of our work at Hands & Voices, the parent support and advocacy organization that supports families who have deaf or hard of hearing children whatever their communication preference or educational placement, I often feel like we are taking "one step forward, three steps back" in our work for educational systemic improvement. Why? Partly because progress towards successful outcomes for students who are deaf or hard of hearing is an individual experience, and solutions for deaf and hard of hearing students are often complex. Partly because each child's education is affected by the policies, laws, people, and politics of three historically different professional fields—education, special education, and deaf education—and this makes advocacy complicated.

As those who care about deaf and hard of hearing children's education, we do not just advocate for a child's communication, language, literacy, and social-emotional

**Janet DesGeorges**, co-founder and executive director of Hands & Voices, serves as a trainer for the Hands & Voices Advocacy, Support, and Training Program. DesGeorges believes in educating deaf and hard of hearing children through a parent-driven, professionally collaborative approach. She lives in Boulder, Colo., with her husband, Joe, and has three daughters—Leah; Danielle; and Sara, who is deaf/hard of hearing. DesGeorges has presented to groups worldwide about the experiences of families as they journey through life with a child who is deaf or hard of hearing. She welcomes questions and comments about this article at [janet@handsandvoices.org](mailto:janet@handsandvoices.org).

*Photo and illustrations courtesy of Janet DesGeorges*

**The Hands & Voices Advocacy, Support, and Training (ASTra) Program**

ASTra is a replicable Deaf and Hard of Hearing Educational Advocacy Program that embodies the mission and vision of Hands & Voices, which is to provide support to families with children who are deaf or hard of hearing (D/HH) without a bias around communication mode, method, and educational setting so that every child who is D/HH has the opportunity to achieve their full potential. ASTra content is derived from years of direct advocacy experience working with families in schools, attending advocacy trainings from legal experts, providing trainings, and the Hands & Voices Educational Advocacy Guidebook (©2013).

ASTra can be implemented by a Hands & Voices Chapter independently or in collaboration with an agency or program partner. An agency or program partner can instigate the start-up of an ASTra Program only through the local Hands & Voices Chapter in accordance with the operational procedures of this program.

On this page are links to lots of resources and information about ASTra, including materials that are available by password-only access to Hands & Voices chapters who have an ASTra program or are in the start-up process.

**Questions? E-mail us**  
at [astra@handsandvoices.org](mailto:astra@handsandvoices.org)

**Read ASTra Testimonials**  
Read what people are saying about the H&V ASTra Program

**Appendix A of the Operations Manual**  
All the documents a Chapter will need to start and maintain an ASTra Program. \*\*ASTra personnel only.

**Hands & Voices Educational Advocacy Support to Families**

Many families struggle in their attempts to improve educational programs for their children, and the support they find is usually not experienced with the unique issues facing deaf or hard of hearing kids. Hands & Voices is often asked to provide educational advocacy support to families (and professionals) who have questions about special education law and its applicability to students who are deaf or hard of hearing. In our H&V chapters, it's not at all uncommon to find an H&V trained advocate supporting a family who is struggling with their child's educational services and communication access. H&V chapters can provide families with advocacy resources, support, and in some cases, attend an IEP meeting with a family. View our [chapter listings](#) to see if this service is available in your area. While we're not attorneys, and we can't give legal advice, we do feel strongly that experienced parents can be great assets to other families new to educational advocacy.

## Enter Promising Practice Hands & Voices Advocacy, Support, and Training Program

Hands & Voices has been conducting training informally and formally with parents and professionals for many years. In 2015, we launched the Hands & Voices Advocacy, Support, and Training (ASTra) Program with a belief in parent-educator partnership at its core. Rather than creating separate trainings for parents and professionals, we believed that what we had to say from the parent perspective could be helpful for professionals as well. The dual parent/professional focus and the sometimes intense but respectful discussions that follow benefit both groups. Parents learn about the stressors that tug on professionals, and professionals learn about the frustrations of parents; both learn and work together towards more effective education for deaf and hard of hearing students. We consistently receive high ratings from professionals and parents, and a new sense of shared purpose often arises towards the end of each session.

ASTra embodies the mission of Hands & Voices, which is to provide support to families with children who are deaf or hard of hearing without a bias around communication mode, method, or educational setting so that every child who is deaf or hard of hearing has the opportunity to achieve his or her full potential. The content of ASTra trainings is derived from years of direct advocacy experience working with families in schools, attending advocacy trainings from legal experts, providing trainings, and the *Hands & Voices Educational Advocacy Guidebook* (DesGeorges, Johnson, & Seaver, 2013). ASTra offers a flexible program to provide parents and professionals with resources that focus specifically on deaf and hard of hearing educational issues.

ASTra offers training on three levels:

- **Basic Training Level 1**—Tailored for parents, family members, and professionals, this training is for those who seek to increase their knowledge and skills in advocating for their own child and the children with whom they work.
- **Advocate Training Level 2**—Intended for parents, deaf and hard of hearing adults, and professionals, this training is for those who seek to be designated Hands & Voices ASTra advocates, to advocate for families other than their own as official representatives of Hands & Voices.
- **Train the Trainer Training Level 3**—Designed for parents, deaf or hard of hearing adults, and professionals, this training is for those who seek to become ASTra trainers themselves.

### Moving Forward: Treasuring Hope

Despite my moments of despair, I see and participate in important moments of progress and hope. Recently, for example, I attended an IEP meeting during which the professional team struggled to qualify a hard of hearing student for services. While the team focused on academic scores, the family—understanding the need for the presence of other deaf and hard of hearing students in their child’s life—focused on issues that were more social-emotional. As I watched, the professionals addressed the family’s concerns and discussed them openly. Ultimately, they were able to ensure services by assessing the student’s needs based on the family’s input and utilizing the appropriate assessment tools.

Partnerships between parents and professionals have the potential to create a brighter future for all children, and partnerships are growing. They are evident in movements such as:

- The Radical Middle (<http://radicalmiddledhbh.org>), an organization that attempts to bridge the gap between research and practice in deaf education



**Above:** DesGeorges with her daughter Sara, who is deaf/hard of hearing.

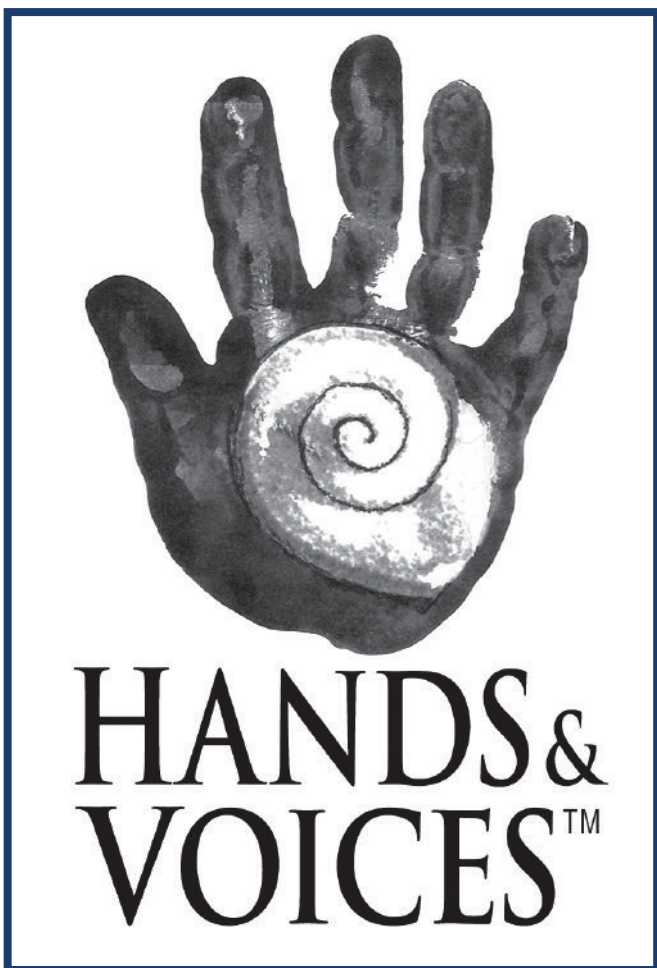
- A.G. Bell/Lead-K Agreement ([www.agbell.org/Resources/Articles-Documents/View/AG-Bell-Statement-on-LEAD-K-Agreement](http://www.agbell.org/Resources/Articles-Documents/View/AG-Bell-Statement-on-LEAD-K-Agreement)), two organizations coming together to support state-level legislation efforts for all deaf and hard of hearing children
- Common Ground Project ([www.ceasd.org/child-first/common-ground-project](http://www.ceasd.org/child-first/common-ground-project)), which seeks understandings across different school settings

In each of these groups, individuals come together with a common goal and willingness to truly partner.

When I have my moments of despair, I reflect on the work of Hands & Voices, bringing together the parents, professionals, and, above all, the students we have assisted and the partnerships that have been formed based on shared understandings and, at times, compromise. I predict partnerships between educators and parents will continue to gain momentum; these partnerships will help us emerge into a better future and allow all our children to receive the education and access that is their birthright.

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# Partnership: More Than Cooperation

By Janet DesGeorges

Partnership is ... a relationship where professionals and families share power to plan and deliver support together, [each group] recognizing that [the other has] vital contributions to make in order to improve quality of life for people and communities (National Co-Production Critical Friends, 2015). Often groups use the term *partnership* when, in fact, partnership is not at all what they have in mind. The following shows the levels of support and assistance that accumulate to result in a relationship that may be considered a partnership (Craig, 2004).

- 1. Coexistence**—Parents and educators may be aware of each other but do nothing to elicit support or assistance from each other:
  - Families and family-based organizations know about professionals and professional systems and vice versa, but neither seeks out or works with the other.
  - Direct relationships between families and professionals are nonexistent.
  - There is no interdependency or perceived need to collaborate.
- 2. Networking**—As parents begin to get involved with children’s education, contact with educators leads to increased awareness on the part of both parents and educators about ways each can contribute to the education of children:
  - Informal discussions are held with families and professionals.
  - Information is shared.
  - Formal visions, missions, or tasks do not exist between parents and professionals.
- 3. Cooperation**—In response to individual challenges, parents and educators begin to cooperate on discrete issues:
  - No long-term relationship is implied; no ongoing or formal commitment to each other exists.
  - Parents and educators may acknowledge some common issues, interests, and agendas.
  - Some documentation may exist that parents and families are formally working with professionals.
- 4. Collaboration**—Parents and educators are aware of the importance of each other’s contribution to their child’s education and anticipate each other’s input as decisions are anticipated:
  - Trust begins to develop; it is based on negotiated and agreed-on actions.
  - Shared decision making exists.
  - Families and professionals feel they add value to each other’s work.
  - Each may give up some power or control; each may experience a cultural shift.
- 5. Partnerships**—The importance of working together is accepted, and parents and educators rely on each other’s assistance:
  - Parents, families, caregivers, and professionals work from an agreement based on shared values.
  - Risks, rewards, resources, accountability, vision, ideas, and decision making are shared.
  - Each accepts formal relationship obligations; accountability exists for families as well as for professionals.
  - Supporting structures, processes, systems, and mechanisms are developed. There may be employment, funding, or contracting of parent partners within the educational agency.

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## E4: A New Workshop for Families



The Clerc Center has created a new workshop called E4 to support the parenting journey for families of deaf or hard of hearing children. This workshop discusses four concepts: Expose, Educate, Embrace, and Elevate.

The earlier families *expose* themselves to the resources available to support their

deaf or hard of hearing child's language growth and success, the more the risk of language deprivation is reduced. Moreover, it is critical that families be exposed to the myths about deaf and hard of hearing children and language acquisition. After families acquire this knowledge, they need to be directed to

evidence-based practices. With an understanding of the evidence, they can critically analyze research studies and *educate* themselves on how to advocate for their deaf or hard of hearing child to ensure the education their child receives is the best possible option. This workshop also encourages parents to *embrace* their deaf or hard of hearing child's identity by connecting with other deaf or hard of hearing adults to learn and understand what their child may grow up to be and how language is a factor in self-identity and development. And finally, E4 expands upon the evidence-based Clerc Center resources that will support the families' affirmation in *elevating* their deaf or hard of hearing child's language.

If you would like Clerc Center staff to travel to your community to give this workshop, please e-mail [training.clerccenter@gallaudet.edu](mailto:training.clerccenter@gallaudet.edu) or contact your Gallaudet University Regional Center.

### Clerc Center Collaborates with Boston University on Bridges Program

In an effort to continue innovating and exploring best practices in deaf education, Kendall Demonstration Elementary School (KDES) partnered with the Boston University (BU) Bridges program. This was the third yearly partnership created by the BU Bridges program with various schools. The program was designed and led by Todd Czubek and Kristin DiPerri of BU and aims to provide a model for translating bilingual educational theory into meaningful,

practical terms. The fundamental premise of the BU Bridges program is that effective training, teaching, and learning require sustained and scaffolded opportunities to apply accessible ideas in comprehensive ways.

The collaboration allowed BU students to apply new teaching strategies as the KDES K-5 teaching staff observed the strategies in practice while supporting the student teachers. Some of the new strategies involved the use

of kinesthetic activities, handshape holders, picture dictionaries, and technology. KDES teachers were provided with ready-made materials designed for deaf and hard of hearing children. These resources were intended to be used after the BU Bridges project concluded. The week-long collaboration was a one-of-a-kind learning opportunity for everyone involved—KDES students, teachers, graduate students, and administrators.

For more information about this BU-inspired project, please contact Czubek at [taczubek@bu.edu](mailto:taczubek@bu.edu).





## New LGBTQIA Training Launched: A Groundbreaking New Resource for Professionals



The Clerc Center is excited to announce a new training designed specifically for professionals employed in deaf and hard of hearing educational settings working closely with LGBTQIA students, with an added focus on transgender students. Blake Culley, Kendall Demonstration Elementary School (KDES) psychologist, and Larissa Clapp, KDES counselor, created the training in collaboration with the Clerc Center's Planning, Development, and Dissemination staff. With the current trend of increased visibility of LGBTQIA issues in our current society and in our schools, it was only natural that the need for specialized training designed

by deaf education professionals for educators working with deaf and hard of hearing individuals became prominent. As the nation's leading resource center on information, training, and technical assistance for families of and professionals working with deaf and hard of hearing children, the Clerc Center proudly took the initiative in meeting this need.

Included in the LGBTQIA training, led by Culley and Clapp, are basic terminology, Do's and Don'ts, basic legal obligations of schools, the importance of creating supportive atmospheres, the benefits of providing a safe space, and inclusive accommodation tips as well as a Q&A and consultation.

The training was first launched at the Michigan School for the Deaf by Culley and Clapp, generating rave reviews and positive comments. Many staff were

open and very inquisitive about how to better support their students who are LGBTQIA. Then Culley flew to Fremont, Calif., to provide training to the entire staff of the California School for the Deaf, Fremont (CSDF) and gave several presentations about their personal journey navigating their life as a deaf, transgender, nonbinary person to CSDF students, staff, and the community. Students at CSDF enjoyed asking Culley many questions about their journey, and the students, staff, and community members were fascinated with Culley's progress. Each person left with a better understanding of the transgender community.

If you would like to have this training presented to your school or community, please e-mail [training.clerc.center@gallaudet.edu](mailto:training.clerc.center@gallaudet.edu) or contact your Gallaudet University Regional Center.







conversations. First, there was a live video discussion session with Smith and Dr. Laurene E. Simms, a leader in educating and steering the field of teaching deaf and hard of hearing students. Second, there was a Twitter chat during which participants shared their ideas and thoughts gathered from the week's discussions.

This week-long event was followed by an in-depth exploration of Smith's research of educational interpreters through a three-part online book club discussion of *More Than Meets the Eye: Revealing the Complexities of an Interpreted Education*.

For more information about the Clerc Center Online Community and upcoming events, visit <https://clerccenteronline.ning.com>.

## Clerc Center Online Community

Among the many resources offered by the Clerc Center is the Clerc Center Online Community, which has five specialized groups: Early Intervention, Parents, Professionals, Educational Interpreters, and Closed

Groups.

In the fall of 2018, the Clerc Center Online Community hosted a multi-part event entitled "Debunking the Myth of 'Just' Being an Educational Interpreter." Activities were initiated with an archived

presentation by Dr. Melissa Smith, an interpreter educator, forming the basis of discussion for the week. The emphasis of the event was the interactive engagement of participants with online discussions. The week ended with two events featuring stimulating

## Clerc Center Hosts 2019 Education and Advocacy Summit

The Clerc Center, in partnership with the Conference of Educational Administrators of Schools and Programs for the Deaf along with Gallaudet University's Welcome Center, Department of Deaf Studies, and Department of Government, hosted its second Education and Advocacy Summit: Deaf Education on February 26, 2019. There were actually two summits—one for professionals and one for youth. The Youth Summit involved approximately 40 deaf and hard of hearing high school students who came to learn more about the Congressional process and lobbying, learned from Gallaudet's government

major students. This event was overseen by two professors who have law degrees: Tawny Holmes and Dr. David Penna. The youth event was also facilitated by the National Association of the Deaf's youth program.

The professional summit, with 120 participants, was for deaf education administrators and professionals as well as special education administrators, and it was organized by Bridgetta Bourne-Firl and Taiyabah Naeem of the Clerc Center. Thanks to the Council of Administrators of Special Education for sharing this opportunity with their administrators. The participants learned about the new National Association of State Directors of Special Education guidelines via a



newly created informative video. Michelle Koplitz, of the U.S. Department of Health and Human Services, shared updates about the Maternal Health program that focuses on Early Hearing Detection and Intervention. The U.S. Department of Education's Office of Special Education Programs' (OSEP) director Laurie VanderPloeg also presented at the summit,

sharing updates about OSEP. Finally, five-minute updates on the areas of LEAD-K, NTID's Regional STEM Program, Gallaudet's new Early Language Access Program initiative, and the Clerc Center's free resources were shared with schools for their own use.

Come join us at next year's event, to be held February 25, 2020!



# Deaf Education: Let Advocacy and Collaboration Pave the Way

*By Rachel Coleman*

**Rachel Coleman** is the executive director of the American Society for Deaf Children ([www.deafchildren.org](http://www.deafchildren.org)), the oldest national organization founded by and governed by parents of deaf children. She is the Emmy award-nominated host and creator of “Signing Time!,” the American Sign Language vocabulary building series, broadcast on PBS stations, Netflix, Nick Jr., and [www.mysigningtime.com](http://www.mysigningtime.com). Coleman and her husband, Aaron, reside in Cottonwood Heights, Utah, with their youngest child, Lucy, who has spina bifida and cerebral palsy. Their oldest child, Leah, is a proud deaf transgender person who is a senior at the National Technical Institute for the Deaf/Rochester Institute of Technology majoring in individualized studies with the concentrations of deaf cultural studies, design, and social inequalities.

Leah began preschool with a Deaf teacher as well as a one-to-one aide who was fluent in American Sign Language (ASL). This environment not only benefited our own deaf child, but the access to a complete visual language benefited each child in that preschool class. Having our deaf child’s educational needs met in the exact way we wanted was no accident; it was a result of advocacy and collaboration.

Collaboration first came through conversations with other parents of deaf children—parents who had already gone through this same process. We learned from their mistakes and from their successes. We relied on the expertise and kindness of Deaf professionals, like Dr. Lawrence “Larry” Fleischer, who attended Leah’s Individualized Education Program (IEP) meeting as an advocate. Dr. Fleischer armed us with research and facts, and he shared his own life experience.

Originally, our school district had hoped that providing an ASL interpreter in a typical preschool class would meet Leah’s

needs. We explained that our deaf 3-year-old didn’t know English, and as hearing parents, we weren’t fluent in ASL. Leah didn’t need someone to interpret what an English-speaking teacher was saying; our child needed to acquire a first language. In order to do that, Leah needed access to fluent signers who could model a visual language. Additionally, this would provide

Leah with the opportunity to acquire language incidentally. We had learned that having one fluent signer in the classroom was not enough; two fluent signers were necessary for a complete visual language model.

I recently sat down with Dr. Marc Marschark, director of the Center for Education Research Partnerships at the National Technical Institute for the Deaf, who, in no uncertain terms, expressed that parent involvement is paramount when it

comes to a deaf child’s success. While I wish the research showed that everything I chose for my own deaf child is right for all deaf children, it doesn’t. Instead, we find that there is no one-size-fits-all approach

**The best IEPs  
are collaborations  
created by a  
team of experts  
who trust and  
support one  
another  
throughout the  
process.**

when it comes to educating deaf and hard of hearing children. We must consider the child, their strengths and needs, follow their lead, and be flexible.

As a student's needs change, it is important that their IEP be reviewed and adjustments be made if necessary. One afternoon as the IEP team members discussed Leah's educational needs, they wondered if an ASL interpreter was still necessary in Leah's mainstream high school classrooms now that Leah had a cochlear implant. Leah stepped into the role of self-advocate, and as the only cochlear implant user on the IEP team, Leah's firsthand experience proved invaluable. Our child shared, "In an ideal environment, I can understand a good amount of spoken English with my cochlear implant, but most classrooms are not ideal environments. ASL works for me in every environment." Students

who are able to advocate for themselves play a crucial role in educating and informing other members of the IEP team.

Over the years we have had IEP meetings where we felt frustrated or intimidated. One time we left the document unsigned since we felt the services listed were convenient for the school but would fail to meet our child's needs. One team member pushed for what had worked for a different deaf child, not realizing it would not work for our deaf child. Remember, IEP team members are only human; this is why an IEP is not determined by only one person.

Over the years, we have also had IEP meetings that were relaxed and easy. We've worked with administrators and teachers who stood shoulder to shoulder with us, committed to solving and

resolving all concerns. The best IEPs are collaborations created by a team of experts who trust and support one another throughout the process. Parents are the experts when it comes to their children. Students bring their own expertise, especially if they have the ability to self-advocate. Educators and school administrators know which resources and services are available. Teachers are involved in the day to day implementation of an IEP, and they support students in reaching their goals.

We all want what is best for our children, for deaf and hard of hearing students. We might define "what is best" differently, and that's okay. Working together, we can leave deaf education better than we found it. Advocacy and collaboration pave the way.



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