



RETHINKING AUDITORY DEPRIVATION

Proceedings of the
California EHDI
Stakeholders Symposium

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Letter from the CAD President



July 2021

Letter from the CAD President

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I am proud to be the President supporting this publication of our most recent, and our fourth, Early Hearing Detection and Intervention (EHDI) symposium in 2020. The word, symposium, is defined as having a conference dedicated to one topic. All of our four symposiums have had been dedicated to deaf children's language acquisition and empirical evidence of the virtue of including American Sign Language as a part of EDHI intervention services.

Our first one, in San Diego in 2015, was a huge success that CAD decided to continue with our annual EHDI and biennial CAD symposiums. Our 2020 EHDI symposium exemplified the importance of bringing the essential stakeholder of EHDI, Deaf adults, along with other typical stakeholders of parents, educators, and medical professionals. Throughout this publication, you will see how our line of presenters were unified in their quest to ensure that deaf children and their families acquire a visual language like American Sign Language. We believe that ASL is one of the better ways for deaf children to acquire English literacy and achieve grade-level academics. Please refer to CAD's 2017 Language Policy Report (<https://cad1906.org/language-acquisition-policy-report-by-marla/>) for more information about issues of language acquisition and audism.

In this publication, you will read about Longo's *raison d'être* for his continuing deaf education advocacy. Osborne discussed the need to be culturally humble whereas both Berke and Hall used the power of semantics to make their points. Hall used the ASL gloss, DRY HOT-DOG, to suggest in English that we ought to move on from the decades-old debate of auditory deprivation vs language deprivation. It symbolizes the era of using ASL gloss to make points as we would with French words like "joie de vivre" (joy of life) or Spanish phrases like "mi casa es tu casa" (my house is your house). Sager presented her doctoral findings about the perspectives of audiology student, and Evans proposed that audiologists ought to rethink the concept of auditory deprivation in deaf children. Kadu presented a parental view of the importance of language acquisition, and to end the pivotal symposium, Farinha presented an overview of Deaf Coach Program as a tool to end language deprivation syndrome.

I must thank both Julie Rems Smario from the California Department of Education and Pamela Snedigar from Gallaudet University Regional Center for their in-kind support. Likewise, I am grateful for the sponsors, presenters, and volunteers. We would not be able to host our most recent symposium without the support of Gallaudet University Regional Center, Ohlone College, Sprint, and Sorenson Communication. As always, the volunteers provided most of the behind-the-scene work. Thanks to Sharon Gough, Marla Hatrak, Abigail Longo, Susan Margolin, David Smario, and Mingchen Yang.

"This was a great meeting" many of you have said to me. Thank you for being so supportive! I am inspired to continue my commitment to support deaf children's language acquisition through CAD's hosting future EHDI conferences. It is one way to make sure that *our* vision as deaf members of California is present within *our* society.

Kavita Pipalia
CAD President

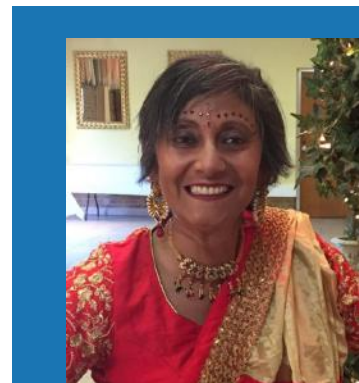


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Collaborative Partners



Why We are Here Today: Onward to Positive Collaboration in California

MARLA HATRAK
CHAIR, CAD POLICY COMMITTEE
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There are many stakeholders within the newborn hearing screening policy and programs. There has always been one missing stakeholder group: deaf adults and deaf advocates. The purpose of this presentation was to present compelling reasons why our newborn hearing screening programs need to involve deaf adults in their system.

Introduction

California Association of the Deaf (CAD) hosted its first Collaborative and Educational Symposium not only for deaf Californians but also for early hearing screening and intervention services professionals in 2015. CAD believed that the field of early hearing screening and intervention was lacking the perspective of the Deaf community. The symposium was so successful we have hosted three so far and will be hosting our next one in January 2021. Thank you all for coming today, especially on a Saturday. Everyone in this symposium is here because we care about the language acquisition and development of every deaf child aged 0-5.

The National Association for the Education of Young Children (NAEYC) is a nonprofit association established in 1916, representing early childhood teachers, para-educators, center directors, trainers, college educators, families, policymakers, and advocates. I would like to discuss two of NAEYC's programs, Code of Ethical Conduct and Statement of Commitment and Certification Program Standards.



TODAY MORE THAN EVER, THERE IS EVIDENCE THAT THERE IS A CORRELATION BETWEEN LANGUAGE ACQUISITION AND BRAIN ARCHITECTURE. SO IS COGNITION CO-RELATED TO LANGUAGE DEVELOPMENT. LANGUAGE IS THE CORE OF ALL DEVELOPMENTS.





They have a wonderful nine-page position statement outlining an intensive list of ethical conduct and a statement of commitment to the following groups of stakeholders:

- Ethical Responsibilities to Children
- Ethical Responsibilities to Families
- Ethical Responsibilities to Colleagues
- Ethical Responsibilities to Community & Society

I would like to bring your attention to one specific principle outlined in their Code of Ethical Conduct and Statement of Commitment under Ethical Responsibilities to Community & Society.

Principles (Collective)

p-4.11- When policies are enacted for purposes that do not benefit children, we have a collective responsibility to work to change these policies.

If you would like to know how CAD perceived language deprivation syndrome, this language policy report is recommended reading. This language policy report is a brief introduction to why we have a collective responsibility to change those policies that would exclude not only American Sign Language but also deaf stakeholders.

The law does cover the inclusion of consumers in early hearing screening programs. Please check (C) in the following section:

- (1) IN GENERAL In carrying out programs under this section, the Administrator of the Health Resources and Services Administration, the Director of the Centers for Disease Control and Prevention, and the Director of the National Institutes of Health shall collaborate and consult with:
- (A) other Federal agencies;
 - (B) State and local agencies, including agencies responsible for early intervention services pursuant to title XIX of the Social Security Act [42 U.S.C. 1396 et seq.] (Medicaid Early and Periodic Screening, Diagnosis and Treatment Program); title XXI of the Social Security Act [42 U.S.C. 1397aa et seq.] (State Children's Health Insurance Program); title V of the Social Security Act [42 U.S.C. 701 et seq.] (Maternal and Child Health Block Grant Program); and part C of the Individuals with Disabilities Education Act [20 U.S.C. 1431 et seq.];
 - (C) consumer groups of, and that serve, individuals who are deaf and hard-of-hearing and their families;
 - (D) appropriate national medical and other health and education specialty organizations;
 - (E) individuals who are deaf or hard-of-hearing and their families;
 - (F) other qualified professional personnel who are proficient in deaf or hard-of-hearing children's language and who possess the specialized knowledge, skills, and attributes needed to serve deaf and hard-of-hearing children, and their families;
 - (G) third-party payers and managed care organizations; and
 - (H) related commercial industries.

The Road to Kindergarten Readiness

Language Policy for Deaf Children Ages 0-5



California Association of the Deaf

September 2017



<http://www.cad1906.org/2017/10/04/cad-language-policy-for-deaf-children-ages-0-5/>

The Early Hearing Detection and Intervention law stipulates that, along with other groups such as schools and parents, "...agencies including community, consumer..." would be involved in coordination and collaboration. Furthermore, they ought to be involved in policy development. Agencies and organizations serving Deaf communities within California have attempted to become involved, and we have not been welcomed with open arms by the early hearing screening professionals.

What's Our Problem?

70% deaf babies and toddlers are language delayed or deprived (CDE.gov).
8% deaf and 15% hard of hearing K-12 students read at grade level (O'Connell, 2009).

These kinds of statistics need to be the core of our concerns and discussions. Although there are no past data for K-12 deaf students' reading levels because their scores are not typically disaggregated from Special Education, we do have new data as a result of SB210. 70% of deaf babies and toddlers aged 0-5 are already language delayed or deprived. Their chances of catching up are probably good, or probably not. Who would know since it is a very precarious situation? Will they acquire language? Or will they not catch up?

What are we supposed to do? What are we doing to change those statistics? That's why we are here today. I know not only deaf people are concerned, but also parents and medical/hearing professionals. NAEYC assures us that we are on the right path in identifying a collective responsibility, and the law gives us the right to be involved.

Why is this happening?

We are typically focused on auditory deprivation. Is auditory deprivation the reason why deaf children struggle to acquire English and achieve academics? Although it is probably an issue in itself, the real issue is the deprivation of language. Language deprivation syndrome is a more plausible explanation for deaf children's academic struggles. There is a huge difference between auditory and language deprivation. Below are some of the reasons for our continuing struggles to ensure deaf children have language by Kindergarten:

- Lack of or ineffective access to language (Gulati, 2019)
- Medicalization (Maudlin, 2015)
- Ableism (Hehir, 2002)
- Audism (Humphries, 1977)
- Hearing technology not a panacea for language development (Hatrak & Peterson, 2017)

We have to admit we cling to all our reasons for old ways. "That's what I learned in school." "I learned that way." "I have seen all and made my own observations." I am very seasoned and experienced in teaching..." "I have taught 20 years."

Can we just chill out?

Let us all together drop all of the arguments. Drop everything and learn new things. Today is a new day. Tomorrow is another new day. It is positive. It is positive to let go of our old habits. It is hard, yes, but it can be done if we all are in this together.

Difference between Communication, Language, and Speech

"This is by far the most common question I get asked. I am actually very surprised at how many people who work in this field of education cannot define the difference between the two... these terms [speech, language and communication] are important for parents and educators to understand."

-Katie, a pediatric speech pathologist and blogger
<http://www.playingwithwords365.com/2021/01/what-is-the-difference-between-speech-and-language/>

Many teachers, many parents, many professionals—actually, many people, do not know the difference between communication and language. We frequently see rhetoric that would say "communication is important" or "must provide them with communication." It is more important to provide access to language. When provided with language, they can then communicate. We must re-learn old rhetoric about communication tools, and communication modes.

What is speech?

Speech is how we say sounds and words.

"Professionals are wedded to the old ways of doing things. We need people who are willing to be a little bit more accepting and less challenging of new information and new research as things come to light and not take it personally."

-Renatta Cooper

Speech includes:

- Articulation using mouth, lips, and tongue
 - Voice: using our vocal folds and breath
 - Fluency: rhythm of speech
- <https://www.asha.org/public/speech/development/speech-and-language/>

What is communication?

- The imparting or exchanging of information or news;
- The conveying or sharing of ideas and feelings.

Oxford Dictionary

What is language?

Language is made up of socially shared rules that include the following:

- What words mean
 - How to make new words
 - How to put words together
 - What word combinations are best in what situations.
- http://www.asha.org/public/speech/development/language_speech/

Why Language is essential

- To be able to communicate
- To develop our brain architecture
- Cognitive development
- Social-emotional development
- To learn to read
- Being Kindergarten-ready
- To read to learn academics

This is the topic that is least discussed and should be the main topic. Two people who have language can then communicate. If one does not, efficient communication does not happen. Shifting the main topic really requires us to change our very own paradigms about language and communication.

Today more than ever, there is evidence that there is a correlation between language acquisition and brain architecture. So is cognition co-related to language development. Language is the core of all developments.

“However, they do not alter the fundamental ethical issue: Children need to learn language. They must learn it from parents, teachers, and their community. The more languages they learn, the better these children will be able to communicate.”

(Lantos, 2014,
www.pediatrics.org/cgi/doi/10.1542/peds.2014-1632)

There had been a lot of historical examples and references to deaf children's need to learn language. It is time to bring these references to the table. This can be done only through interacting with deaf community.

"I admit the ease with which a Deaf child acquires sign language and its perfect adaptability for the purpose of developing its mind."

-Alexander Graham Bell, 1884



Photo courtesy of Rhode Island Commission of the Deaf and Hard of Hearing



Photo courtesy of Visual Language and Visual Learning, Gallaudet University



Photo by Clare Cassidy

Is language part of intervention strategies? Look at the last bolded lines.

(2) POLICY DEVELOPMENT

The Administrator of the Health Resources and Services Administration, the Director of the Centers for Disease Control and Prevention, and the Director of the National Institutes of Health shall coordinate and collaborate on recommendations for policy development at the Federal and State levels and with the private sector, including consumer, medical and other health and education professional-based organizations, with respect to newborn and infant hearing screening, evaluation, diagnosis, and intervention programs and systems.

(A) Early intervention includes referral to, and delivery of, information and services by organizations such as schools and agencies (including community, consumer, and family-based agencies), in health care settings (including medical homes for children), and in programs mandated by part C of the Individuals with Disabilities Education Act [20 U.S.C. 1431 et seq.], which offer programs specifically designed to meet the unique language and communication needs of deaf and hard-of-hearing children.

Apparently, language is not part of the interventions provided to deaf children. So, this begs the question why we have not provided deaf babies and toddlers access to language. It is the law.

Why don't we start doing that? Today...it's a positive day to do away with our prejudices, biases, and rhetoric.

"It is easier to build
strong children than
to repair broken
men."

-Frederick Douglass

collaboration

Whole Child Development & LRE: Language Rich Environment

DAVID LONGO

PRINCIPAL

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I will start my presentation with a couple of questions.

Does early language deprivation affect cognitive development?
YES

Does early language deprivation affect psychosocial development?
YES

I know that everyone knows the answers to these two questions. This will be my focus for today.

Although I will be talking about the impact of language, we also need to discuss the social-emotional development of the child as well. This cannot be ignored.

Without full access to language, the child's privilege of social communication is taken away. Lack of social communication inhibits development of a healthy, strong sense of self, inhibits developing resiliency in order to deal with adversity, and impedes executive functioning.

-(Breivik, 2005; Hauser, Lukowski, & Hillman, 2008)



NOT ONLY IS IT IMPORTANT TO HAVE A CRITICAL MASS OF PEERS, BUT ALSO TO HAVE STAFF, ADULTS, AND PROFESSIONALS AROUND WHO ARE ABLE TO COMMUNICATE IN THE CHILD'S LANGUAGE AND BE SOMEONE THEY CAN LOOK UP TO.

Executive functioning encompasses a broad array of skills. Here are some examples of various research showing how executive functioning impacts mental health, social-emotional development, future success, and a whole range of things.

Executive Function Higher order cognitive functions important for learning and social behavior.

Aspects of life	The ways in which EFs are relevant to that aspect of life	References
Mental health	EFs are impaired in many mental disorders, including:	
	- Addictions	Baler & Volkow 2006
	- Attention deficit hyperactivity (ADHD)	Diamond 2005, Lui & Tannock 2007
	- Conduct disorder	Fairchild et al. 2009
	- Depression	Taylor-Tavares et al. 2007
	- Obsessive compulsive disorder (OCD)	Penadés et al. 2007
	- Schizophrenia	Barch 2005
Physical health	Poorer EFs are associated with obesity, overeating, substance abuse, and poor treatment adherence	Crescioni et al. 2011, Miller et al. 2011, Riggs et al. 2010
Quality of life	People with better EFs enjoy a better quality of life	Brown & Landgraf 2010, Davis et al. 2010
School readiness	EFs are more important for school readiness than are IQ or entry-level reading or math	Blair & Razza 2007, Morrison et al. 2010
School success	EFs predict both math and reading competence throughout the school years	Borella et al. 2010, Duncan et al. 2007, Gathercole et al. 2004
Job success	Poor EFs lead to poor productivity and difficulty finding and keeping a job	Bailey 2007
Marital harmony	A partner with poor EFs can be more difficult to get along with, less dependable, and/or more likely to act on impulse	Eakin et al. 2004
Public safety	Poor EFs lead to social problems (including crime, reckless behavior, violence, and emotional outbursts)	Broidy et al. 2003, Denson et al. 2011

(Hauser, 2018)

The Deaf Child's Bill of Rights, AB 1836 passed in 1994, was intended to be a critical step in the support of a deaf child's socialization and decisions on programming. Questions to ask during an Individualized Education Program (IEP) conference include:

Does the student have sufficient numbers of schoolmates who are similar in age, language and learning ability?

Are the teachers and other professionals who work with the child skilled in the child's language and way of communicating?

Are the critical elements of the educational program (i.e., academic instruction, school services, and extracurricular activities) available in the child's language and way of communicating?

It is not just about having an interpreter in the classroom, but do they have a critical mass of peers who are like them in those ways? Not only is it important to have a critical mass of peers, but also to have staff, adults, and professionals around who are able to communicate in the child's language and be someone they can look up to. Just placing an interpreter may not provide the student access to everything available to them within an educational setting.

I am going to share a couple of stories. As I said, I am a principal of a regional program in Orange County. As part of my role, I would be invited to a variety of meetings, and many families come to visit our program. Those families' school districts have to refer to us for placement. Many parents ask to visit, but they have to ask their district for approval.

This was a situation about a year and a half ago. A family came to visit our middle school program. They really liked it and wanted their daughter to attend. They called a meeting to ask for the district's support. This was taken from a letter sent to the parents declining their request.

The District considered your request that B attend the OCDE DHH Program. Your District, XYZUSD, is rejecting your request at this time because your District of residence offers a program for DHH students that includes specialized academic instruction, language and speech, and audiological support within your child's district of residence.

This was how it was worded...there was more to it. This district felt that they had an appropriate program to offer to meet the student's needs within their local district and it became a question of Least Restrictive Environment (LRE) to keep her close to home. They thought that would be sufficient. Then they went on to say: (Venado Middle School is part of the program I administer)

The DHH Program at Venado M.S. is a total communication program where the primary mode of communication for many of their students is through sign language. **Furthermore, two of their 3 teachers are deaf**, and, in their classrooms, they provide instruction in sign language with additional support, sometimes, orally, in English. Many of their students rely exclusively on sign language as their primary mode of communication.

I saw some jaws drop...you see the emphasis placed here. I bolded that part of this for that purpose.

Does that alarm you in any way? It did for me. To me, it is blatantly discriminatory. They declined placement because two of my three teachers are deaf. I do not want to talk about this too much, but it is something I want us all to think about throughout the day. This is happening out there. This is the kind of thing we in the field are facing.

This is a more recent one. An 8th grader was recently referred to us. He has some history of behavioral issues. He grew up in oral programs his entire life. On the IEP, it said he could read at a 4th grade level. When he arrived at our program, we realized he was only reading at a high 1st-grade level. I was invited to their district IEP meeting to share information and answer any questions they may have. When the district proposed our program as the placement, their classroom teacher said:

“Teaching him sign would be criminal.”

I heard the general gasp in the room. I swear this is verbatim. This was just two months ago. This was said in my presence. Imagine what would be said behind our backs.

Now, go back to the Deaf Child's Bill of Rights. Do you remember the year that was passed? 1994...it is 2020 now. 26 years later, this is still their mentality.

This is taken from a movie titled, “The Silent Child.”

The girl's name is Maisie Sly. This is a short 20-minute film. The Silent Child is a story about her. She was about 4 or 5 years old and struggling with language. Her family hired a social worker to help her get ready for kindergarten. The social worker started teaching her sign, and she thrived! But, the family resisted. This scene above is at the end of the movie when she started school.

My Raison d'Etire: Get the kids off the wall!

I'll share a personal story. For those of you who do not know, my younger brother is Deaf. As he grew up, he started in oral programming. In early elementary school years, he was in small self-contained classrooms. In third grade, when he was about 9 years old, my parents saw that he was having problems. He was behind socially, academically...he was simply struggling. My brother and I were always close. He is the reason I do what I do. Anyhow, what did my parents do? They sent the 12-year-old me into his classroom.

So, I sat and observed the class quietly, and sure he was struggling. But then it came time for recess. All the kids went running out to play, and what did my brother do? He went and stood up against the wall and just stayed there. I could not believe that what was happening...that's what he did every day. So, of course, I went up and played with him, but I was heartbroken to think that had been

what he did every day. Now, 46 years old, he still has not recovered.

The Silent Child movie ended the same way. Sorry... spoiler alert, but this is the scene with her standing against the wall.

So, again as a reminder for us all today, I want you all to think of ways you can:

Get kids off the wall!

This is my motivation every day. I am asking you all to think this way. It is not just about academics but the social aspect as well, especially when you are discussing LRE.

So, please keep that in mind as you go through the day.





Discussion Question:
What is the one thing you can do to get the
kids off the wall?

language

Cultural Humility

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Cultural humility is a lifelong process of self-reflection, self-critique, and commitment to understanding and respecting different points of view, and engaging with others humbly, authentically, and from a place of learning.
-(Tervalon & Murray-Garcia, 1998)

Right here, it is about love, open-mindedness, gratitude for life, appreciation of what we have, and what we can do as an ally.
I am giving you some background about myself. I am Creole Black. I have an older deaf sister, and I am a middle child with a baby

sister who is hard of hearing and a hearing baby brother. There are four of us, and our parents have different religions. This would explain why I have embraced diversity and different points of view. My mother was a devout Catholic, and my father a Muslim. Hence, my parents decided not to impose their religions on their children. That was how I was raised, and consequently, I have accepted Buddhism. My oldest sister was a Jehovah Witness, but is now a Christian. My baby sister is a Christian. My baby brother is Muslim.

So, because of all of the different mindsets and perspectives within my family, I was able to embrace different points of view. There were some perspectives that I did not necessarily agree with, but it did not give me the right to “fight back.” I would try to figure out why I was bothered and why I felt that way. What I would typically do is ask questions to help me understand their points of view. Maybe I would walk away and still not agree with their points of view. That is perfectly okay.



DIALOGUE IS ALWAYS ABOUT LEARNING.
DO AWAY WITH KNOW-IT-ALL. ENGAGE IN
ACTIVE LISTENING. ASK FOR
CLARIFICATIONS ON VOCABULARY.
DIVERSITY ALSO MEANS DIFFERENT
THOUGHTS, POINTS OF VIEW, FEELINGS,
RESPONSES, AND ARTICULATION.

The concept of cultural humility is a part of my dissertation because my concentration is on teaching Black deaf students. Oftentimes in deaf programs, either mainstreamed or deaf schools, we do not discuss our own cultures, such as who I am as a Black person. We assume that students' families will communicate those values. But, do those students have communication access at home? We do not really know.

So, I have been thinking about what Black deaf students have been missing and what we need to know about them and their cultures. It is important for us to be cognizant of the need to be humble, too. Frequently, when we learn new information, we make the decision that since the information does not match "my philosophy," we can disregard the information. To be honest, you cannot do that. This is a life-long learning opportunity. Maybe what worked yesterday will not work today.

Our culture is personal and deeply rooted. It includes our environment, thoughts, values, convictions, and feelings.

Oftentimes, we are so deeply rooted in what we were taught. Even though one might have a sense that it was wrong. One might be scared to broach, to discuss, or to ask why Grandfather said what he said. You might be told "that's who Grandfather is." It is wrong to dismiss such an inquiry. It is okay to challenge, but not with an intent to make the other party feel lousy. That should not be the intent. Just ask, "I am curious. Why did you make that remark?" If the other party becomes defensive, then you can let it go. Ask again another time. Then let it go again.

Some of us might feel, "My way, only my way. That's my thinking. That's it." It should not matter if one is old. You lose when you insist on sticking to your convictions. Harper (1993) proposed the power of presence and recommended a practice of ASSESS:

- Ask questions in a humble, safe manner,
- Seek Self-Awareness,
- Suspend Judgment,
- Express kindness and compassion,
- Support a safe and welcoming environment, and
- Start where the patient is at.

The power of presence. In the classroom or in the halls, we often are preoccupied and texting on our phones. We need to put away our phones and greet our students with positive vibes. Find out how they are doing. That way, you will really learn what is happening around the school. Even at Starbucks, put down your phone and watch what is happening around you for at least five minutes. Breathe in and breathe out. You might find that there is a family with a deaf child trying to communicate with them. This could be your opportunity to come and meet the family. Introduce yourself to the family, even if the family might be resistant to your presence. The whole point is to be visible and to look around. Carpe diem to educate parents with a deaf child. Even if the parents disregard your presence, you will have left an indelible memory.

Asking questions in a humble, safe manner. When in any situation, particularly a hostile environment, or a meeting or a conflict, I like to ask questions. "Are you trying to say it this way....?" Or "Can you tell me this....?" "What did you mean?" "Help me understand...." "Help me frame this differently." "I am not clear on that. Mind elaborating?" Even if you are fuming inside! When you ask questions, you become more curious and less angry.

One must be humble when asking questions. It means not asking hostile questions or making persuasive remarks. It is more to ask questions because you are curious. And saying, "oh, I see." Even when you know the other party is wrong, stay humble. Reframe softly and in an engaging manner. That is really important. Once you resist and become frictional, you will lose the battle.

Dialogue is always about learning. Do away with know-it-all.

Seeking self-awareness. It is an ongoing process. I feel this way. Then I ask myself why. Why did I react negatively to this?" It is good to ask why. Always seek self-awareness. "How was my day?" Look back on your day and then reflect on those things you wished you had done differently. What would I address? How could I have presented the information differently? On the other hand, it can also be

positive thoughts. “Yay, I did that.” “I felt good about that.” Acknowledge everything bad and good.

Suspending judgment. Hold your judgment. Even body language and facial expressions convey judgment. You have to use active listening, even in the back of your head, you are asking, “What?” Keep a straight face. Show interest. Be curious. Have fun but remain curious. Maybe you saw comments that startled you. Remain non-judgmental. With a straight face, ask kindly “Why did you say that?” rather than with an attitude, “Why did you say that? I did not like what you just said.” It is right there that you lose that opportunity to learn from others.

Expressing kindness and compassion. We often forget to be kind. Sometimes, it seems easier to engage in confrontation. To be kind seems like an afterthought, and thinking to oneself, “shoo, I should have hugged,” or “I should have been more patient or thoughtful.” Or engaging in road rage, for example. Maybe the other driver was driving because of an emergency. Instead of getting upset, we should automatically try to be thoughtful or kind by asking “I hope the other driver is okay.” Let it go. It is not always about you.

I value my family because of our different religions. Christmas is a very interesting time. How we celebrate birthdays. How we come to table for dinner. How we do things in the morning and all that. We have learned to let go and be compassionate, although in the back of my head, “do I have to get up early in the morning?” Begrudgingly, I realize that it is important to my father. Because of that, I have developed compassion. I would rather use compassion than anger.

Supporting a safe and welcoming environment. Support safe, welcoming environments like the symposium here today. It is fundamental to providing support. For example, if you are in a training program that does not support teaching sign language, you try getting through the program and realize that the teachers might not know the difference. Now when you are out in the community, listen to the people who live the experiences.

Start where the patient is. Be there for the students, for example. Instead of insisting that all students pass certain milestones, be there with the students all of the way. Check in whether they are doing ok. Be there. Be present. Understand their perspectives and where they are. Maybe you had the wrong information.

My favorite narrative, a tea cup. Often, we fill our tea cup without stopping. It is overflowing. It represents the attitude of a know-it-all. “I know all that.” “I already know. You don’t need to inform me.” Maybe, and even though you might know, what’s wrong with learning new things. “Hey, I never thought about that.” “Oh, that’s a different way of looking at that.” I always make sure I empty my tea cup every day, every minute. I might even go back to the person with whom I just argued, and conceded that the person was right. I am trying to understand you better.” Better to say, “thank you for your feedback.” “thank you for that information.” That way, no one loses.



When you engage in a dialogue, and you become judgmental, people become tense and leave the conversation, feeling angry. Then nobody learns. You cannot have a dialogue where you are more concerned about outcomes. It is better to be focused on process. Take notice of people who show emotion of displeasure, or anger. That would be good opportunity to check in.

Dialogue is always about learning. Do away with know-it-all. Engage in active listening. Ask for clarifications on vocabulary. Diversity also means different thoughts, points of view, feelings, responses, and articulation. Realize that there is not one way of thinking and feeling about issues. One should not expect that all others will follow one way. That is not how it works.

I would be asking myself how I feel? Am I good? If I feel disheartened? Then I would see whom I can ask to talk it out. I ask myself questions, or I meditate to relax.

Perspective-based vs prejudice-based. Your perspective is not the only one. There are different perspectives. Or to be prejudiced by saying “...that’s the way they do it...,” or “Black tends to...,” “Deaf tends to...,” “Hearing tends to...” The sign for tendency should be disregarded. It is better to ask others to help you to understand, or to ask what one’s culture would do in such situations. Do not simply say they tend...” That’s where prejudice-based thought becomes dangerous.

Inclusive. I am guilty of that. Sometimes, I would invite everyone and then be reminded that I have forgotten deaf-blind people.

I would have to remind myself to be inclusive. Make a checklist, and ask around if I missed anyone. I want to be sure to be inclusive because we truly learn from each other.

Non-threatening environment to evaluate personal assumptions and stereotypes. When one feels hurt from a conversation, it is better to acknowledge that one's feelings are hurt. Ask the other person if the two of you could talk about it. It would be a soft approach that enables the other party to support you. It is a beautiful concept to promote.

Do not be focused on being politically correct. Being politically correct can be awkward. What do I call her/him? Or did he prefer to be called African American? It is better to ask questions. We are more than just Black. We are truly intersectional.

Cultural Humility (HUMBLE) Model*

H: Humble about the assumptions you make.

I recall a situation where I assumed what the other party said. The other party came up to me and said it was not what she meant. I apologized and asked her to help me understand what she meant. Whenever necessary, help to reframe what just transpired. I wanted to make sure my student felt comfortable enough to stop the meeting to say, "hold on" and clarify herself right on the spot. As a teacher, I gave the student authority to clarify herself or to ask for clarifications. It is not disrespectful to do so.

U: Understand your own background and culture

You have to understand how one's background impacts how one perceives others or how one would approach others.

M: Motivate yourself to learn more about the other person's background

Do not assume that you know what the other party is. One might grow up in a community representing United Nations although one might be Black. It is easy to assume that all Blacks grow up in Black neighborhoods.

One's old beliefs might work, but when you learn new information, you need to evaluate the old beliefs with new information. If the old beliefs do not hold up, get rid of your old beliefs, or if possible, integrate both old beliefs and new information.

B: Begin to incorporate this knowledge into your work

L: Lifelong learning

Only when you pass away will you stop learning.

E: Emphasize respect and negotiate service plans

Learn from experiential reality.
We frequently do not ask other people for their experiences.

One must respect all others and be aware of positional power. For example, there is inequitable power between a doctor and a patient. It is important for doctors, teachers, and principals to be mindful of social change. That would mean we think about how we can support the individuals in front of us. Make sure they live their lives as fully as possible. They must feel good about who they are. Even if, with your knowledge, you don't agree with them. You really want to support the individual.

This respect must include negotiating plans as well. Instead of telling the person all you know, ask the person what they would like to do. Check in how the individual feels about the negotiation. Sometimes one's home is not conducive to a teacher's request for specific homework about their home life. Be mindful of the individuals and their homes, of what they have and what they do not have. That's the opportunity to ask questions of the individuals to get to know them. Do they have a support system? What does their home environment look like?

Become an agent of change.

This means I have to unpack and process. It will always be taking two steps forward and taking one step back to unpack or to process something.

Learn about people from members of the group.

It is important that you realize that not one Black person represents every other Black person. There are Black people with different cultures. Do not assume one represents all.

Learn from healthy and strong leaders who strive for social transformation and healing.

There are Deaf leaders and allies from whom you can learn. Feel free to approach them. When engaging in social transformation, it is equally important to take time off to heal.

Learn from experiential reality.

We frequently do not ask other people for their experiences.

Learn from constant vigilance of your biases and fears.

One must be fully aware of one's own biases and fears. More importantly is to be aware of unconscious and implicit actions.

Learn from being committed to personal and institutional action against racism, sexism, audism, ableism, heterosexism, and so forth.

We have to be committed not only to personal action but also to institutional systems such as policy, operations. I want to mention audism.

Audism

Audism is a term used to describe a negative attitude toward Deaf or hard of hearing people. It is typically thought of as a form of discrimination, prejudice, or a general lack of willingness to accommodate those who cannot hear. (Humphries, 1977)

Be willing to learn from others that are different from you.

Invite people to your house. There might be a variety of reasons why some people do not invite others. Do not assume that they are not trustworthy. Invite people from different cultures.

Be curious, explore, and inquire more often when working with families.

Being curious does not mean becoming a reporter. Be curious of people's cultural artifacts such as their jewelry, or clothes.

These are some of the tips to practice cultural humility as you work, interact, or engage with people that are different than you.

**Discussion Question:**

How can you practice cultural humility everyday?

welcoming

The new 4-Letter F word: Why "Just Fine" is not OK!

MICHELE BERKE, PH.D.

PRINCIPAL

CALIFORNIA SCHOOL FOR THE DEAF, FREMONT



I have an older brother who is hearing. My grandparents on my mother's side are all Deaf. On my father's side, both he and his brother were Deaf. But his parents would not sign. So, in my family, there is an interesting mix.

The new 4-letter F word

I am curious what you think. I am sure you are all familiar with one, right? What do you think my new 4-letter F word is? Any ideas? A hint? Ok, here is a hint. It is 4 letters. First letter is F. Fail! That is a good one but it is not that. I know you know what this word is even though you suggested fail. Any other guesses? Free! I wish, but we know in this life nothing is free! Fact? No. Fear? Wow! All of these are great F words but let me show you.

There are many stakeholders in our field: parents, people in the K-12 educational system, people who are in the early start system, audiologists, SLPs, Interpreters, community members. Everyone is invested in our Deaf children.

When we think about the F word, the first word that comes to mind is not one we need to repeat. However, there is a new 4-letter F word that is very common in our field. It is not Fail, Free, Fact, or Fear. While they are all good guesses, the word I'm thinking of is: Fine!

Why 'just fine' is not OK!

Fine! That kid is fine! They will be fine. Just fine. It is 4-letters. It starts with an F. And in our field, we hear/see this over and over again. How many of you have experienced that? (nodding head) You'll be fine, fine, fine. That child will be just fine.



WHEN A CHILD IS LABELED HARD OF HEARING OR PEOPLE SAY THAT THE CHILD IS JUST FINE, WHAT THEY ARE REALLY SAYING IS, "IT'S OK TO FAIL FIRST. AND THEN, WHEN THEY DO FAIL, THEN WE WILL FIGURE OUT WHAT TO DO NEXT."

Ok, we are going to take a little journey about why “just fine” is not ok. Things that happened in the past and we thought that there would be change. But they did not. And that is depressing. In my previous job at CSD, I was the Student Outcomes Specialist, responsible for data. And, almost every day, I was depressed because students would come to middle school or high school just wanting an education, wanting access. They had an education beforehand but they came not just delayed in language and reading, but delayed in math, and socially-emotionally, as well. And now, I’m working with babies and their families. And I still see the impact, even that early.

**While we think of "just fine" as a positive phrase,
in our field, it is not acceptable.**

That term has been used as an excuse for not providing full services or support for our Deaf children. Even worse, it has been used as an excuse for not providing full access to language. At the California School for the Deaf, the data shows that the majority of students who enter in middle or high school are delayed in reading, math, and their social-emotional well-being. They come to CSD wanting an education and specifically, wanting access to their education.

There are two examples of “just fine” situations that happened and continue to happen. Not too long ago, in 2012, parents were in a meeting for her child, who has a mild hearing level. As parents, there was the concern that the child was missing out on information being shared in the classroom. The teacher said the child was doing just fine. The principal said the child was doing fine. The D/HH itinerant said, “don’t worry, the child is just fine. We’ll track and keep an eye out.” The child did not need an IEP nor a 504 because the child was just fine. That child is now 15-years-old and along with a little eye-rolling, has had experiences where maybe the child really wasn’t “just fine.” These examples will be shared later.

In December 2019, there was another IEP meeting for a child who was just turning 3. The child has a unilateral hearing level. The local school district recognized that the unilateral hearing level qualified this child for services. The district offered a playgroup once per week for 30 minutes. A speech language pathologist (SLP) would come in twice a month and provide support for the child during playgroup. A D/HH specialist would also come by once a month to provide support for that child.

On the one hand, that opportunity will allow for the child to have social interactions with typically-developing peers. However, it does not recognize that a unilateral child may be at-risk. Instead, the parents were told that the focus should be on the ear that could hear and that the playgroup environment would be just fine. The parents stated that they wanted to focus on the “deaf” ear because they wanted to make sure that the child is getting everything possible including spoken language and sign language. They wanted their child to be exposed to everything so that the child will be Kindergarten-ready. Saying that a child is just fine doesn’t acknowledge the possibility that they may be at-risk.

From 2012 to 2019, how much has changed?

Here’s a question. Mild, unilateral are both considered hard-of-hearing. I am not trying to put anyone on the spot, but I am wondering what does hard-of-hearing mean? What is the definition? Decibels. It has to do with decibels. Which decibels? Participant said, “I don’t know the number. Maybe ask an audiologist!” We have three audiologists here today! Another participant said, “it is not about decibels, it is about identity.” Your silence is telling me something. What you’re telling me is that there really is not a definition! Really! Seriously!

These two examples (mild hearing level and unilateral hearing level) are both considered “hard of hearing.” What does that term really mean? There are those who think it may have to do with the decibel level that a person has access to. Others think it may be more about an individual’s identity. In reality, there is not a true definition for hard-of-hearing.

One time in my previous job analyzing data, I asked the state of California because they have deaf children performing this way on an assessment, and hard-of-hearing children are performing that way on an assessment. So, I called the California Department of Education (CDE) and asked, “What does HH mean? We were all trying to figure it out.” CDE’s response was: “Well, the IEP team decides!” Really?!? So, we use Deaf/HH, D/HH everything and there is no definition for hard-of-hearing? And a team of people decides if a child is going to be labeled hard-of-hearing? I have a problem with that!

The California Department of Education disaggregates state-wide assessment data by deaf and hard-of-hearing. This assumes that someone knows the distinction however, the CDE response was that “The IEP team decides!” if a child is labeled as deaf or

hard-of-hearing. It is problematic that whether a child is deaf or hard-of-hearing is decided by a team of people that often, especially when they are young, does not include the child/student themselves.

It is the federal law that the IEP team decides but it is still problematic!

What are they really saying?

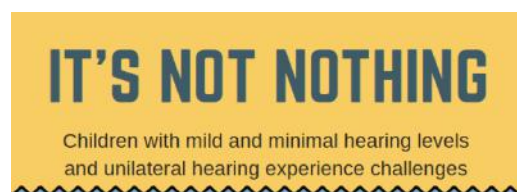
1. It is ok to fail (and then we'll provide services)
2. Let's focus on the good ear rather than recognizing the potential risks
3. Let's forget (or ignore) that a strong language foundation (regardless of hearing level) is critical to Kindergarten readiness

When a child is labeled hard of hearing or people say that the child is just fine, what they are really saying is, "It's ok to fail first. And then, when they do fail, then we will figure out what to do next."

The language foundations mentioned in David Longo's presentation are critical because they tie closely with kindergarten readiness. And that is why California was the first state to pass Language Equity and Acquisition for Deaf Kids (LEAD-K). California has SB210 that assures that a child's language milestones are tracked and discussed at every meeting with families. Whether or not that is what is taking place at every meeting, it should be.

The real reason behind "just fine" is that it all comes down to money. Who is going to pay for the services? School districts have not been getting enough funding from either the state of California nor the federal government. Who is going to pay? That's why it is easier to say that a child is "just fine" because otherwise, if they need all of these services, someone is going to have to pay for them. And then, maybe we can push the problem down the road and we'll worry about it later. It is really not in the best interest of the child. But it is in the best interest of the system.

It's not nothing!



In California, there is the California Newborn Hearing Screening Program Learning Community comprised of different people throughout the state of California. This group, facilitated by Julie Rems-Smario, meet monthly. They have been advocating for our babies. The group has been discussing the issue of mild/unilateral hearing levels and "just fine" and how these kids are falling through the cracks.

This brochure, developed by Rachel Narr and Rebecca Lewis should be given to every family when a child is identified with a mild or unilateral hearing level. Because "it is not nothing." And, it is not fine! One in 5 children may have a mild or unilateral hearing level and are identified by the age of 19. That represents possibly 20% of our school-aged kids. This has significant impact on the social-emotional needs of children. Consider the concept of Incidental learning: what happens on the playground, or in the cafeteria? If the environment is noisy, it is overwhelming. Kids are missing out. They may not see or "hear" how to resolve conflicts on the playground.

The potential implications of this are revealed in this true example of a local Deaf community college professor. When this professor was going through a divorce, he was teaching Deaf students at a community college. His students asked him, "Why are you going through a divorce?" That was a very personal question, and he struggled with that until he viewed it from their perspective. He realized that many of the students had divorced parents, and they never understood why their own parents divorced. They never "heard" or "saw" their parents arguing or fighting. Maybe they saw angry faces, but they never understood what was the reason for the divorce. The professor was able to take a step back from why he himself was getting a divorce, and could then explain in general terms, why people get divorced. These are college-aged students, growing up and never understanding why or

Definition
Minimal = PTA 16-25 dB HL
Mild = PTA 26-40 dB HL
PTA = Pure Tone Average at 500, 1000, 2000, 4000 Hz

15-20%
of children have detectable hearing differences in at least one ear by age 19.

77% of kids with permanent hearing differences have mild or minimal hearing levels

what was happening in their own family. And a lot of that may be due to missing out on incidental learning. They may miss out on conversational cues or avoid group settings because it is just too hard.

SOCIAL EMOTIONAL EFFECTS ARE REAL

- Children often miss out on incidental language.
- Children may be accused of "laziness" or day dreaming.
- They can easily miss conversational cues and be perceived as awkward.
- Avoidance of group settings.

What may seem like to be a mild condition to clinicians may actually be a significant issue to a child's well-being.

Borton, et.al., 2010

Another example is from the child with the mild hearing level who was doing just fine in the public school. When he was in elementary school, they had an annual May Day dance. One year, as he was getting dressed, his mom asked him if there was anything special he needed to wear. He replied that there was nothing special. When his mom arrived at the school, it became clear that in fact, there was something special he was supposed to wear. All the boys were wearing white shirts. He happened to be wearing a vibrant shirt that was definitely different and loud compared to the white shirts. When asked, "what shirt did you think you were supposed to be wearing today," the reply was that no one ever talked about it. The mother asked the teacher if they were

supposed to wear something special, and she said that yes, they had a whole class discussion about it and the boys agreed they would wear white shirts. While that boy might not have really cared about fashion or clothes, he might not have realized that he stood out. But there are kids who would be sensitive to things like that, and it would have a social-emotional impact on them to be the only one who missed something like that.

Equally as important is the impact on a child's education. Often children may be exhausted trying to attend and figure out what's going on. Often grades are behind. Many may have been told that they were just fine when, really, they were at-risk. Another example of the potential of both social-emotional and academic consequences is shared in this example with the same child. Without getting x-rated, that same child was going to have sex ed in school. The mom was fine with but thought it would be better to pre-load information.

She bought a book to read together to make sure that he had the vocabulary and some knowledge before he learned it in school. So, as they were looking at the book, he pointed to the book and said, "Mom, they spelled 'vagina' wrong!" Of course, the mom said, "I think the book knows how to spell vagina!" But the child replied, "It is supposed to be a 'B.' Bagina." Oh! Issues of mild hearing level! B-V, B-V. It is hard to see or hear that difference. Can you imagine if he showed up to school talking about the Bagina? That would have been humiliating! Consider how stressful that could have been had he made that mistake in front of his peers. Is that fine?

What can parents do?

Parents should know their child's language milestones. Make sure your child has an IEP or a 504 plan. Put the money aside and figure out what services and support the child needs. Ask for things that may be simple and even inexpensive. For example, preferential seating, captioning on videos, allowing the child to ask questions are all things that don't cost money. Help your child to recognize that they may be missing out on something. The child should be empowered to understand their hearing level and encouraged to be assertive. Teach them to ask. Make things explicit. Extra-curricular activities are also important. Drama, sports, yearbook. The bottom line is for all the stakeholders is to advocate, advocate, advocate.

What should professionals do?

And for the professionals, do not ignore the obvious. The kids are at-risk. Provide support, and counseling. Be sensitive to the potential of the social-emotional impact on the child. All children with mild or unilateral hearing level should have an IEP or 504 (Lieu, Tye-Murray & Fu, 2012).

With that in mind, are our children just fine? Think about it. No, they're not.

EDUCATIONAL IMPACT



- 10 x more likely to be academically unsuccessful.
- Experience listening fatigue.
- Attention problems are common.
- Can experience behavior problems.
- Increased risk for learning disabilities.



35% EXPERIENCE FAILING GRADES OR REQUIRE RESOURCE ASSISTANCE

QUALITY OF LIFE



- Experience persistent general fatigue
- Higher stress levels
- Less energy
- Few friends



Discussion Question:
How do we re-frame the conversation so that the stakeholders understand that children with mild, unilateral or so-called HH (whatever that means) are at-risk for language deprivation?

quality

Audiologists: Rethinking the Concept of Auditory Deprivation in Deaf Children

MALLORIE EVANS, M.A., FAAA
EDUCATIONAL AUDIOLOGIST



Thank you, David, for the introduction. I am Mallorie. I am an educational audiologist. This is my 18th year as an educational audiologist. I really enjoy what I do because it's always changing. I have learned so much over these last 18 years, and it excites me that I have so much more to learn. So, after this presentation, there will be opportunities for productive discussion, and I really hope that everybody is ready for this. Where are all my audiologists "peeps" in the audience? This is for you! Okay audiologists, are you ready?

Audiologists as part of the medical home

So, because this is an Early Hearing Detection and Intervention (EHDI) Stakeholders' symposium, I wanted to start with some language that we typically hear in the EHDI system. You know, we talk about the "medical home." Audiologists clearly have a status within the medical home when we talk about newborn hearing screenings and identification of Deaf babies, right? We have a place of power in the medical home that gives us an authority that, many times, I don't think audiologists recognize or really "own."

Audiologists say, "I'm here to do my part. I identify, I diagnose. That's what I do, that's it!" We do not really feel we are that important. I am not suggesting that what we do is unimportant. It is just that we do not recognize that we are the ones making a huge impact on families. I can assure you that you do have impact on families because I work with a lot of families and a lot of parents.

When we ask parents about their experiences through the newborn hearing screening process, through Early Start, they say the information they get is overwhelming. However, what they remember most is what is said by the audiologist.



IF OUR BRAIN GETS MULTIPLE INPUTS THROUGH MULTIPLE PATHWAYS, WHY ARE WE NOT TAKING A MULTIMODAL APPROACH TO LANGUAGE ACQUISITION? OUR BRAIN IS A VERY COMPLEX ORGAN, BUT WE KEEP NARROWING THINGS DOWN AND SIMPLIFYING IT TO ONE PATHWAY.

Every single time. They remember what the audiologist told them. Whether they remember it accurately or not is a whole different issue, because you hear what you hear in the context of your brain filtering tons of information. That means that the words we use and the way we convey them have a long-lasting impact, not only on the parents, but on the children because it influences the way that parents make decisions about their children.

We are viewed as the “experts.” Who gave us that authority? I really don’t know. Maybe that’s something we can talk about, but we have it. We’ve had it for generations, and our clinical experience as audiologists lets people cling to the advice that we give. So, while we are very well-intentioned in wanting to provide information, providing our professional opinions, giving feedback, sometimes we tend to do harm. It’s not malicious in any way, but we don’t recognize that the way we say things to parents has a long-lasting effect on how they make decisions on language and cognitive development.

Language and modality bias

So, I do want to talk about language and modality bias. We do need to talk about bias because it is very important. As audiologists, clearly our training and our focus is on the auditory system: how sound gets through the auditory system and up to the brain to be processed. Nobody’s going to argue that is not what we do. It is. For adults, we talk about communication. One of the big things when we are working with adults is working on teaching “communication repair strategies.” These are for adults who have lost their hearing, are getting hearing aids, and are trying to navigate social interactions. We give them conversation repair strategies because these are adults who have long-established, strong language, and for them, it is truly something they lost and are trying to regain or accommodate in whatever way they can.

We are viewed as the “experts.” Who gave us that authority?

For a long time, we applied that same strategy to children, when it’s a completely different thing that we’re talking about. Pediatric audiologists focus on the auditory system and how it can be made to function to support spoken language development. Now, it’s taken a long time for us in the field to even use the phrase, “spoken language development” because we always said, “language development.” What is the problem with just saying “language development,” especially from an audiologist? It is the implication that spoken language is the only language. It is not allowing for the idea that there are different modalities to language. So, it’s very important that when we are talking specifically about spoken language (which is appropriate to do when we are addressing that particular modality), we are very intentional about saying, “spoken language.” I don’t ever talk to a parent while going over audiology-type stuff and just throw “language” out there. I’m very specific about what I’m saying. If we are talking, in that moment, about spoken language, then that is what we are talking about. If we are talking about visual language, for example, ASL, then we’re going to talk about that. But you have to be intentional in what you’re saying, because if you’re not, then you are creating, or continuing, an implicit bias that spoken language is the priority or the main way that the brain processes information.

So, the old concept of, “let’s talk to them now, and if that doesn’t work, we can sign to them later,” is inappropriate.

Linking auditory deprivation to decreased executive functioning (EF).

There are some studies that have been coming out over the past few years that are looking beyond just language development. They are looking globally at executive functioning in Deaf children. I listed a couple here. I am throwing a couple things out there so you can look a little deeper into things. There are several studies that linked auditory deprivation to decreased executive function. While that link has been made in multiple studies, the problem is that the results could also be explained by a significant lack of a solid and completely accessible language foundation during the critical period of language acquisition (M. L. Hall et al., 2017). That critical period of language acquisition is the same regardless of language modality.

So, the old concept of, “let’s talk to them now, and if that doesn’t work, we can sign to them later,” is inappropriate, because now what you have done is made it difficult for the child to become really deeply proficient in any language at all. So that critical period applies not just to spoken language, and not just to auditory input, but visual as well. Multiple modalities. We need to be very careful about our biases about language for deaf children. So, while these studies did show deficits in executive functioning, the solid link to auditory

deprivation or lack of auditory input was not shown. We did have this study from M. L. Hall et. al. (2017) that found that those deficits in executive function in Deaf children were more closely linked to language deprivation syndrome than specifically to lack of auditory stimulation. That's something to think about. The two concepts become conflated because there are some aspects that overlap, but they are still two separate things.

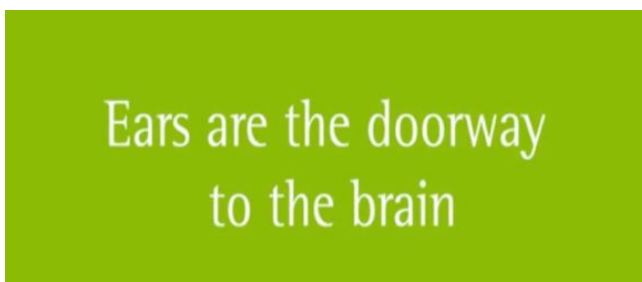
Audiologists sharing information.

When we talk about audiologists and the kind of counseling we give, we give informational counseling. We know how to explain things that we do. We know how to explain an audiogram. We know how to talk about how the ear works. We are really good at giving information. We are not really good at affective counseling. Like seeing when a parent has completely shut down and is not taking in anything that you are telling them. We just give. We give, we give, and we give. Parents really struggle with that. Years and years will go by, and if you ask a parent if they understand their child's audiogram, they have no idea. They can tell you the hearing levels, but they can't tell you what that means. They don't really understand it. The information is not getting in there for many reasons. Please understand that we (audiologists) are not trained in affective counseling.

So that is a problem when we are giving information, especially information related to language development in general. We can talk about hearing technology all day long. It is our "bread and butter," or our "wheelhouse." It's what we do. It's our safe place. It's what we went to school to learn. If you want to talk about a hearing aid, let's talk about a hearing aid! If you want to talk about a cochlear implant, let's talk about cochlear implants. Great! But then a parent asks, "Well if I get a cochlear implant for my child, what do you think? Should I sign to them?" That's a dangerous question for an audiologist, especially if we have not been trained in anything related to Deaf Ed, or if we don't have a lot of background in language development.

We get a little bit of coursework, but we typically do not go in depth, so it is a dangerous question for us to answer. So, because we see a lot and we think we know (and sometimes we do), we also know a lot of wrong stuff, or a lot of very old ideas. We think that because technology has gotten so much better and more sophisticated, that kids don't "**need**" sign language, or kids don't need to "rely" on sign language. Do you notice that we don't use the word, "**rely**" when we talk about spoken language? We don't say, "Oh, we don't want them to "**rely**" on spoken English!" So why do we say that about ASL? I have never understood that kind of mindset, "We don't want them to rely on ASL." So, did you mean we don't want them to rely on language? I'm not sure why we would ever say something like that out loud, but we do, and we should stop it because it is very damaging and pervasive. Once you plant that seed in a family's mind, it is very hard to walk that back.

I pulled this screen grab from a presentation where someone showed this: "Ears are the doorway to the brain." Really? OK, so ears are the doorway to the brain. What does that mean if your ears don't work? What are you saying? My question is, what is problematic about that framing? This is something that was being shown to parents. "Ears are the doorway to the brain," along with this graphic. Here are your doors, and the world is coming in through the ears and up to the brain. So what happens if these ears don't work? Your brain doesn't get stimulation? We know that's not true because the brain gets stimulation in multiple ways.



What a powerful thing to plant in a parent's head during a really vulnerable time. This is what scares parents into pursuing approaches that may or may not be successful for their child. Regardless of whether or not it is successful, the amount of work we are asking those babies and those children to do in order to make those parents feel like they're getting information into those babies' brains, is not fair to the parents or child. We need to be **really** careful about saying things like that. We are overstating how much the auditory system impacts language and cognitive development. Like I said, that kind of framing scares parents. "They need stimulation, they need access! I have to implant them; they have to be in listening and spoken language environments. They have to be immersed in listening and spoken language environments!" I hear that constantly. If they're not immersed in it, they're not going to learn it. If they're not immersed in it, then their brain is not going to develop the right way, and those pathways are going to be reass-

igned. As if pathways being reassigned is inherently negative. Our pathways get reassigned all the time for all kinds of things. It's not an inherently negative thing. But when you frame it as, "ears are the doorway to the brain," you can bet that parents are going to make a lot of decisions out of fear and misunderstanding.

Determining a child's language modality.

I'm going to be very blunt with us as audiologists. It's not our job to determine what modality a newborn, let alone a small child, should be using or should be getting their language through. It's not up to us to determine, but we do it all the time. We do it with authority, and it's very damaging. If our brain gets multiple inputs through multiple pathways, why are we not taking a multimodal approach to language acquisition? Our brain is a very complex organ, but we keep narrowing things down and simplifying it to one pathway. When is one pathway ever the best thing? It's just not. We really need to take a step back and look at how we are talking about the auditory system. Is the auditory system important? Sure, it is! It is one of five senses. Great. If there is potential to develop those auditory pathways, then that is also great, but it doesn't mean that it has to be done at the expense of developing the visual modality, tactile, kinesthetic. Why are we saying that the auditory pathway is the only one or more important than any of the others? There really is not a good justification for it.



Discussion questions:

What are some programmatic changes that can be made to audiology training programs regarding the concept of auditory deprivation as it relates to cognitive and language development?

How can we get into the training programs, the concept of auditory deprivation and how we are framing it and how we are relating it to cognitive and language development?

rethinking

Dry Hot Dog: Moving Beyond Auditory Deprivation

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Hello, everyone! I was here at the EHDl symposium last year, and I am honored to be invited back. I want to start with a quick disclaimer. The science and research behind language deprivation can be very complicated. My presentations are usually an hour and half to two hours, sometimes three hours. The conference organizers were very strict today in giving me only 20 minutes! I had to pick what seemed most relevant to the conference theme, but I am happy to chat more in-depth with anyone after this because this presentation is very simple since it would be impossible to condense everything into 20 minutes.

D-R-Y H-O-T D-O-G. Does anyone know what that means? In American Sign Language, it basically means I am done with the discussion. In this context, it means I am personally ready to move on from the “debate” of auditory deprivation or language deprivation. I will present some basic research and concepts, and then we’ll see if you all agree with me by the end of the presentation.

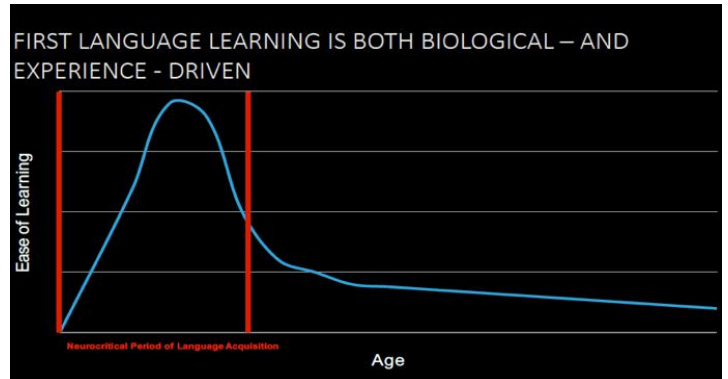
Innate language acquisition requires both biology and experience. In developmental science, there is a famous historical debate of nature vs nurture and which of these two influences human development more. The answer is really both. It’s not a competition. Both are equally important to human development. We have noticed, within language acquisition research, that it seems really important to have as much accessible language exposure before approximately five years old. When we are born, our brains are primed to begin learning as much language as they can in their environments. After about five years old, brain development seems about ready to “move on” to learning other things. In this aspect, our brains are assuming we have gotten a good-enough language foundation for learning and start focusing on other things.



THE MAIN DIFFERENCE BETWEEN AUDITORY AND LANGUAGE DEPRIVATION IS AUDITORY DEPRIVATION BEING CONCERNED WITH ACCESS TO SOUND, AND LANGUAGE DEPRIVATION BEING CONCERNED WITH ACCESS TO LANGUAGE.



Here, you can see on the curve that, during this time, the brain can very easily acquire language. After a certain amount of time, it becomes much harder. We notice that those who get their first language exposure after about five years old tend to struggle a lot more. They never really become natively-fluent signers or speakers, whether they are hearing or deaf. If hearing children are exposed late somehow, they, too, would struggle just like deaf children. But we see language struggles much more often in deaf children who experience late language exposure. So just to emphasize, we generally know it is very important to expose children to language as early as possible. That is uncontroversial in brain science. Now, I will show you another perspective of that concept.



disclaimer: this is 100% conceptual and very simplified

Now we are thinking about the 0–5-year period. We know that the brain has its own biological processes for language development. Now you can imagine that line intertwined with the language experiences of the home environment, having peers, and going to school. These everyday experiences interact with brain biology. When we consider first language acquisition, at some point, the biological processes for *very easily* establishing that foundation will move on but everyday experiences will help continue developing language foundation and skills. So, in the beginnings of brain development, it is very important to expose a child to as much accessible language as possible.

A TALE OF COMPETING HYPOTHESES

▶ Auditory Deprivation

- ▶ Dominant medical and education-led approach for 150+ years
- ▶ The main problem is access to sound
- ▶ Sign language exposure is strongly discouraged, and seen as distracting from learning how to hear and speak

▶ Language Deprivation

- ▶ “New” deaf-led approach in past 10 years
- ▶ The main problem is access to language
- ▶ Any and all accessible language exposure is seen as beneficial.

We have long had “debates” about two conflicting perspectives for deaf child development. Auditory deprivation focuses on babies born deaf and not having access to sound, which means they cannot access spoken language. This means their priority is fixing access to sound which will solve all the concerns and issues. Historically, this also meant excluding sign language to ensure a complete focus on developing hearing and speech skills.

Over the past 10-15 years, there has been a lot more discussion about “language deprivation.” This has been happening mostly with the deaf community leading that discussion. The main differences between auditory and language deprivation is auditory deprivation being concerned with access to sound, and language deprivation being concerned with access to language. It does not matter if that language is auditory or visual. It is just important that a deaf baby gets access to language, period.

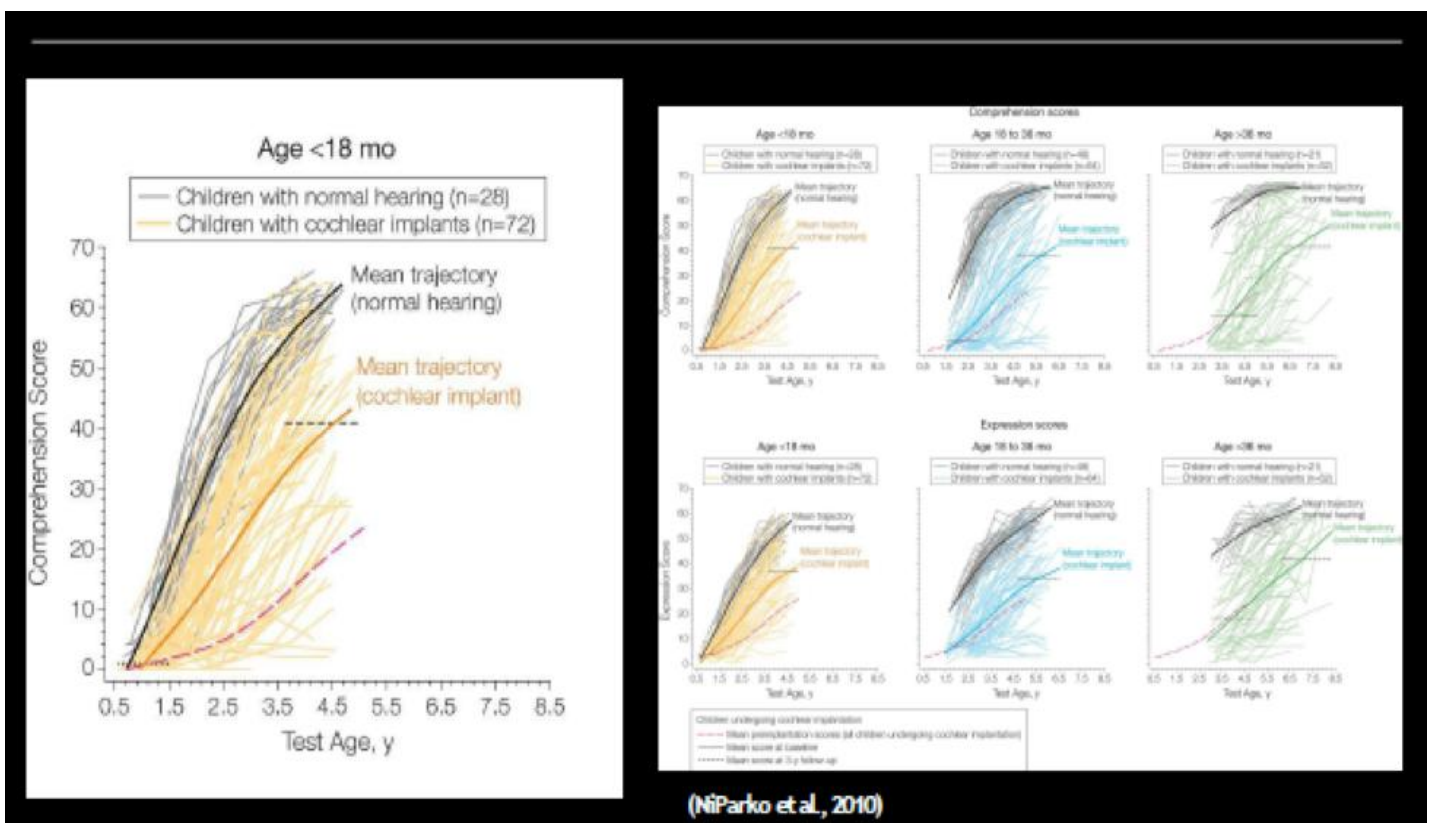
Now, I do not like to just present by myself and bore you all. I tend to interact a lot with the audience. I will show some studies, and I want you all to become scientists. I am not the only expert in this room because you all are experts, too. We will all discuss this together and figure out if the studies I show help answer the question of auditory vs language deprivation.

I will show you some studies, and we can look at what each hypothesis predicts. For language acquisition, the auditory deprivation hypothesis predicts that hearing children will always do better than deaf children because they have full access to sound. It also predicts that there will be no difference between signing and non-signing deaf children because they are both deaf. The language deprivation hypothesis predicts that signing children will be equal to hearing children because they both

have strong language foundations. It also predicts that signing implanted children will do better than non-signing implanted children, because signing children have more access to language in that early brain development period. I want you all to tell me if the following studies help test the auditory deprivation or language deprivation hypothesis.

A TALE OF COMPETING HYPOTHESES WITH COCHLEAR IMPLANTS AND SIGNED LANGUAGE

- ▶ Auditory Deprivation
 - ▶ Predicts that hearing children will do better than signing and non-signing implanted children
 - ▶ Predicts no difference between signing and non-signing implanted children
- ▶ Language Deprivation
 - ▶ Predicts no difference between signing implanted children and hearing children
 - ▶ Predicts that signing implanted children will do better than non-signing implanted children

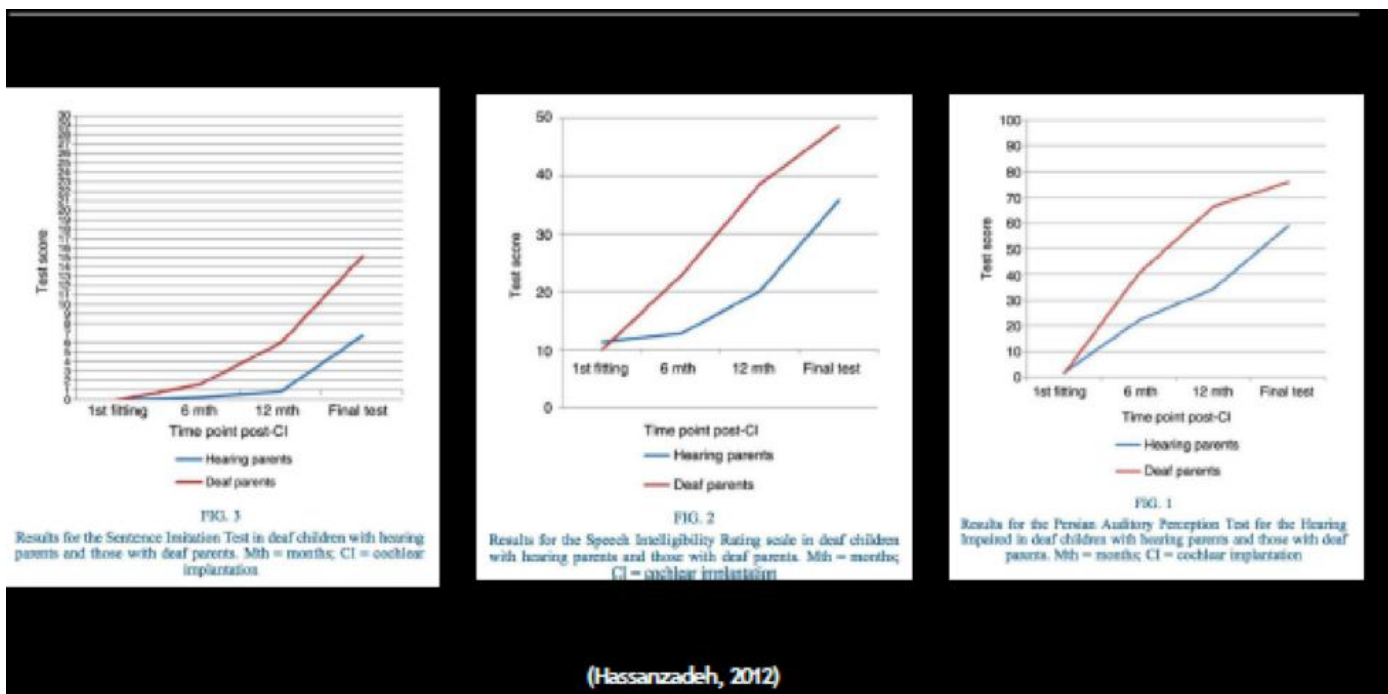


This is a well-known study that compares implanted children to hearing children. The study examined how well the implanted children could hear and comprehend, and speak with the cochlear implant. In the graphic on the left, the yellow lines are the deaf children with cochlear implants. The bold black line and the many lighter black lines are hearing children. What do you all notice at first glance when looking at this graph? [Audience: The yellow lines are not equal to the black lines]. Does everyone agree with that, anyone disagree? Good, any other observations? A lot of variability, yes. The black lines, the hearing children, are generally clustered together and the yellow lines are very spread out.

Does this study help us figure out if the problem is auditory deprivation or language deprivation? Who thinks its auditory deprivation? Language deprivation? [Audience: Both] Why both? [Audience: Auditory technology does not really give the same benefit as hearing children have. Deaf children do not have their hearing abilities. Their language development is still missing because technology does not give full access to hearing.] Yes, good, I will expand on that a bit more. This person was right that both hypotheses fit this study. Why? Because signing children were not included in this study. So deaf children with full language access were not included in the study. Their research design did not include visual language in their variables.

This type of cochlear implant study is very common in its design within the field in that they usually do not include sign language. Not including sign language in research design would cause bias in the interpretations of the results about deaf-hearing differences to be an assumed consequence of auditory deprivation. In science, we have a concept called confounders. A confounder is basically something that you did not account for in your research design but could explain your results equally well; this means that your results are already skewed from the beginning in your research design. So, this type of cochlear implant study actually could be explained by either, or both, auditory deprivation or language deprivation hypotheses. They did not rule out language deprivation due to not accounting for it in their design.

There is one more thing I want to point out with this study. The group of yellow lines you see are the best-performing children in this study of the three separate groups. The group of yellow lines are children who were implanted under 18 months, blue is 18-36 months, and green is more than 36 months. It is hard to see with the projector, but the 18-36 months and more than 36 months are even more variable and scattered than the under 18 months group. The hearing researchers concluded, based on this data, that seeing slightly less variability in the under 18 months group means deaf children should be getting implants earlier. Now, when I, a deaf researcher, look at the same data, I see language deprivation. Each line is one kid, so let's look back at the yellow group. Some of the yellow lines are basically flat here on the bottom while all the hearing children are up here. One deaf kid especially is perfectly flat here on the bottom. What does his everyday life look like? Is he socializing with his friends, having a happy life, or is he isolated and behind in his development? I think that's something important to keep in mind--something often lost in research is that we are talking about human beings. Each line is a person.



Now, this study studied implanted children too, this time in Iran. The researcher became curious about what the implant would mean for signing children from deaf families who did get the cochlear implant. They predicted that cochlear implant performance, when compared to non-signing children, would be worse for the signing children. They tested sentence imitation (how well you can hear and repeat a sentence), speech intelligibility, and how well they heard with the implant itself. To be clear, there was no kind of signing test, only listening and speaking tests. The red lines in the graphs are the signing children, blue the non-signing children. Does this support

auditory deprivation or language deprivation? Why weren't the signing kids doing worse than the non-signing kids? [Audience: Language] Language, yes. Yes, these results contradict the auditory deprivation hypothesis. Remember, auditory deprivation hypothesis predicts that signing does not matter because both groups do not have access to sound.

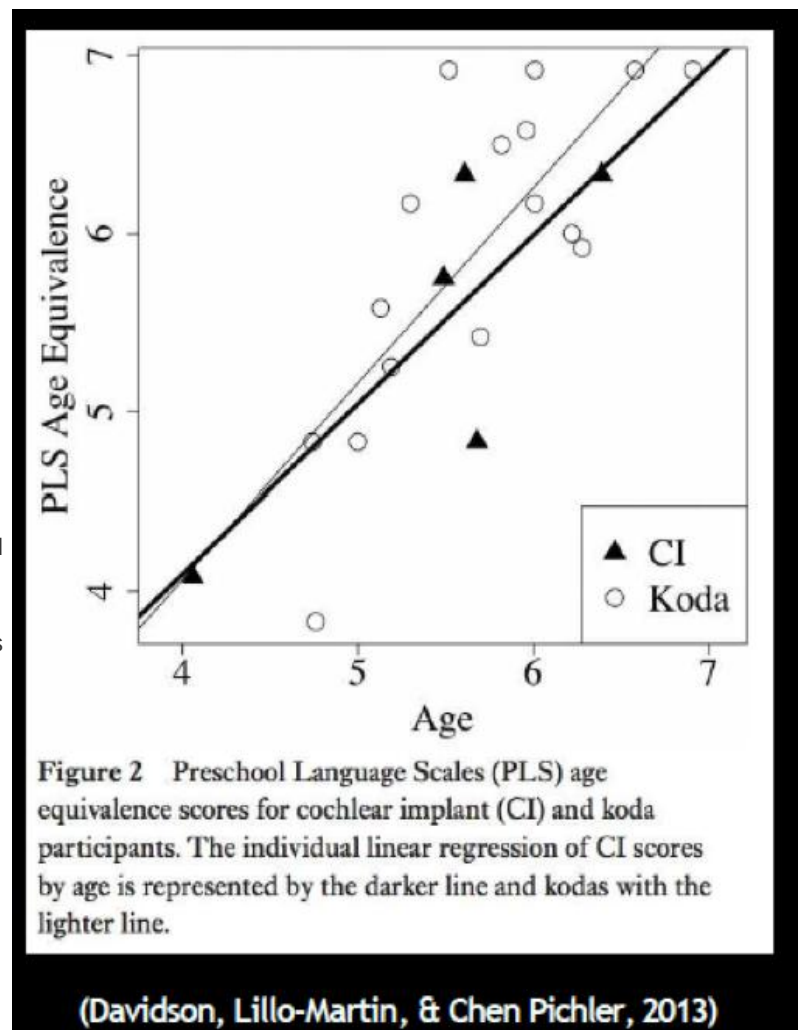
The signing group was better. This was unexpected for the researcher. What do you all think about that? Was this surprising to you, or did you expect this? [Audience: I expected that] Why did you expect that? [Audience: It does not matter if it's signing or spoken, important they get language.] Yes, you are right. I want to emphasize this again: the signing kids were doing better than the non-signing kids *for the cochlear implant*. Ah, but what about hearing children? Well the signing implanted children will still be worse than hearing children because they do not have access to sound. Let's see in the next study.

Ok, let's do a quick recap. Non-signing implanted children did not match hearing children in the first study. Signing implanted children did better than non-signing implanted children in the second study, but maybe signing implanted children are still behind hearing children because of less access to sound. So, the next group of researchers are from the University of Connecticut, who wanted to follow up on this type of research by comparing bilingual kids to other bilingual kids. Let me ask you, who are another group of people that acquire both American Sign Language and English? CODA, yes. CODAs (Children of Deaf Adults).

Because bilingual language development is different than monolingual language development, they wanted to make more direct comparisons of these implanted children. They worked hard and found deaf children who were implanted and signed from birth, and their hearing siblings. They tested both their ASL and English development, and their listening and speaking skills. This graph is one example of the language testing in that study. The bold black line represents the implanted children, and the other being the hearing Kids of Deaf Adults (KODAs). You can see both lines are following each other very closely. Now, are we very concerned about KODA language development? No, we aren't. Actually, they tend to become bilingual interpreters using both ASL and English.

No one is ever concerned about KODA language development and them falling behind while being exposed to ASL or anything like that. So, these native-signing implanted children are basically in-line with their KODA siblings. What does this mean for our auditory deprivation and language deprivation hypotheses? Audience: Both KODA and deaf kids have language access at home.] Right, so the auditory deprivation hypothesis would predict that implanted deaf kids would be behind their KODA siblings because they do not have access to sound while KODA children do. Remember, the implant does not make deaf children hearing, and neither is it a cure for hearing loss. There's still a maximum benefit you can get from implants that does not match normal hearing abilities, and it's very variable depending on specific children. Despite that, these native-signing children stayed on par with their hearing siblings using the cochlear implant. Ok, is everyone still with me? Is that clear?

So, we already have some research evidence. Why did I pick implants for research evidence? Because the implant is usually used to warn parents not to allow their deaf children to use sign language, and focus on just hearing and speaking. But this emerging research evidence seems to suggest that sign language actually helps cochlear implant outcomes. Ironically, this would mean that all the history and parents being told not to sign with deaf children was working against their own goals of ensuring listening and speaking skills. So why are we seeing this? Let's go a little further.

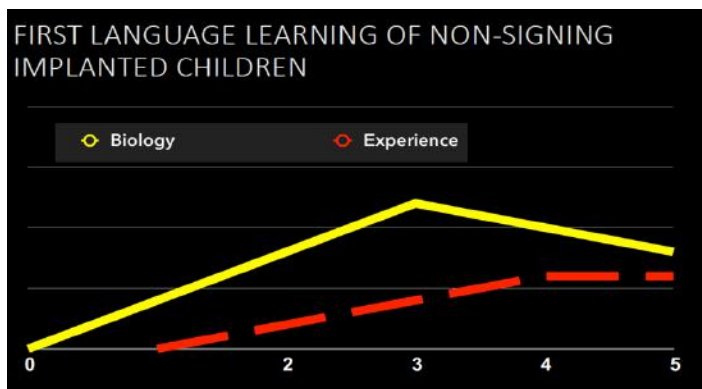


A TALE OF COMPETING HYPOTHESES WITH COCHLEAR IMPLANTS AND SIGNED LANGUAGE

- ▶ Auditory Deprivation
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- ▶ Language Deprivation
 - ▶ Predicts no difference between signing implanted children and hearing children
 - ▶ Predicts that signing implanted children will do better than non-signing implanted children

So, the two predictions of the auditory deprivation hypothesis did not fit the data. Remember, the first study's research design did not actually include language as a variable, nor consider sign language access. All the research on deaf children to date that does not include sign language is likely confounded – and worthless. Not thinking about language access when they interpret their results introduces a big dilemma about how to handle their data. Thus, the predictions of the auditory deprivation hypothesis were not proven, and the predictions of the language deprivation hypothesis fit the research evidence. That's why I am DRY HOTDOG, done with the "debate" of sign language vs not giving sign language.

Now let's talk a little bit about why we are seeing these results.



Remember, I explained that biology and experience are intertwined for language development. For any child born in a family where they can access the household language, hearing or deaf of deaf, their language development is intertwined as would be expected. They are getting immersive language exposure while the brain is primed for that. Now, if I am deaf and born in a hearing family, that biology and experience intertwining does not happen. Hearing families tend not to use sign language, and the deaf child cannot access spoken language. Thus, biology and experience become two separate processes – if parents are told not to sign, that means experience becomes delayed to 1 year old, 1 ½ years old, even 2 years old until they get the implant. While experience becomes

delayed, does the implant. While experience becomes delayed, does the brain biology stop? Does the brain recognize the experience delay and wait until the implant? No, it does not. The brain development processes are still happening.

Another point to remember – when the implant is set up, the brain has no idea what to do with the implant. There's a lot of training involved to make sure that maximum benefit of the implant can happen. Does language access automatically happen right after the cochlear implant surgery? No, it does not. There is a lot of training, and it requires a lot of work. I am also not hearing, remember, so I am not getting full access to hearing either. Their experiences are based on a lot of training, and not full access. By the time I might be progressing with the implant, I am now five years old, and my brain biology development is ready to move on. But I haven't established a full language foundation yet because of the delays and inconsistent access. This whole history of people withholding sign language from deaf children works against human biology, the biology of brain development.

Typically, people would say that deaf children just not could not achieve anything because they were deaf, but we know better. It's because of not having access to language. Earlier, Mallorie emphasized auditory deprivation is not language deprivation. If sign language did not exist, yes hearing loss would mean auditory deprivation and no access to spoken language. But we already created the perfect solution for that problem a long time ago, sign language. Giving deaf children access to visual language is a perfect fit for human brain development.

That leads us to the final point: signed languages are more effective for preventing language deprivation right now than cochlear implants are for preventing auditory deprivation. I think it's time to use our strength. Visual language gives full access to deaf children, and cochlear implants should be optional. If a child and family decide they want listening and speaking too, sign language will support that.

IN SUM

- Consequences of auditory deprivation are more accurately described as consequences of language deprivation
- Signed languages are more effective at preventing language deprivation than cochlear implants are at remediating auditory deprivation

I do think the heavy emphasis on cochlear implants and hearing aids historically is a bit backwards, and instead ought to be optional. Some people do well with the technology; some don't, but is sign language optional? No. Brain development requires timely language exposure, it must be immersive, and it must be fully accessible. We can't wait until a child is 2, 3, 4, 5 years old going into school. They cannot wait that long.

Here, the constant framing of auditory deprivation, instead of language deprivation, is part of the problem.



Discussion Question:

Why do less than 10% of deaf children in America and less than 2% worldwide receive early sign language exposure when...

- All known research evidence and everyday experiences of deaf people points to the neurocognitive benefits of early signed language exposure (like any other natural language);
- Poor outcomes continue to persist with the auditory deprivation model for 150+ years.
- Signed languages are accepted as real languages by every professional field (linguistics, psychology, public health, etc.) except early intervention and deaf education.

going beyond

Exploring the Attitudes & Beliefs of Audiology Students Toward People Who Are Deaf or Hard of Hearing

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RETIRED CONSULTANT
CALIFORNIA DEPARTMENT OF EDUCATION



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y name is Nancy Grosz Sager, and I am here to present my dissertation study, "Exploring the Attitudes and Beliefs of Audiology Students Towards People Who Are Deaf or Hard of Hearing." I am retired from the California Department of Education. One of my goals in retirement was to go back to school to get my doctorate, so I did that. My message to you all is, it is never too late! My service dog, Buzz, is here for your entertainment, because I don't have a clever title or any jokes for you.

The research I did explored a problem that I had seen over 40 years in the field of Deaf Education. While current research demonstrates that sign language supports and enhances the development of spoken language, some audiologists, speech pathologists, and teachers of the Deaf have not incorporated this research into their approach with parents of Deaf and Hard of Hearing children.

The purpose of the study was to explore and understand the cultural attitudes and beliefs of audiology students about people who are Deaf or Hard of Hearing. I studied audiologists because audiologists are the first professionals that parents of Deaf and Hard of Hearing children meet. I wanted to study audiology students, because I wanted individuals who did not have firmly established professional opinions.

My doctoral dissertation research question was:

- What are the attitudes and beliefs of audiology students about people who are Deaf or Hard of Hearing?

A sub-question of this main question was:

- What are the attitudes and beliefs of audiology students about sign language?



COLLABORATE WITH DEAF ADULTS AND WITH TEACHERS OF THE DEAF AS FAMILIES GO THROUGH THE DECISION-MAKING JOURNEY. IT IS NOT A ONE-TIME DECISION.



A second sub-question that emerged from the research study was:

•What are the attitudes and beliefs of audiology students about their role in the educational system as it relates to Deaf and Hard of Hearing children and their families? This question was not an original research question. In other words, the audiologist's role in the system was a recurring theme of the students during the interview, and prompted me to add this question.

I wanted to start with a definition of the word "audism," which appears now in the American Heritage Dictionary of the English Language. The definition of audism is either "the belief that people with hearing are superior to those who are deaf or hard of hearing" or "discrimination or prejudice against people who are deaf or hard of hearing."

I believe that most hearing people are audists by nature, simply because they have never met any Deaf or Hard of Hearing people. They don't know. And so, they just assume that people who are Deaf or Hard of Hearing want to be hearing. But I do not believe that there is any place for audism in the professions of teaching, speech language pathology, or audiology.

So, I wanted to study audiologists, because what audiologists say has a strong influence on people. Mallorie just affirmed, too, that people tend to believe what audiologists say.

The data I used was:

1. the Attitudes to Deafness Scale, which is pretty old, and so I did revise some of the questions on the Attitudes to Deafness Scale, with the permission of the original author.
2. I interviewed six of the students, and
3. I used some archival data, which were readings from a Deaf Culture class the students were taking.

My conceptual framework was the Systems Theory; I studied the Educational System, through the lens of Cultural Disability Theory.

When I hear that term "for kids who need it," I then think that they were automatically throwing sign language into category of a necessary evil.

My findings on the Attitudes to Deafness Scale...the scores ranged from 22 to 132. A score below 77 indicated that the student had a medical point of view towards people who are Deaf or Hard of Hearing. A score above 78 showed that they had a social/cultural view towards people who are Deaf or Hard of Hearing. I was actually surprised--pleasantly surprised--to find out that most audiologists scored in the social/cultural range. Only one student scored in the range that was lower than that (78), and that student didn't provide me with an email address, so I couldn't interview that person.

On my interview analysis, I had three coders. It was actually the Deaf person who was on my dissertation committee who said, "you know, you have a really strong bias (which I did) and so you need to have two other people read these interviews with you--people who have very different points of view--to see if you all come up with common themes." I had a hearing clinical audiologist. And I had a Deaf Ed.D student. I did a "within-case" analysis of the interviews. In other words, I looked at each individual student I interviewed. And then I did a "cross-case" analysis, where I looked at all of the interviews. I looked at themes that were jumping out from the interviews.

What I found with the "within-case" analysis was that even though all of these students scored in the social-cultural range on the Attitudes to Deafness Scale, EVERY student displayed a very strong mixture of medical views and social-cultural views. It made no difference how much sign language they had studied. They all just had these very mixed points of view. Sometimes, within the analysis of the same student, the points of view conflicted with other points of view that they expressed. Their vocabulary tended to be very medical, because they were in a medical field. At least, they viewed themselves that way. Here are some examples that I pulled from the interviews.

Some of the things that they said I viewed as very medical, and the two coders concurred as well. For example, in response to a question I asked about

Examples – Medical vs. Cultural

Medical

- Give them some time to accept that their baby isn't perfect
- I think it's just my duty to diagnose it, how bad it is, and to tell them exactly what it is
- ...me, as a normal human being...
- No parent wants to be told that something bad is going to happen when that's not necessarily going to be the case

Cultural

- I can be part of a patient's journey
- ...give these kids both languages – you know, you're technically raising a bilingual child
- They may feel more comfortable at a Deaf school, just because they may be the only one, or one of a few, at a typical school
- I feel like the critical period is equally as important for either one

"if a child had mild or moderate hearing levels, would you inform the parents that those hearing levels might become severe or profound with time?" the student said "absolutely not, because no parent wants to be told that something bad is going to happen when that's not necessarily going to be the case."

On the other hand, some of the things they said were very cultural. For example, talking about the effects of auditory deprivation, and how they needed to be able to hear so that they could acquire spoken language, one person, when asked "Do you think that's the same when they are acquiring sign language?" said after a moment's reflection, "I feel like the critical period is equally as important for either sign language or spoken language." So those were examples of things that they said that were from the cultural point of view.

In the cross-case analysis, these are the things that jumped out to me and to the other coders.

1. The students tended to use very medical and very audist terminology, such as "normal," "not perfect." They used the term "communication options" instead of "language opportunities."
2. However, they tended to have a very social-cultural view of the success of a Deaf or Hard of Hearing child or adult. They viewed people who are Deaf or Hard of Hearing as leading very typical lives - having jobs, going through the activities of daily living, raising children, driving cars, whatever.
3. They definitely separated Deaf children from Hard of Hearing children. That was brought up in Michele's presentation this morning. They saw a distinct difference between people who are Deaf and people who are Hard of Hearing. They viewed that difference, they said, functionally - so that the people who were Deaf were the people who could not hear well enough to acquire spoken language, and people who were Hard of Hearing were people who could hear well enough to acquire spoken language - although I don't know how you would know that for a child who is just born - a newborn baby.
4. This was actually a huge surprise to me. They talked a lot about "options," but they talked about those "options" as only for Deaf children. They did not talk about options for children who they deemed to be Hard of Hearing. Children who were Hard of Hearing were expected to be prescribed hearing aids or given a cochlear implant, and then to acquire spoken English and blend into hearing society. They did not see any other option for those children who they deemed to be Hard of Hearing.
5. The options that they saw for Deaf children were seen as a "this" or "that" kind of option. You either have to choose "this" or "that." They talked about them in terms of "routes." They said you can choose the "technology route" or the "ASL route" - which was a huge shocker to me for a couple of reasons. One, I don't see "technology" and "ASL" as opposites. I mean, "technology" is a "thing" and "ASL" is a language, so I did not quite see how we were seeing them as opposites, but I also don't see them as being mutually exclusive. I think you can choose a hearing aid and also choose ASL. There was some openness to bilingualism, especially with one of the people I interviewed who was very open to the notion of bilingualism.
6. They talked about a "critical period" for listening and spoken language development, and they talked a great deal about the negative effects of "auditory deprivation." That's the topic we are discussing here today. They talked a lot about that, but there was no mention of "language deprivation"--they never mentioned that.
7. They talked a lot about isolation, though - both of children who are born Deaf or Hard of Hearing and of people who later become Deaf or Hard of Hearing through age, or injuries.
8. They talked about Deaf Culture. When I asked them about Deaf Culture, they said that Deaf Culture is "great," but they viewed it as very discriminatory. They saw it as people who are "capital D Deaf." They talked a lot about people who are "Capital D Deaf" vs. "lower-case Deaf" and that people who are "capital D Deaf" don't like people with cochlear implants, who wear hearing aids, or who are oral Deaf.
9. They talked a lot about technology. They saw technology, for adults, as very much a personal decision. They saw their job as giving options, and then letting the person decide. But, for children, they said parents decide for the children. And the two people who scored the lowest on the Attitudes to Deafness Scale and who had never taken sign language themselves, both said that they would encourage spoken language and technology.
10. In terms of ASL, they very much viewed ASL as a true language. Four of the people I interviewed studied sign language before,

and they all said they wished they could sign better. However, all of them - and all three of the coders noticed this - tended to prefer spoken language over sign language. They saw it as superior. And sometimes they were apologetic about that. Sometimes they said, "Sad to say, but a student who can speak is better off than a kid who can't speak" or "Sorry, but a kid who can talk is better off than a kid who can't talk." Sometimes, ASL is seen as a last option, and so they would say "of course we support sign language, for kids who need it."

When I hear that term "for kids who need it," I then think that they were automatically throwing sign language into a category of a necessary evil. I had actually put that into my dissertation - seeing sign language as a necessary evil - but the audiologist who was a coder and my committee chair kind of cringed at that. So, I changed it to "ASL is seen as a last option." The two students who had not taken ASL would very much encourage spoken language, because they saw that as preferable to sign language.

Their beliefs and attitudes about their role in the Deaf education system kind of jumped out of the interviews. They saw themselves as part of the medical team. And they saw their role as telling parents about their options: parents can choose the technology route or they can choose the ASL route. And the interviewees saw this as a one-time deal. They were going to tell the parents about the routes they could choose, and then the parents would pick the route they chose, and then both parents and the audiologists would go on from there. The two students, again, who scored lowest, were very much in favor of spoken language.

They never mentioned that they would make a referral to Deaf adults or to the Deaf mentor or Deaf coach. The interviewees never mentioned it, so I asked them about their perspectives of Deaf adults. Their views were very mixed. One interviewee said "That's a great idea. I never thought of that. That's the best idea yet." Whereas another person said "Absolutely not. I would not refer them to a Deaf adult. I would make that decision about when they are ready." They did not see themselves as having a collaborative role with Deaf people.

As for the role of the teacher of the Deaf, they had almost no knowledge about what happens to Deaf children when they go to school. Only two of the audiologists said they would refer to school. And they did not see any role for themselves within the education system.

So, my recommendations to the audiology students and audiologists were:

1. Words have power. When you talk to parents of Deaf kids, the things that you say to parents and the words that you choose to use are very, very powerful. Please choose positive words when you're talking about Deaf children.

2. Focus on the negative impact of "language deprivation," not only of "auditory deprivation," and how SB 210 can help pinpoint language deprivation.

3. Replace the term "communication options" with "language opportunities." I think other presenters have already discussed, earlier in this conference, about the difference between communication and language. We want them (parents) to provide the children with language, and we want them to know that they can choose both sign language and spoken language; they don't have to choose one or the other.

4. Provide all information about all language opportunities to parents of all Deaf and Hard of Hearing children. Do not separate Deaf and Hard of Hearing children and not present the options or opportunities to those parents who have Hard of Hearing children.

5. Adopt a more inclusive definition of Deaf Culture.

6. Learn more sign language. They all said "There aren't any opportunities for sign language here" and they actually lived in a very large city where there are tons of opportunities for them to learn sign language.

7. Be more involved with the Deaf and Hard of Hearing communities. They all said they didn't know how to do that. And again, they lived in a large city with lots of Deaf people.

8. Collaborate with Deaf adults and with teachers of the Deaf as families go through the decision-making journey. It is not a one-time decision.

And I think I'm done.



Discussion Question:

What changes could audiology programs make to ensure that children do not grow up without language?

attitude

The Story of My Deaf Baby

HARSHADA KADU
PARENT



My name is Harshada, and this PowerPoint presentation is going to be the story of my Deaf baby. She is now 9, but she is still my little one! A little bit about me before I go into the details of the story.

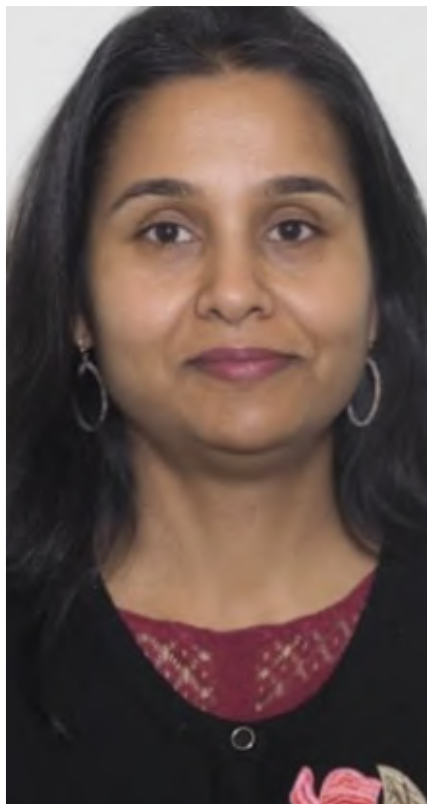
I was born and brought up in India and moved to California 10 years ago just as an experiment because my husband works in technology. And I have a Bachelor's degree in Architecture. That's my educational background. I also have a Post Graduate Diploma in Training and Development. Then my daughter was born here, and we were so thankful that she was born here.

And now I work as a Parent Links Mentor for NorCal Services for Deaf and Hard of Hearing (NORCAL). Mostly I get families from Alameda County. I am now a full-time mom of two children. My daughter, who is 9 years of age, is Deaf. My son, who is 5, is hearing. And right now, I am also a student of Ohlone College, Fremont taking some more ASL classes (audience applause) and hoping to catch up some more. So, this is a little bit about me. We also have a dog. His name is Zen. Now he is over a year old. So that's about me so far.

I have decided to share my daughter's story with all of you because, as a hearing parent, I was always at the receiving end when it came to early intervention. The story goes this way. I was a first-time mother. Very excited to have a child. My daughter is born. I had an extremely, extremely difficult labor. We had a c-section, and then it took me almost 3 months to recover because I was traumatized physically. It was a very difficult labor for me. And while I was still under the effects of anesthesia after my child was born, the nurse told me, "Your daughter failed the hearing test!" And I had no idea they even took her for the test.



AND THEN THE DEAF COMMUNITY KIND OF ENTERED INTO OUR LIVES AND WE JUST LET THEM IN. AND THEY LET US IN, AND IT WAS A COMPLETE TRANSFORMATION FOR ALL OF US. BECAUSE WE SAW HOW IT CHANGED OUR DAUGHTER'S LIFE. THERE WAS NO STOPPING HER!



So, I was like “What test are we talking about here?” She responded, “We do this newborn hearing screening, mandatory for everybody!” I said, “Yes, I do know about it. I had signed up for it.”

The nurse repeated, “She finished it, and she didn’t pass. Let’s try again tomorrow.” So that was the third day. I was still in the hospital. They tried again. She said, “It’s not working. Something might be wrong. Maybe the equipment is wrong, or I don’t know. Just go home, and come back. Your daughter just won’t pass.”

I went back home not caring what that really meant because I needed time to heal and to recover from the birth. For three months, we did not return to the doctor. They kept calling, “Oh, when are you doing the evaluation, the assessment, the diagnostics?”

Finally, we did it. And by the time my daughter was 4 months of age, they told me, “She has bilateral profound hearing loss!” (which I do not like to say). She was my first child. I was a new mother in a new country. Completely new. I had no idea!

I was just, I was still trying to adjust to life here. New culture. New mother, having had a difficult childbirth, and still thinking about what this test means because I had no idea. And then after we did the evaluation when she was four months, we found out that she is Deaf. And then our life just changed. It was like a completely different life. We had not imagined we would ever have a result like this in our lives.



"Sorry! Your baby is Deaf!"

And then we sat with the audiologist in her office. She told us, “I am so sorry! Your daughter is Deaf!” Then it hit us! Until then, we were not thinking anything about it because we had no idea what failing the test meant. And the minute the audiologist said, “Sorry! Your child is Deaf!” she started getting into too many details and information about what we should do next, instead of waiting for us to process what this information means. We thought it was too much, too early. She should have given us some time to process what actually it means. The negativity started building up right there in the office of the audiologist when she said that “I am so sorry!” She started explaining how bad it was for my daughter which meant how bad it was for us.

Being hearing people, we never had any idea about what it meant to be Deaf so it was extremely traumatic for us. There was lot of emotional drama going on in our lives for one year. Just to get away from it, we went back to India for four months. I was like “I have to get away from all this and just go there!” For four months, my husband and I pretended as if nothing has happened. We believed that she was hearing, she was not Deaf. And we did not care anymore because we realized that we were not enjoying our new baby.

For most of the first six months in the United States, we were doing the tests, and we were kind of processing this information. What did it mean? We were going through this emotional drama and the pressure in terms of “this is what you should do, this is what we think you should do.” The pressure was from everybody. The audiologist, the surgeon, the ENT surgeon, pediatrician, our friends, extended family, cousins, and just about everybody had an opinion about how we should raise our daughter. But in India, nobody had any opinion because nobody knew that she was Deaf. We had decided not to tell anybody other than my parents and his parents because we thought if we informed others, the process would start all over again for us. We did not tell anybody there so, all for us, it was like a normal life.

Then after my daughter was almost 12 months, we came back. And then the early start teacher suggested that we should get the information that we were supposed to get for a Deaf baby which means “Go and see the School for the Deaf.” And we were astounded, “Do we have a school for the Deaf, and where is that?” And we were living in San Jose, 9 miles from the school for the deaf. She said, “Visit the school for the Deaf in Fremont, and then decide what you really want in terms of communication options.”

Because until then we had only one option which was medical intervention. We thought either we are going to buy hearing aids or we are going to do cochlear implants because that’s what everybody did. And that’s what we were told. We were not really thinking about American Sign language (ASL), or Deaf school.

We visited the school, and then we really understood what being Deaf meant. We got the tour of the school, and my husband and I were shell shocked! We stood there in the parking lot, and, in 5 minutes, my husband said, "This is it! This is the place! This is where our daughter is going to be until she turns 18 years of age!"

Just think about it—just imagine—any hearing parents with deaf children. Just imagine. Because for us as hearing people, it was like "ok, you are Deaf, and this is it! There is no possibility for you anymore." That was our thinking process and the medical professionals kind of, now in hindsight, built on that. They were like "Ok, if you really want your daughter to be successful, you have to make sure she picks up speech."

You can understand how you are emotionally trying to deal with it in the first place. Then, you meet another set of people—deaf people—who are not really dealing with it at all. When we visited the classroom, I told my husband, "What's wrong with us? Everybody is so happy here! (audience laughing) What's wrong with us? Why are we not getting over it? What is it that we want?" It was a total shift, and we thought "Ok, just forget about it!" And for the next three years, I did not visit the audiologist at all. We did not feel the need.

We wanted the best education for our daughter. We wanted her to have a very successful life. We wanted her to have a career, and we thought everybody at the school had a career and very successful life.

We were totally convinced we were doing the right thing with the school for the Deaf because we wanted her to have the childhood that we had. Simple, easy, and natural which was what she was getting at the school for the Deaf. We did not want it to be a struggle for her. Struggling every day to catch up. Struggling every day to be a part of the group. Instead, she had so many friends and so many social events.

And then the Deaf Community kind of entered into our lives and we just let them in. And they let us in, and it was a complete transformation for all of us. Because we saw how it changed our daughter's life. There was no stopping her! Because she already started schooling at 18 months of age, she was way past whatever assessments she would have by the time she was 3 years of age. We were like "Oh this is great! This works perfect!"

They were not given the information they should have been given.

We thought, "Why is it that so many hearing parents do not want ASL? And we started judging other parents. We thought, "Why would they choose the oral route? Why would they not choose ASL?" And then we took a step back and thought about it. We thought we were in their position once. They were not able to meet the right people in their lives. They were not able to have the right influences in their lives. They were not given the information they should have been given.

This is one of the pictures with her friends. Softball is one of her favorites. I picked this picture because these are her buddies. The kind of opportunities she started getting in terms of Deaf social events, Deaf sports, competitions. We could not imagine her having these in another set up, for example, a mainstream school.

My hearing friends, who until then, were very skeptical about our Deaf school decision, would wonder why we were doing this to her. They thought we ought to have sent her to a mainstream school where she can be like other children. They believed that was where she can succeed like them, but they changed! They changed their approach. They said, "This is perfect! Why aren't other people doing it?" I said, "We have stopped judging other parents because we know they are not getting the information that they are supposed to get."



Newborn Hearing Screening Program

What were my experiences with the newborn hearing screening program? I thought it was a great program in identifying babies very young, but, based on my experiences, I thought it was too much, too early. For me, at least, because it took me at least three months to become healthy again.

I kept thinking...had the nurse chosen a different set of words, had the information been conveyed in a different way, had they been more positive about it! It probably would not have been so traumatic for us as a family to come to terms with our deaf child.

My experience was more in terms of trying to fix my baby for the first year, for the first one year, one year and a half. And not trying to focus on her as a whole person, which I still regret, because I felt she kind of lost one year from the time of her birth. We did not focus on her as a whole child. We were more worried about what auditory input she was getting, and what auditory input she was not hearing.

My suggestions would be, after the information is conveyed to the families, families should be encouraged to meet other parents. The more socializing, the more the healing. Based on personal experiences, I know mothers need to meet other mothers. Fathers need to meet other fathers. The more the families socialize, the better they are able to make decisions. That would be the best way to exchange information that otherwise parents would not be getting from anybody else.

Deaf mentors should be part of the newborn hearing screening program. Because unless you meet a Deaf person, you cannot understand what your child can become. You have to have a Deaf mentor in this program because they are the ones who are going to guide you every step of the way. You know your child is going to reach adulthood later in life, and you have a mentor right there who is going to help you in terms of language, in terms of how to socialize, how to get things done, who to go to, or to navigate through the world.

All the families must be told to visit all the local educational programs, Deaf and hard of hearing programs, schools for the Deaf. Based on my experience so far, the early start teachers do not talk about the school for the Deaf. They do not talk about "Go visit this campus. Go visit another program." I was very lucky to have an early start teacher who was very open! And the reason for that was because she had a best friend who was Deaf. She knew what being Deaf meant! But not everybody is lucky in terms of having a teacher who is so open and so unbiased.

So, we feel, all the early start teachers should encourage families to visit different educational programs and then decide for themselves. Spend some time in classrooms to figure out how the education is going to look for the Deaf child.

So, this is one of the artworks by my daughter. Powerpuff girls are her favorite. (audience laughing) Yeah! She is still obsessed with it. So, this is her representation of who she is. She is meeting these Powerpuff girls, Bubbles, Buttercup and Blossom.

My daughter: Hello.

Bubbles, Buttercup and Blossom: What is she saying?

Then they are saying: We can fly. We can fight crime.

We have eye lasers.

My daughter: Oh! I am Deaf! I sign!

They are begging her: Can you please teach us to sign? Please!

My daughter: Yeah! Ok! Fine!

(audience laughing)

I'll teach you how to sign!

(audience applauding).

She teaches them some signs.

The Powerpuff girls: Yes! This is it! Now we know how to sign!

(audience laughing).





Discussion Question:

Should ASL be taught to all the babies immediately as soon as the early start services start, especially for hearing families?

connection

Deaf Coach: Language Acquisition Service

SHERI FARINHA

CEO

NORCAL SERVICES FOR DHH



How many parents are here? Hands waving!! Respect.
 How many teachers are here? Hands waving!! Respect.
 How many interpreters or school support staff are here?
 Hands waving!! Respect.
 How many community members are here? Hands waving!!
 Respect.

How about bout deaf community advocates? Hands waving!! Respect.

How many of you are EHDI stakeholders? Can't be just a few of you!

I am telling you ALL of you in this room are really THE EHDI stakeholders! All of you are equally important. All of you help shape and make the Deaf child a success.

Bravo to you all! Hands waving!! Respect.

NorCal Services for Deaf & Hard of Hearing is a non-profit community-based organization serving Deaf & Hard of Hearing individuals in 24 northeastern counties of California. Founded and managed by a team of Deaf and Hard of Hearing individuals, NorCal Services for Deaf & Hard of Hearing has been an organization 'of, by and for' the Deaf and Hard of Hearing community since 1977.

We provide a wide variety of services and programs. One of the special programs we also provide is Deaf Coach: Language Acquisition Services.

Why have Deaf Coach Program?

Since AB1836, we have had been asking that "language" and "communication" be discussed at IEP conferences. Prior to AB1836, this discussion of "language" was missing and not a part of IEP conferences. The simple question of "Which language are you using?" had not been asked. It was supposed to be simple.



SINCE THE PASSING OF AB1836, WE SAW OVER AND OVER HOW IDEA DOES NOT REALLY FOCUS ON LANGUAGE ACQUISITION SERVICES.

Since the passing of AB1836, we saw over and over how IDEA does not really focus on language acquisition services. There are different parts to IDEA, particularly Part C, for example, family training, home visits, audiological services, language services, and different options for different kinds of services.

Where are language acquisition services? That's why we introduced and passed SB210: Language Equity and Access for Deaf Kids (LEADK). SB210 mandates tracking and monitoring language acquisition and development—using language milestones—for deaf babies and toddlers aged 0-5. There are goals and assessments every six months with the objective of tracking and reporting on an annual basis. The reports are focused on how deaf babies and toddlers are making progress on language milestones. We work with Early Start teachers who are working with families. Early Start teachers and Deaf Coaches would discuss what milestones are being targeted. SB210 requires that in cases where deaf babies continue to struggle with language milestones, the IEP team would assemble again to address potential issues or to propose alternative language learning strategies. All those language acquisition services need to be written in the IFSP or IEP.

Federal Law IDEA Part C includes services for Deaf & Hard of Hearing Infants ages 0-3:

- Family training
- home visits
- speech-language
- pathology services
- audiology services
- sign language services
- cued language services
- assistive technology devices
- assistive technology services

WHERE ARE LANGUAGE ACQUISITION SERVICES?

NORCAL just completed a Deaf Coach training curriculum, as a result of a grant received. We did pilot trainings throughout the State of California. Marla Hatrak was the Project Author, along with Alice McGill, Esq. and Sheri Farinha, M.A. as Deaf Coach Curriculum Administrators.

Who are the Deaf Coaches?

There are eight Regional Deaf Access Service Providers in California who receive funding from California Department of Social Services (CDSS). They, along with two Option Schools with Deaf Coach services, participated in the pilot trainings. Each agency currently has Deaf Coaches provide support to families with Deaf Children.

Deaf Coaches are fluent in ASL/English or English only. Regardless of whether language milestones are part of IFSP or IEP, Deaf Coaches will work with the Deaf child and their families.

What do the Deaf Coaches do?

When is the right time to bring in a Deaf Coach? The earlier the better. Right from when the infant is identified Deaf and Early Start Services have begun is the most primal time when Parent Mentors introduce to the family the idea of having a Deaf Coach for further support. Why? Language acquisition.

What else do the Deaf Coaches do?

Really, everything that has been discussed in this symposium are topics that Deaf Coaches can broach with families. Other areas of focus include:

- vocabulary,
- family engagement, and
- introduction to other Deaf adult or community events, community resources.

Depending on their IFSP and IEP, families can have Deaf Coaches for as much as one-and-a-half hours or two hours a week or as infrequently as once every month. With consultation with the Early Start teacher, each family can decide how frequently they would like to receive Deaf Coach services.

The benefits of Deaf Coach services

- Connecting families with a deaf child to a positive adult role model who is Deaf;
- Supporting the deaf child's teacher and family on language milestone goals; and
- Providing the families with an understanding of ASL, English, Deaf Culture, and the Deaf community.

- To better understand the milestones, please go to CDE's website to see the list: <https://www.cde.ca.gov/sp/ss/dh/sb210langmilestones.asp>

Who would be interested in Deaf Coach services?

- Families with deaf children aged 0-5. Does not have to be within the age range of 0-5, older students also could benefit from Deaf Coach services.
- School-aged deaf students who show delay in language development and would benefit from Deaf Coach services.

Qualifications of Deaf Coaches?

- Must pass a background check with the Department of Justice
- Anyone who works with children is required to have their fingerprints taken
- Ability to communicate well
- Rapport with families from all colors of the rainbow
- Prefer high school and college degree
- Commitment to meeting with families
- Follow up with reports
- Attend all trainings and quarterly meetings

How do I get Deaf Coach services?

- Either the Early Start Teachers or the child's parents can request a Deaf Coach as a language service provider in the IFSP or IEP.
- Use the district's standard agreement to subcontract with one of the Agencies
- Description of service and hourly rate of service determined by that Agency and LEA
- Time period: July 1 – June 30.
- Include the number of families in the district to be served.

What does NorCal need?

- Teacher's contact information;
- Child's family contact information;
- Language milestone goals to be achieved;
- Teacher's attendance at the first visit to introduce Deaf Coach to the family.

Who helped start Deaf Coach program in California?

Teachers like Cheryl Esson are partners with NorCal to help families set up services. Deaf coach services can be provided as a school-based service if written as a service in the IFSP or IEP. The teacher, Deaf Coach, and family all work together to support the Deaf Child's language acquisition for Kindergarten-readiness.

It takes a village to raise a child. And we are the village.



Discussion Question:

What are the ways YOU can support Deaf kids to get Deaf Coach services in your area/district?

support



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