

Infusing Deaf/HH Leadership and Partnership throughout the EHDI systems



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Imagine a world...



- Where families with newly-identified children who are deaf or hard of hearing have contact with screeners, physicians, audiologists, early interventionists, psychologists, counsellors...other parents who are deaf or hard of hearing
 - Individuals with intelligible spoken language, hearing aids, cochlear implants
 - Individuals with native/fluent American Sign Language.
 - Individuals who are bilingually fluent in ASL and spoken English
 - Individuals who are multi-lingually fluent in more than one spoken language or more than one sign language system

Infusing Deaf and Hard-of-Hearing Individuals through the EHDI system



- JCIH Early Intervention supplement recommends that EHDI programs have as a goal that individuals who are deaf or hard of hearing are infused throughout the system
- Family contact with deaf or hard of hearing individuals should be common such that parents can report that they have had diverse interactions with many adults who are deaf or hard of hearing
- JCIH Goals 3, 10 & 11

JOINT COMMITTEE ON INFANT HEARING EARLY INTERVENTION SUPPLEMENT (2013)



- Goal 3a (pg. e1328). Intervention services to teach American Sign Language (ASL) will be provided by professionals who have native or fluent skills and are trained to teach parents/families and young children.

JOINT COMMITTEE ON INFANT HEARING EARLY INTERVENTION SUPPLEMENT (2013)



- Goal 10. (pg. e1337) Individuals who are D/HH will be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels. Their participation will be an expected and integral component of the EHDI systems

JOINT COMMITTEE ON INFANT HEARING EARLY INTERVENTION SUPPLEMENT (2013)



- Goal 11 (pg. e1338). All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH. This goal intends that families have access to meaningful interactions with adults who are deaf or hard of hearing who have the knowledge and skills to mentor, support, and guide families in culturally and linguistically sensitive ways and to serve as communication/language and social role models and mentors for deaf and hard of hearing children and their families.

Deaf and hard-of-hearing interactions



- Screeners
- Physicians
- Audiologists
- Counselors, Psychologists, Social Workers
- First contact – Part C coordinators- in Colorado Co-HEAR Coordinators
- Early intervention specialists
- Sign Language instructors
- Mentors
- Parents of deaf or hard of hearing children who are themselves deaf or hard of hearing
- Researchers

Did you know?



- In 2015, the Presidential Award for Excellence in Science, Mathematics and Engineering Mentoring was awarded to a Johns Hopkins neuroscientist, [J. Tilak Ratnanather](#), who is deaf with expertise in brain mapping. Dr. Ratnanather was educated at the University College of London, Oxford University, and the City University of London and John Hopkins and he is dedicated to giving back to others who are deaf or hard of hearing.

INFUSION WITHIN SUCCESSFUL SYSTEMS

BASELINE DATA



- Colorado families don't have to specially arrange contact between families and someone who is deaf because the families have many contacts with a variety of people and families who are deaf or hard of hearing
- How does this happen –
 - System has to set the goal
 - System has to collect the data
 - ✦ How many early intervention specialists are themselves deaf or hard of hearing?
 - ✦ Are there any audiologists in the state who are deaf or hard of hearing?
 - ✦ Are there any physicians in the state?
 - ✦ Are there parents who are deaf or hard of hearing who have children who are deaf or hard of hearing
 - ✦ What is the first contact system – are deaf or hard of hearing people represented there
 - ✦ Counselors and social workers and psychologists – are any deaf or hard of hearing

TRAINING, FILLING IN THE GAPS



- Based on the data – set a plan to encourage systems to seek out qualified individuals who are deaf or hard of hearing
- To encourage training programs to identify, select and graduate students in audiology, speech pathology, deaf education, early childhood special education who are themselves deaf or hard of hearing.
- Establish a system for sign language instructors who are themselves deaf or hard of hearing and native or fluent sign language communicators
- Establish a system for deaf/hard of hearing mentors who can provide families with information about growing up deaf in a hearing family

FUNDING, TRAINING PROGRAM, FIDELITY



- Identify a funding mechanism
- Assure that these positions are not volunteer positions
- Establish hiring criteria and training
- Identify advocates – meet with the most influential individuals from their profession who are willing to promote agendas – highest quality of sign language and visual communication and spoken language and auditory communication strategies available at the earliest possible time, infusion of individuals who are deaf or hard of hearing throughout the EHDI system

Allies



- Audiologists
- Physicians – especially Cochlear implant surgeons
- Teachers of the Deaf
- Speech/language pathologists
- Psychologists, Social Workers, Counselors
- EHDI coordinators
- Parents



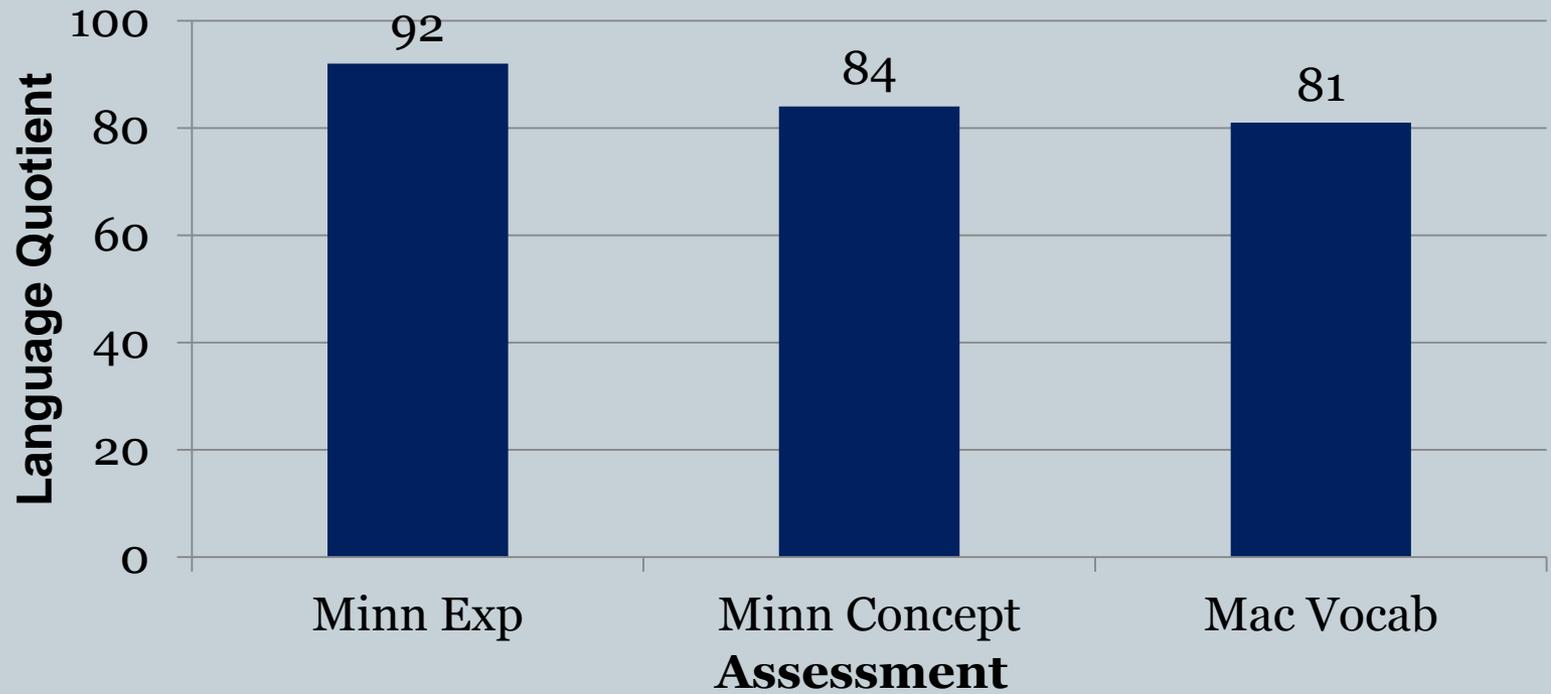
Language Outcomes across 12 States:
Strengths, Limitations, and Predictors of
Success

Presenters

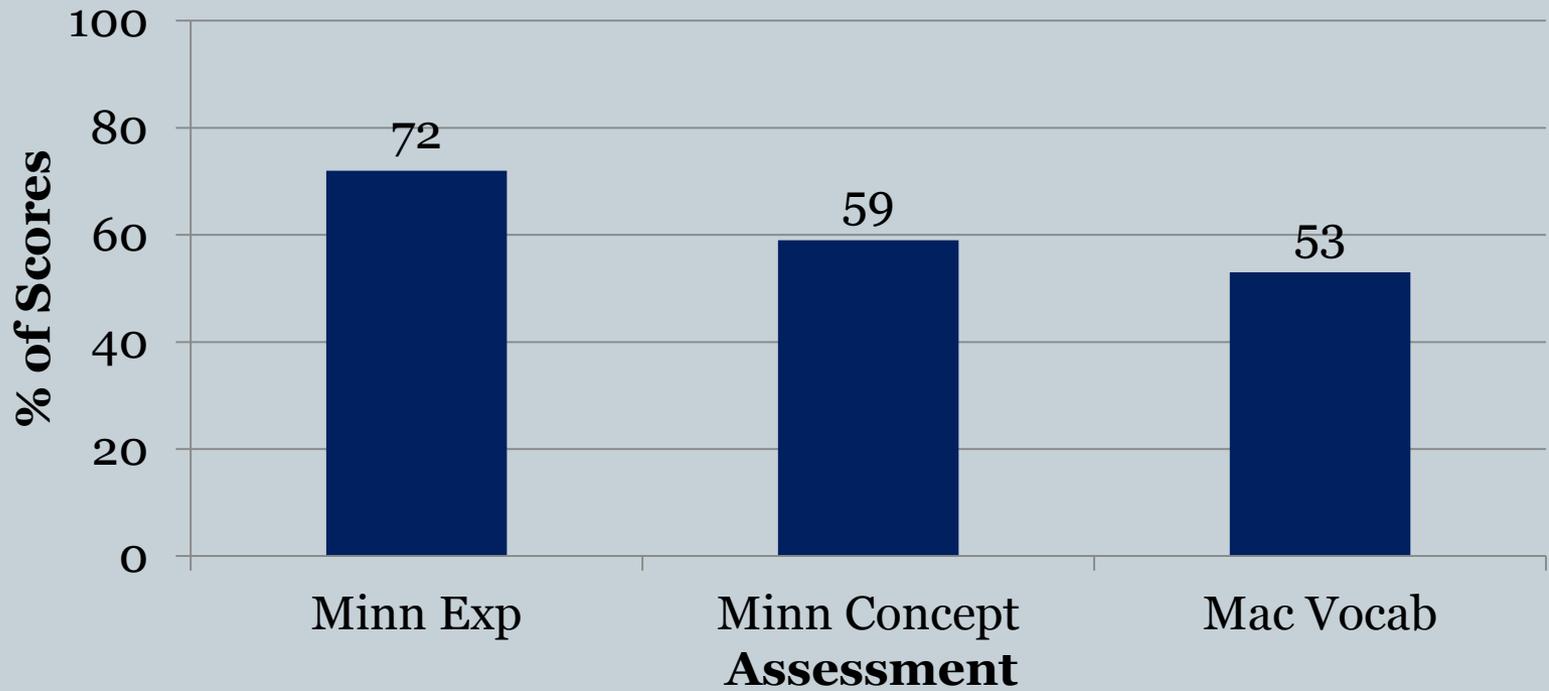


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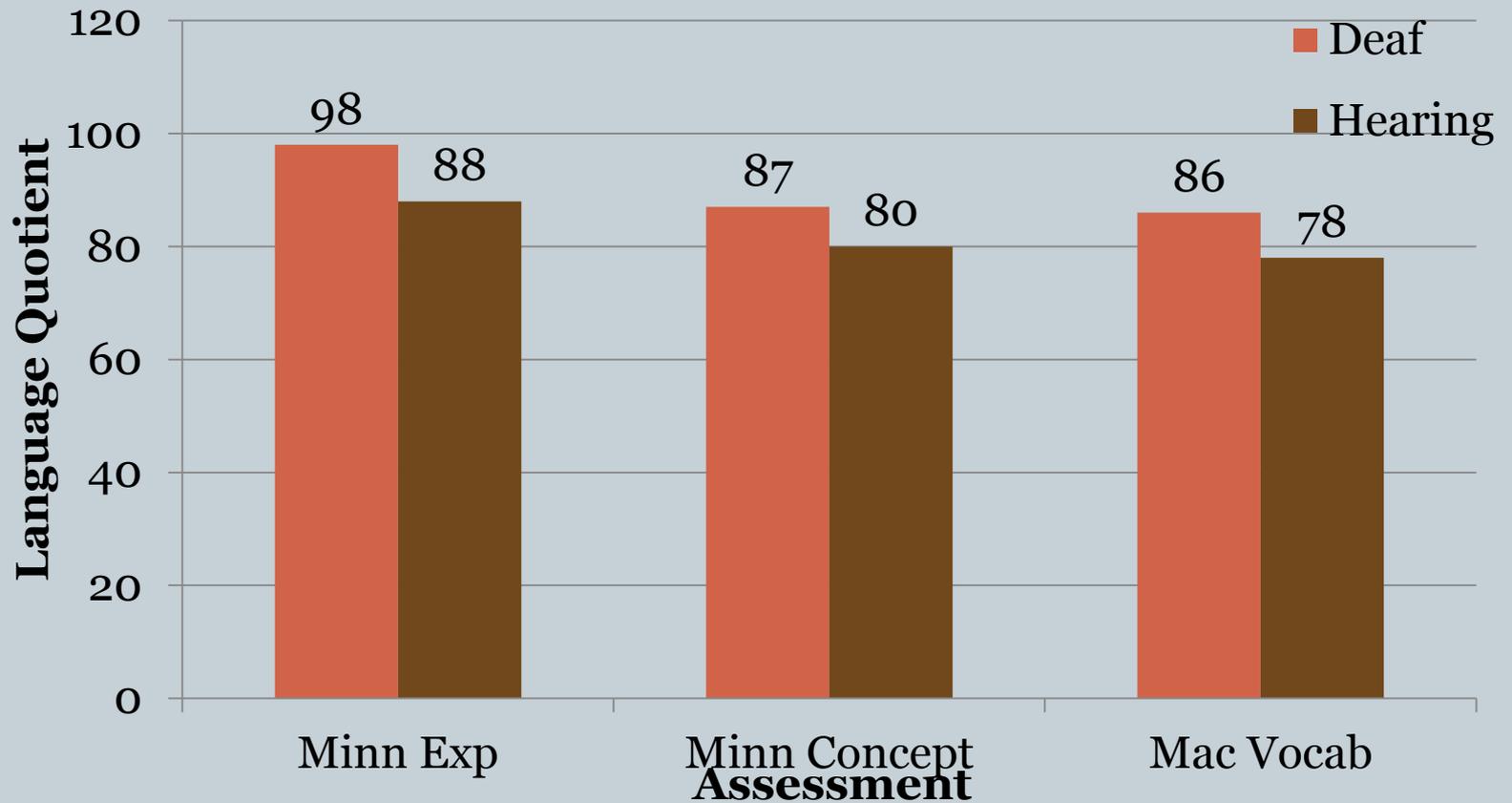
Median Language Quotients



Percent of Scores in the Average Range (LQ = 80+)



Deaf vs. Hearing Parent(s)



DEAF/HARD OF HEARING PARENTS



- N=40
- 25 are Deaf communicating in American Sign Language as a native language
- 15 are Hard-of-hearing or Oral deaf using spoken English as the language in the home with their children

Language outcome effect



- There was no significant difference in the outcomes of these children between children of Deaf parents using ASL in the home and children of deaf and hard-of-hearing parents using spoken English in the home.
- Both groups had children with significantly higher language outcomes than children whose parents were normally hearing and there was no difference in the language outcomes of these two groups.

How do Deaf/deaf/hard of hearing parents of children who are deaf or hard of hearing communicate with their children?

- Far too little research exists providing information about Deaf/HH parents communicate with their children.
- The few research articles have focused on American Sign Language and visual language/communication strategies.
- To my knowledge, there have been no studies investigating how parents who are deaf or hard of hearing teach their children spoken language.

What do parents say? (Johnson, 2011)



- 457 families
- Diverse in communication mode, amplification technology
- 56.2% indicated that D/deaf/hard of hearing role models were very important
- 27.9% indicated they were moderately important
- 47.9% indicated that access to D/deaf/hard of hearing adults was very important
- 27.1% indicated that access was moderately important

Partnering with Deaf Adults: Creating Positive Outcomes for Children and Families



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

Shelly Strickfaden, parent of a two-year-old boy who is hard of hearing

Why include Deaf or hard of hearing adult on your team?



- Most parents with a newly identified deaf or hard of hearing child are themselves hearing. It changes the identity of the parents/family.
- Parents may have had limited experiences with someone who has a congenital hearing loss.
- Begin introducing the child and family to a new community.
- Deaf and hard of hearing adults provide parents with a positive and hopeful perspective as well as genuine, real life experience.
- Credibility
- It is the closest thing we have to a crystal ball!

Parents ask three basic questions:

What's wrong with my child?
What will my child be like later?
What can be done to help my child?

Bagnato, Neisworth, & Munson, 1997

Deaf adults are uniquely qualified to address these
issues

Personal Questions asked of four Role Models



- I saw on the internet that deaf adults have a low reading level – is that true?
- What will my child's speech be like?
- You have good speech – how can I make sure my baby does?
- Do you wear hearing aids... why or why not?
- Will you get an implant? Why or why not?

Questions from the Anxious Heart



- Should I stop playing my guitar? Should I stop singing to my child?
- Kids are cruel.... How can I make sure that my child won't be teased?
- You have a good self esteem – how do I develop that in my child?
- When will I stop crying?
- What about school... can my child go school with his sister? Or does she need a special school? Did you go to public school?

What about the day to day?



- Personal questions.... Do you have kids? A spouse?
Hearing or deaf?
- What about sports?
- Can you talk on the phone?
- Can you drive?
- How do you hear in the dark?

If hearing professionals know the answers.... Why a role model?



Parents appreciate a **personal perspective** from a D/hh role model.

It increases the families openness to examining issues in greater detail.

What does this connection provide for families?

- **Calms anxiety**
 - “It’s going to be ok – I can see that”
 - “I imagined a lot of things that could go wrong but I never thought about a hearing loss – I can’t even imagine it”
- **Build relationships with the modalities at hand**
 - Parents think they have lost a modality forever
- **Communication**
 - Can not have a relationship without communication
 - Equalize relationship (communication) between parent & child

Why Involve a Deaf Adult After Identification?



- Most parents of newly identified children do not realize how meeting a deaf or hard of hearing adult will help them until after they have had the opportunity
- Our D/deaf/hard of hearing professionals interact with families, not because they are D/deaf/hard of hearing but because they have professional knowledge and skills that can enrich the family's life.
- We don't ask families whether they want to interact with a hearing professional, nor do we ask them if they want to interact with someone D/deaf or hard of hearing.
- System must create opportunities for parents to meet deaf and hard of hearing adults
 - Presentations
 - Workshops
 - Home visits
 - Social events

Parents who see deaf and hard of hearing adults as valuable members of THEIR team, begin to understand the potential in their child.

Involve a deaf adult soon after identification



- Introduce the child and family to this new community.
- Help normalize their new world and all the experiences, and the feelings that go with it!
 - What it looks like is not as awful as parents may have imagined.
- Role Models demonstrate positive possibility.
- The family may feel more comfortable addressing practical concerns in a less formal, more personal setting.

D/HH Role Models can:



- Articulates what the child can not...YET!
- Lend ability and creditability for the child's upcoming/future needs
- Assist the parents as they discover the potential and strengths of their child.
- Give hope and encouragement through the inevitable ups and downs of those early years.

Something to look forward too:



- **New ways of communicating and thinking becomes the new normal for families**
 - Driving with light on for visual cues
 - Say goodnight with light on
 - Going upstairs facing the child
 - Watching for opportunities to close the gap (incidental learning)
 - Awareness of sound

Building Strong Families at Home



- Deaf adult assists the parents in building a relationship with the modalities at hand
 - Parents think they have lost a modality forever. Parents want to know what to expect from their child.
- It is not possible to have a relationship without communication
 - Models communication and relationship building strategies between family members

Building Strong Families in the Community

- The deaf or hard of hearing child lives in a hearing world (family, church, neighbors). Meeting the deaf adult soon after diagnosis provides the family with an early opportunity to ask some of their questions and see these communication strategies modeled.

Roles of Deaf and Hard of Hearing Adults in the EHDI system in Colorado



- Interventionist
- Role model
- Sign Instructor
- Consumer advisor
- Coordinator
- Members of committees and task forces
- Providers with private organizations

Involvement of Adults who are Deaf and hard-of-hearing



- System level
 - Administration
 - ✦ Quality assurance
 - ✦ Creditability
 - ✦ Program development
 - Decision-making
 - ✦ Representation on key committees and task forces
 - Policy setting

The involvement of adults who are
Deaf and Hard of Hearing
are not token members,
but leaders and trendsetters in our
systems of care.

More system issues



- **Need a variety of deaf and hard of hearing adults**
 - Opportunity to meet more than one individual
 - Ability to match adult to parent's concern/questions
- **Job description is important**

System involvement



- Hospitals and diagnostic centers can have a deaf adult on the team to meet with the parents
 - Ex. Parent Mentor position at The Children's Hospital of Denver
- Early Intervention programs can introduce parents to deaf adults as providers, role models, leaders.

Barriers



- **Family barriers**
 - Potential negative experiences with deaf/hh individuals when growing up
- **System barriers**
 - Funding to pay for involvement of qualified deaf or hard of hearing adults
 - Expectations/ job description/training
 - Time constraints
 - ✦ Takes time to build a relationship w/ professionals
 - Professional bias
 - Ownership/ territory

Cultural Barriers



- Deaf, Hearing, Hard of Hearing – What does it all mean?
- Providing role models to non-English speaking families
- Assumptions

Overcoming barriers -Ideas to explore



- **Overcoming Family Barriers**
 - Open, honest communication
 - Sense of humor
 - Providing exceptional role models with great interpersonal skills
 - Professionals inviting a role model to accompany them
 - Panel discussions & social opportunities
 - Play groups with both deaf and hearing parents
 - Partnering with Hands & Voices

Overcoming System Barriers



- Start with whom you know – people currently in the system – they will lead you to others
- Collaboration with other non-profits and agencies
- Grants (public and private)
- Hands & Voices
- Willingness to explore new ideas
- Deaf adults in leadership roles
- Paid – not volunteer - positions

Effective Role Models



- Have a written job description
- Set appropriate expectations
- Establish policies and procedures
- Strength based program, strong role models, strong families
- Coordinator for the project
- Trainings and an awareness of biases
- Follow-up reports on effectiveness
- Talk with other states who have a program currently to find out what works



- **Overcoming cultural barriers**

- Opportunities for parents to meet a variety of role models – deaf, hard of hearing, ASL, oral, etc.
- Permission to explore both cultures (hearing and deaf)
- Train role models in cultural sensitivity in order to meet the needs of the non-English speaking families – ASK!

Building Effective Teams



There are never any token members on a powerful team.

The involvement of adults who are Deaf and hard of hearing brings leaders and trendsetters into our systems of care for the benefit of our children.



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Deaf and Hard of Hearing Professionals as Cultural and Linguistic Brokers



- Liasons
- Cultural Guides
- Mediators
- Catalysts of Change

Cultural Brokers



- 1) assess and understand their own cultural identities and value systems;
- 2) recognize the values that guide and mold attitudes and behaviors;
- 3) understand a community's traditional health beliefs, values, and practices and changes that occur through acculturation;
- 4) understand and practice the tenets of effective cross-cultural communication, including the cultural nuances of both verbal and non-verbal communication; and
- 5) advocate for the patient, to ensure the delivery of effective health services.

Association of Medical Professionals with Hearing Loss



- <https://amphl.org/>
- 86 physicians, medical students/residents with hearing loss were identified
- 56 responded (31 practicing physicians) (25 medical students/residents)
- Approximately $\frac{1}{2}$ of the physicians identified as Deaf, $\frac{1}{2}$ of the medical students and $\frac{1}{3}$ of the residents.

American Academy of Audiology



- Deaf/Hard of Hearing Audiologists meet annually at this meeting.

Informed Choice: Spoken Language



- Informed Choice does not exist unless all families with identified children have access to highly qualified early intervention providers in auditory and spoken language, if they choose to explore listening and spoken language.

Informed Choice: Spoken Language



- It is not known if any state actually offers **every** family the skills of a highly skilled and knowledgeable interventionist

Informed Choice: American Sign Language



- Informed Choice does not exist unless all families with identified children have access to a native/fluent sign language communicator who is deaf or hard of hearing and that this individual has been trained to teach sign language to parents/families and infants, if they choose to explore visual communication in addition to spoken language.
- This is an indisputable issue that should garner unanimous support from all parties – it is impossible for individuals to argue against language instruction from a native/fluent user of the language if one wishes the family/child to be exposed and learn sign language that is native and fluent or to argue against a skilled proficient intervention provider in auditory and spoken language.

System of sign language instruction



- State systems offering this service to all families only exists in a very small number of states
 - Colorado
 - New Mexico
 - Arizona
 - Utah
- Several schools for the deaf have these systems but often their early intervention programs are not state-wide

ASL as accepted as a language at all levels of educational instruction



- States should initiate legislation to recognize ASL as a language at all levels of educational instruction
- Especially higher education

Deaf Child's Bill of Rights



- Assure that all children who are deaf or hard of hearing have decisions made with the input from individuals knowledgeable about language and communication methods specific to children who are deaf or hard of hearing.

Deaf Child's Bill of Rights



- <http://www.cde.state.co.us/cdesped/download/pdf/dhh-DeafChildBillRts.pdf>

Deaf Child's Bill of Rights



- that each child's "unique communication mode is respected, utilized, and developed to an appropriate level of proficiency",
- that teachers and other providers who work with children who are Deaf or Hard of Hearing are specifically trained for this population, including proficiency in the primary language mode of the children with whom they work,
- that an education with a sufficient number of language mode peers with whom direct communication is possible and who are of same age and ability level is available,

Deaf Child's Bill of Rights



- that parent involvement and, where appropriate, people who are Deaf and Hard of Hearing, determine the extent, content, and purpose of educational programs,
- that children who are Deaf and Hard of Hearing benefit from an education in which they are exposed to Deaf and Hard of Hearing role models,
- that programs provide direct and appropriate access to all components of the educational process, including but not limited to recess, lunch, and extra-curricular activities,

Deaf Child's Bill of Rights



- that programs provide for the unique vocational needs, including appropriate research, curricula, programs, staff, and outreach,
- that the least restrictive environment for each child who is Deaf or Hard of Hearing takes into consideration the legislative findings and declarations of this law, and
- that due to the unique communication needs of children who are Deaf and Hard of Hearing, the development and implementation of state and regional programs would be beneficial.

Communication Plan: Student D/HH



- The IEP team has considered each area listed below, and has not denied instructional opportunity based
- on the amount of the child's/student's residual hearing, the ability of the parent(s) to communicate, nor the
- child's/student's experience with other communication modes.
- 1. The child's/student's primary communication mode is one or more of the following : (check all that apply)
 - aural, oral, speech-based
 - American Sign Language
 - English-based manual or sign system
- *Issues considered:*
- *Action Plan, if any:*

Communication Plan: D/HH



- 2. The IEP team has considered the availability of deaf/hard of hearing adult role models and peer group of the child's/student's communication mode or language.
- *Issues considered:*
- *Action Plan, if any:*
- 3. An explanation of all educational options provided by the administrative unit and available for the child/student has been provided.
- *Issues considered:*
- *Action Plan, if any:*

Communication Plan



- must have demonstrated proficiency in, and be able to accommodate for, the child's/student's primary communication mode or language.
- *Issues considered:*
- *Action Plan, if any:*
- 5. The communication-accessible academic instruction, school services, and extracurricular activities the child/student will receive have been identified.
- *Issues considered:*
- *Action Plan, if any:*
- Required IEP attachment for Hearing Disability, Colorado Department of Education

Sensitive periods of development



- Just as for auditory spoken languages, there is a sensitive period for the development of a signed language
- Exposure as early as possible, and as consistently as possible to a native/fluent communicator in sign language is essential to teach the foundations of a signed language
- The most qualified individual to teach families is an individual who is deaf or hard of hearing



- There is no evidence that learning sign language or the use of sign language has any negative impact on the learning of spoken language – as long as the child is fit appropriately with amplification, wears the amplification consistently, and is exposed to a language environment that provides the child with access of at least 12,000 spoken words a day.
- In addition, all of the studies that indicate that children who sign can also learn to speak intelligibly have had high quality intervention from a specialist in auditory skills and spoken language development.



- Because language is typically first learned in the home, the traditional and historical techniques of educating children who are deaf or hard of hearing – such as the bi-bi model are not as readily applicable
- Infants and toddlers are not yet reading English
- However, some families are receiving instruction in sign language – with no spoken language
some are receiving instruction about auditory skills, listening and spoken language – sometimes without the use of sign language and sometimes with simultaneous use of spoken language and sign language

Studies of children who sign focus on the transition from sign language to spoken language



- The studies were not designed to assess the sign language development of the children but whether or not the use of sign language interferes with the development of spoken language
- As a result, studies measure only the spoken language component
- Because there are no standardized tests for the development of American Sign Language – it is not easy to assess the child's development and come up with a standardized age score.



- Deaf sign language instructors were often invited by the families to their cochlear implant candidacy meetings.

Data Data Data



- Collaboration is essential
- Arguments that often dissolve into claims of differences of opinion can be resolved with data

Imagine a World...



- Isn't this the goal of NHS/EHDI programs throughout the world?
- That children who are deaf or hard of hearing have access to the same opportunities that hearing children have?
- Shouldn't professionals that interact in the system be models for the infusion of professionals who are deaf or hard of hearing?