

Ethical Bias: Addressing Professional Obligation when Communicating with Families

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Presented by Lisa Crawford

JCIH 2007 Position Statement Updates

- Families should be made aware of all communication options and available hearing technologies (presented in an unbiased manner)
- Informed family choice and desired outcome should guide the decision making process.
- Information at all stages of the EHDI process is to be communicated to the family in a culturally sensitive and understandable format.

Unbiased: What exactly does it mean?

- Indifferent: characterized by a lack of partiality
- All ideas presented equally
- Not inclining toward or actively taking either side in a matter under dispute

"All things being equal....."

Synonyms for unbiased

■ disinterested, dispassionate,
equitable, fair, fair-minded,
impartial, indifferent, just,
nonpartisan, objective, square,
unprejudiced, impartial, neuter,
neutral, nonaligned, nonpartisan,
uncommitted, uninvolved,
unprejudiced.



Idioms expressing “unbiased”

“Fair and square”

“On the fence”

Indicators of bias

- ⑩ The argument appeals more to the emotions than to logic.
- ⑩ Wording used is intended to oversimplify or over generalize.
- ⑩ The speaker wishes to present a limited view of the topic.
- ⑩ Alternate views presented with scorn
- ⑩ The language is often extreme; statements have all or nothing connotations.

Lora K. Kaisler and Dennis O'Connor (<http://21cif.com/tutorials/micro/mm/bias/>)

Opinion

- **1.**a belief or judgment that rests on grounds insufficient to produce complete certainty.
- 2.**a personal view, attitude, or appraisal.
- 3.**the formal expression of a professional judgment: *to ask for a second medical opinion.*

opinion. (n.d.). Dictionary.com Unabridged (v 1.1). Retrieved February 20, 2009, from Dictionary.com website: <http://dictionary.reference.com/browse/opinion>

Professional opinion:

■ **A belief held by an individual based on his or her experience“with” no intent to mislead but rather to share knowledge formed from personal experience.**

Cornish JK, Leist JC. *Journal of Continuing Education in the Health Professions*. 2006; 26:161-7.

When does the shift from professional/personal opinion to bias occur?

“When we go from appropriately sharing the benefit of our experience/knowledge to intentionally manipulating a family”

(Leanne Seaver - Hands & Voices)

OR

When we act as “gatekeepers” of information

Parent Survey - 99 participants

- Sample set of parents include:
- Parents across the US connected to various parent organizations, internet access, primarily English speaking
- This group, most likely, represents fairly well-informed parents who play an active role in their child's education and communication choices.

Parent Survey Results

- Identified at birth or before 6 months of age - 47.5%
- 13 months to 35 months - 32.3%
- 66.7% of children are now 5 years or older
- 43.4% identified through newborn screening*
- 32-38% various professionals referred for testing*
- 27.3% parent requested testing*

* (does not = 100%, more than one answer allowed)

Parent Survey Results

- Majority have bilateral hearing loss
90.9%
- 46-51% have profound loss in at least one ear
- 7.1% have an auditory processing disorder

Parent Survey Results

50/50 believed they received complete and balanced information about all communication options and educational programs from professionals

Parent Survey Results

Did professionals suggest that you talk with different kinds of professionals to learn more about all communication options or educational programs?

37.4% Yes

62.6% No

Parent Survey Results

When you were learning about your child's communication options and educational choices, was it easy to learn about all the different choices?

Communication

Yes	44.5%	No	55.5%
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Educational

Yes	38.5%	No	61.5%
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Parent Comments

- “We had to search out options and do our own research. Professionals told us we had to ask before they could offer info. They can't be viewed as bias.”
- “every professional I spoke with encouraged me to NOT pursue other programs/methods/treatments”
- “when the medical Dr. did the brainstem test, he said we should institutionalize.”
- “deaf culture area here, not a lot of info provided to us about oral education”
- “was not given any information about options. It was presumed that he would be mainstream and oral only.”

Parent Survey Results

Do you feel like you have to pick one communication or educational option and stick with it or do you feel you have the flexibility to try different options and can change your mind if you feel something might work better?

One option only - 22%

Flexibility to try multiple options - 78%

Parent comments

- “I am a firm believer in exploration and doing what works for the child. I also believe that it is natural to try multiple approaches to communicate and then by nature we use what works the best the most often.”
- “No one knows what will work til you try it! If you don't try it--you wont know what works!”
- “We TOOK the flexibility, even though it was not necessarily supported by the.... providers we worked with. I do know some families who are limited to only one provider in their IFSP; we were lucky that choice was not forced on us.”
- “While I feel you must be consistent - I do feel you can and should introduce many communication options, be it English, Spanish, Signing to your child.”

Parent Survey Results

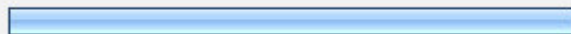


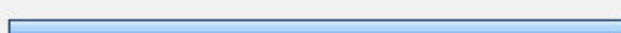
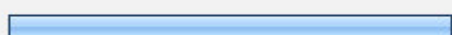
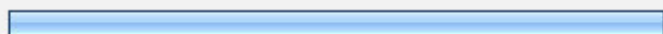
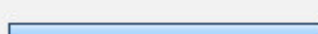
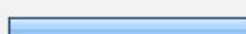
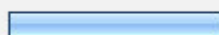
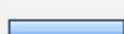

- How did you first become aware that there are many different opinions and controversy about communication choices and educational options for children with hearing loss? (check all that apply)

Professionals explained this to me	37
Another parent explained this to me	18
I learned on my own through books, articles, video, movies	39
I learned on my own because I was criticized by others about our choices	18
I am not aware of any controversy	10
Other - please explain below (DHH Community, already knew..)	20

Parent comments

- “We were bombarded at church, work, and in the community by all kinds of people who had wildly differing opinions within weeks of her diagnosis.”
- “knew there was some controversy, but didn't realize how bad it can be until I experienced it for myself. The experiences I've had have been very destructive. Since leaving....., we have not done anything with the Deaf Community because of the way we were treated by them.”
- “I can't remember which came first -- probably professionals explained it first, but soon after that I came in contact with the poster child for AV parenting. A very unpleasant woman.”

16. What was the most helpful way in which you received information? Check all that apply.

		Response Percent	Response Count
Written materials		69.7%	69
Videos or Movies		38.4%	38
Websites		67.7%	67
Face to face interaction with professional		75.8%	75
Visiting various educational programs in person		54.5%	54
Discussion with other parents (face to face, by phone, parent listserv, email)		80.8%	80
Repeated exposure to the same information		38.4%	38
All materials/topics presented at once (ex. parent handbook)		29.3%	29
Materials/topics presented a little bit at a time		26.3%	26
Other - please explain below		14.1%	14
Add more detail about your choices or explain "other" 			30

Parent comments

- “Our first experiences were very biased, later on we met educated and passionate professionals who not only shared a variety of materials, information, and resources but they provided the interaction and unbiased support we needed to be successful in whatever choice we made. Wow, what a difference they made!”
- “Talking w/ other parents in the same situations, and with adults who are hard-of-hearing to help us understand what's out there, what it's like, etc.”
- “Meeting with adults and children to hear them talk about the experience of being deaf, was a life-changing moment for me. There isn't time to tell you all the things I learned, but it was amazing, emotional, and informative. There were people on the panel who used only signing, some with hearing aids, and some with late CIs and some with early CIs. It was super important, and I would recommend it for every single parent out there.....”

Parent Survey Results

What was the most helpful information/referral/advice you received from a professional and why?



Parent Comments - Best advice

“Best-early intervention folks who told us that no 2 cases of hearing loss are exactly the same and that while some approaches to language and how you communicate and how others communicate with your child are similar, there are differences. Your child's approach to communication is ultimately YOUR decision-YOU have to do what's best for YOUR child and they will support you and guide you to the best resources in your area to assist. No one can make you choose one form over another or force you to limit yourself to one type of communication style.”

Parent Comments - Best advice

“speech therapist told us to check out all options before making a decision”

“deaf teacher: you can always change your mind!!!!”

“The DHH Early Childhood teacher told me, "It's really important for you to ask questions of anyone that works with your child. Ask them: How, Why, What, When, Where, and Who. If people working with your daughter can't answer those questions, you should bring it to their attention, and say that you'd like them to find the answer." It didn't take long before I knew that I knew a lot more about Deaf people than they did. This relieved my anxiety about the fact that they all have masters degrees and I did not.”

Parent Survey Results

What was the worst advice or information you received from a professional and why?

Parent Comments - Worst Advice

“Audiologist at the Otologist's office: "With hearing aids, he can hear as well as you and I can. There's nothing you need to worry about, just keep him wearing the aids.”

“A principal, in an IEP meeting, told me my child was damaged and that any hearing impaired person who uses ASL would never succeed.”

“EI - he'll grow out of it, you worry too much. “

“if you sign to your child, she will never to learn to speak”

“taking away supports in school will force your son to rely more on his own hearing (but he lacks that hearing!! that's why he has had an interpreter all these years) -- from a speech therapist at middle school”

“An ASL early intervention specialist (know-it-all type) looked at our daughter and told us just after 2 visits that she would never be ready for a regular educational setting by Kindergarten - that she would need special classes at least until 3rd. grade. She was completely wrong. Her comments were offensive and frightening. “

Parent Comments - Worst Advice

“I have encountered professionals in both the "oral world" and the "D"eaf world that are certainly biased. ie "deaf schools aren't as good academically", "he will not be accepted into the deaf community", from the oral side to "get rid of the hearing aids" from the Deaf side.”

Parent Survey Results

Do you feel you are in control or professionals are in control when decisions are made about communication and education choices for your child?

Parent in control 91%

Professional in control 9%

“Parents in Control” comments

- “My child is now in college but we were in control of the decisions made for the education of our child. we knew our rights and were able to stick to them to get the best possible education for our child”
- “Ultimately the parent has the final say in their child’s education, even if it leaves the professional unhappy with the parent”
- “Ultimately, I am the one who carries out the decisions at home for my small child. Now that she is older, she definitely has a voice in those decisions, and we look to professionals for information but not the last voice.”

Parent Survey Results

Are you happy with the decisions you made for your child and family?

Yes 92.2%

No 1.1%

Don't Know 6.7%

“Professionals in Control” Comments

- “They make the decisions and then tell us what they are”
- “We were not educated on how to make decisions for our daughter, this has since changed.”

Parent Survey Results

Are you happy with the decisions the professionals made for your child and family?

Yes 7.7%

No 30.8%

Don't Know 61.5%

Summary of challenges:

Over 50% of children still not being identified before 6 months

Only 50% of parents feel they are receiving complete and balanced information

Professionals refer only 37% of the time.

55-61% of parents did not think it was easy to learn about options. * Does not mean they were not told - but it implies the info was not in an “understandable format” (JCIH 07)

Summary - Good News:

78% of parents feel like they have/had flexibility to explore options

91% feel like they are in control of the decisions being made for their child

Conclusions

Challenges remain - (JCIH 2007)

“There is a failure to communicate information to families in a culturally sensitive and understandable format”



Don't limit information to parents! Just make sure it is understandable.



What contributes to parents not understanding information?
Conflicting **biased** information from professionals, D/HH community members and other parents

Conclusions

- Parents need and want information - we can debate about “how much is too much or too soon” and fret over whether they are understanding the information that they are given, but ultimately they have the right to the information and the responsibility to make decisions for their child.



Finally.....

Thank you for your passion
and your dedication
to helping all our children
be successful!