HOW WE TALK AS PROFESSIONALS: REFRAMING THE DISCUSSION

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WHAT THIS TALK IS NOT

- This is not….
  - An expert discussion on Deaf culture
  - A scare tactic by the P.C. Police
  - An indictment of the medical approach
  - Some stranger coming in here telling you how to do your job

WHAT THIS TALK IS

- A frank discussion about the **way** we as predominantly hearing professionals approach and talk **about** and **with** individuals who are deaf/hard of hearing and their families

LEARNING OBJECTIVES

- Identify important differences between some core concepts between communities that may impact interactions with each other
- Explore a concept of being deaf or hard of hearing beyond the singular perspective of the medical pathology model
- Acknowledge the critical importance of the medical professional's role in valuing the family perspective in cultural context, and support informed decision making for children identified as deaf or hard of hearing

COMMUNITIES

COMMUNITIES

- Medical Community:
  - 1) Identify problem based on experience and fund of knowledge
  - 2) Fix the problem

- Deaf Community:
  - 1) Being Deaf is an important part of the makeup of the whole person, and many goals are similar to others but attained through a visual pathway
  - 2) There is nothing that is in need of fixing

COMMUNITIES

- Parents of children recently identified as deaf/hoh
- Highly variable characteristics
  - Shock, grief, denial
  - Advocacy
  - Independence empowerment / "vulnerable child" syndrome
  - Public / private
  - **Intersection**

MOVING BEYOND A SINGULAR PATHOLOGIC VIEW: **TERMINOLOGY**

- Terms like "loss" and "impaired" convey a lack of function that simply may not exist to individuals, their families, and the community(ies) at large
- Use of terminology in specific environments (work colleagues, casual/intimate conversation, etc) may unintentionally "bleed" into other areas of engagement

MOVING BEYOND A SINGULAR PATHOLOGIC VIEW: **INDIVIDUALS**

- Individuals:
  - Zach Ruhl
  - Born with congenital absence of femurs – LE amputation as toddler
  - Co-owner and coach at Crossfit Uncontested, Houston TX

https://www.youtube.com/watch?v=ncKydmfxtEI&feature=youtu.be


GETRXD

MOVING BEYOND A SINGULAR PATHOLOGIC VIEW: **INDIVIDUALS**

- Individuals:
  - Chris Moreland, MD
  - UTHSCSA Internal Medicine residency associate program director
  - Identified as deaf at age 2 years

MOVING BEYOND A SINGULAR PATHOLOGIC VIEW: **INDIVIDUALS**

- "Dr. Moreland has brought a lot of positive energy to the group—and in ways I would not have expected. On a subtle level, having Chris in the group has made us more aware of how we interact with each other."

- -Luci K. Leykum, MD, MBA, MSc, hospital medicine division chief and associate dean for clinical affairs at UTHSCSA

MOVING BEYOND A SINGULAR PATHOLOGIC VIEW: **LANGUAGE**

- Language choice often presented as single modal
- Reasons for focusing solely on pathology model may be impacted by lack of knowledge + comfort with familiarity
- There is often a perceived **lack of equivalence** between spoken/spoken bilingualism and spoken/visual bilingualism

Numbers of Spoken English and Sign Language (ASL) Words

- The Second Edition of the 20-volume *Oxford English Dictionary* contains full entries for **171,476 words** in current use.
- Random House Webster's Unabridged Sign Language Dictionary (2008) by Elaine Costello, Ph.D. identifies **5,600 up-to-date signs** with full torso illustrations.

“There’s only one sign for “boat” =

Evaluating high context language (ASL) with low context measurement (individual word count).

THE NEED FOR PARENT ORGANIZATIONS/INVOLVEMENT

Texas Parent to Parent

THE NEED FOR DEAF ROLE MODELS

THE NEED FOR IDENTITY DEVELOPMENT SUPPORT

- The “vulnerable” child
- The anxiety of missed information

TOREY MACPHERSON ON DEAF ANXIETY

Torey MacPherson is in Hawthorne, California.
October 25, 2018

TOREY MACPHERSON ON DEAF ANXIETY

- "I learned to compensate for my deafness in a hearing world, to make hearing people around me more comfortable with my deafness. I always said "sorry, I'm deaf," knowing that I shouldn't have to apologize for my deafness…"
- "I learned how to mirror hearing people's facial expressions so well that it appears I actually understand what they're saying…With groups of hearing people, I laugh when they laugh, nod when they nod, and hope to god they don't ask me a question, because even if I did ask them to repeat something, my voice was ignored 2 minutes later when everyone started talking on top of each other again."
- "When I'm alone, I'm always looking over my shoulder, thinking someone might be calling my name or trying to get my attention. I never want to appear rude or like I'm ignoring anyone."

TOREY MACPHERSON ON DEAF ANXIETY

- "A lot of people assume I'm not "that" deaf, or that I'm hard-of-hearing, because I can speak well (I'm profoundly deaf…)"
- "When I was in medical school, I would try so hard to make it look like I was on the same playing field as everyone else. In reality, it would take me 5 hours to get through a 1-hour lecture, having to listen to some parts several times to understand what the professor said, give up, then try to find it in last year's notes because this year's wasn't uploaded yet. God forbid the professor had an accent…"
- "I was so stressed, exhausted and miserable by the end of the day. But I wouldn't tell anyone. I didn't want it to look like I was making excuses. I'm fine, I'm great, I always said to everyone, except a few, as I kept on drowning."

THE NEED FOR IDENTITY DEVELOPMENT SUPPORT

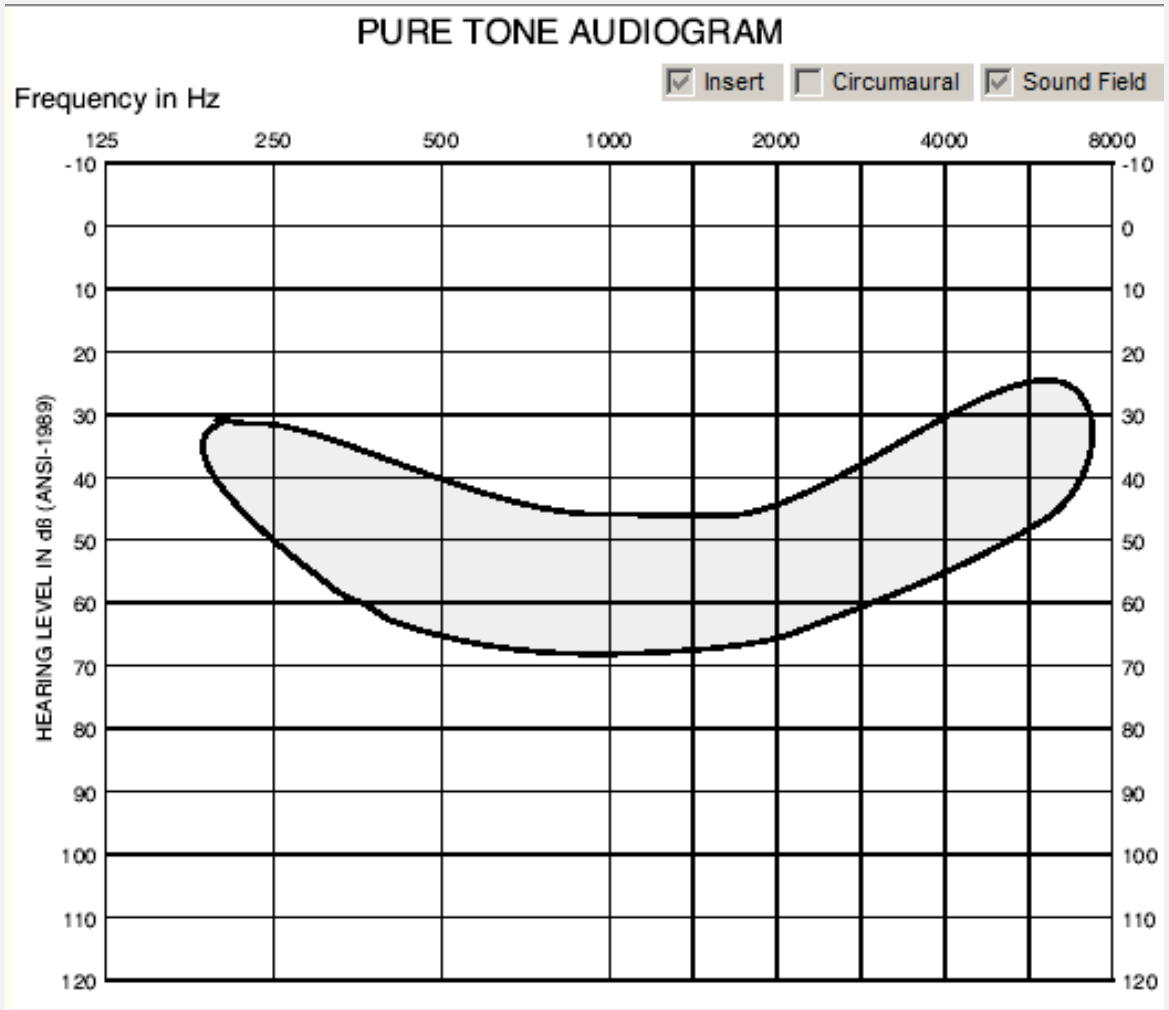
- The “vulnerable” child
- The anxiety of missed information
- The child “made hearing”

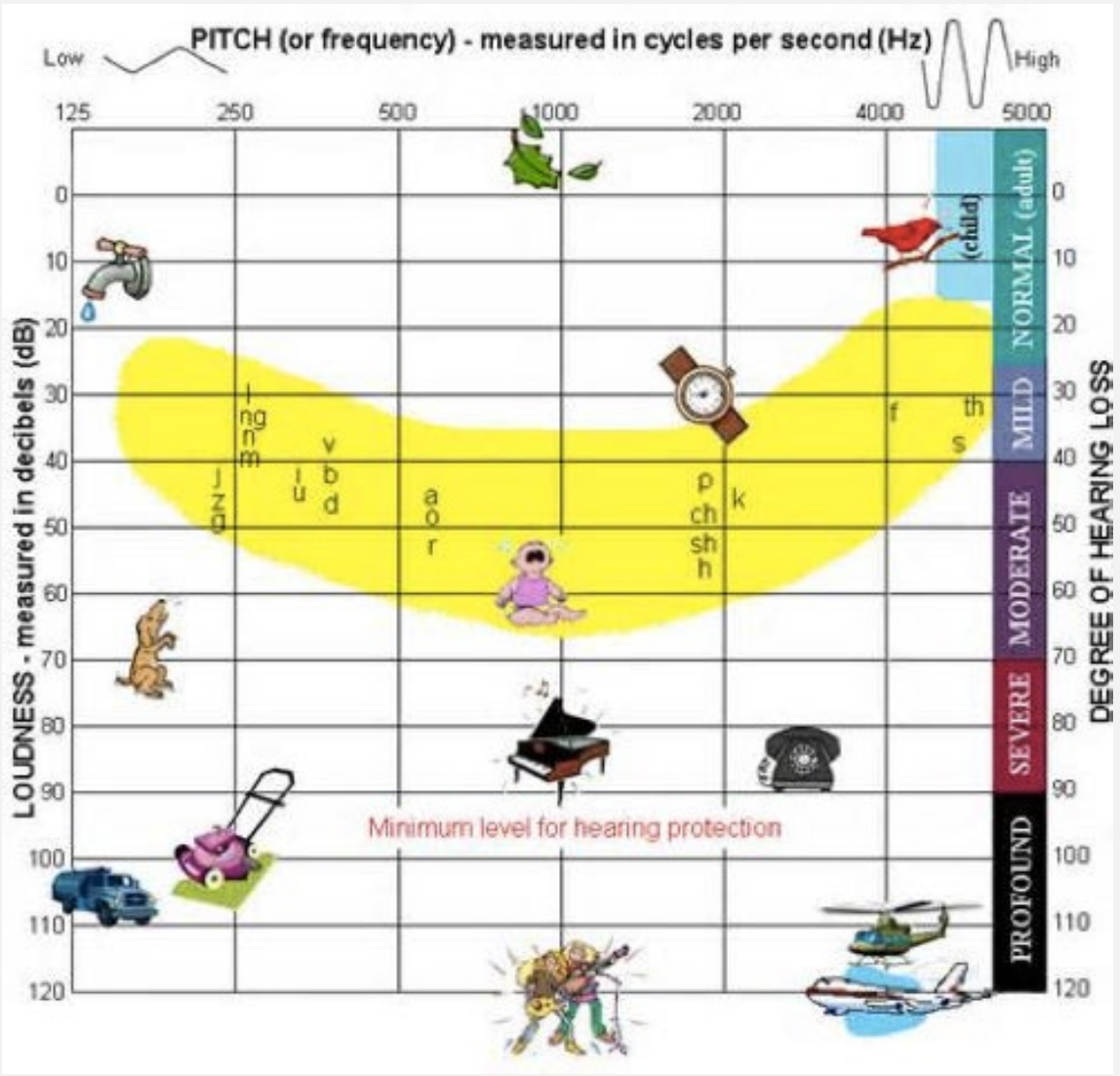
THINGS THAT HAVE WORKED FOR ME

- AGRESSIVELY referring to early childhood intervention, and empowering others in parallel fields to do so as well
- Acknowledging enormous volume of information parents are digesting, as well as LOGISTICALLY how overwhelming that can be (number of professionals, number of appointments, etc)
- Initially using person-first descriptive language ("child with changes in his/her hearing") and then moving into a family-centered paradigm

THINGS THAT HAVE WORKED FOR ME

- Focusing on individual child strengths and maximizing opportunities for learning
- Connecting families with other families and deaf organizations (HV, P2P, genetics support groups, etc) and acknowledging that as professionals we do NOT necessarily occupy that parental role
- VISUAL AUDIOGRAM


PURE TONE AUDIOGRAM
Frequency in Hz
Insert
Circumaural
Sound Field
125
250
500
1000
2000
4000
8000
HEARING LEVEL IN dB (ANSI-1989)
-10
0
10
20
30
40
50
60
70
80
90
100
110
120


PITCH (or frequency) - measured in cycles per second (Hz)
Low
High
125
250
500
1000
2000
4000
8000
LOUDNESS - measured in decibels (dB)
DEGREE OF HEARING LOSS
NORMAL (adult)
(child)
MILD
MODERATE
SEVERE
PROFOUND
Minimum level for hearing protection
ng
n
m
j
z
g
l
u
v
b
d
a
o
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p
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th
s

PARTING THOUGHT

"Poor communication can discourage and alienate families so quickly, but great communication can be such a stabilizing force in a very uncertain time."

-FFC Parent

THANK YOU!

Family-Focused Center for Deaf and Hard of Hearing Children

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