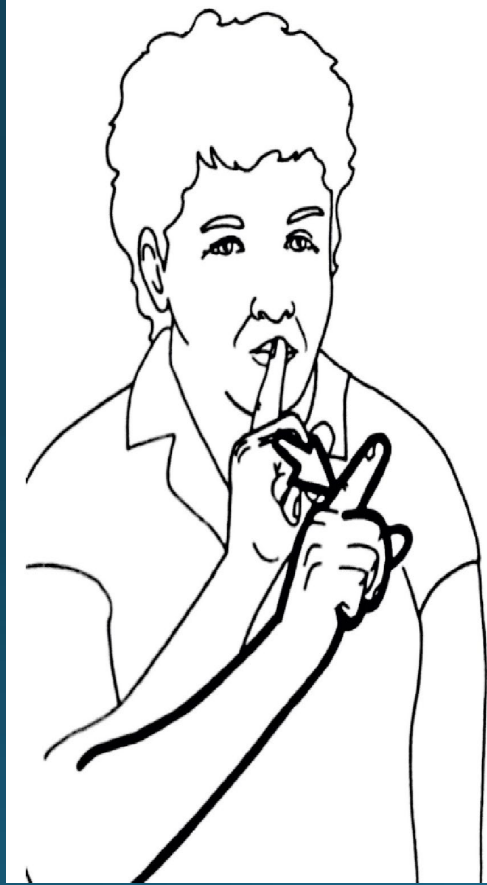


ACHIEVING DEAF HEALTH EQUITY: BEST PRACTICES

James Huang MD FAAFP
Director of Student Health
Service
Gallaudet University

Let's talk about truths and myths!



TRUE



FALSE

All people with hearing loss
can read lips



Deaf people are allowed to
drive in the US



Deaf people cannot use a
telephone



It is okay to use the term hearing
impaired



Deaf people like music



Closed captioning for the Deaf community is adequate for accessibility



Sign language is universal

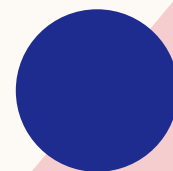


Deaf people are proud to be Deaf
and wouldn't change it if they
could



DISCLOSURE

None



OBJECTIVES

Describe

Describe the unique linguistic and cultural characteristics of the Deaf community



Identify

Identify factors contributing to health disparities within the Deaf community



Implement

Implement strategies to achieve Deaf health equity

IDENTITY: HEARING LOSS

deafness in older age

Spoken (English) is the primary language

Identify with hearing world/ethnicities

View deafness medically

IDENTITY: AMERICAN SIGN LANGUAGE (ASL)

Language that employs signs made by moving the hands combined with facial expressions and postures of the body

ASL has its own rules for pronunciation, word order, and complex grammar

Regional signs

Most countries have their own sign language (BSL, CSL, FSL)



IDENTITY: DEAF CULTURE

Deaf culture describes the social beliefs, behaviors, art, literary traditions, history, values, and shared institutions of communities that are affected by deafness and which use sign language as the main means of communication.

did you know?

Presentation title

The football huddle was first used at a college for the deaf in the 1890s so the players could keep their signing hidden from the opposing teams.



PHOTO: GALLAUDET UNIVERSITY ARCHIVES

DIDYOUKNOWBLOG.COM

"Diversity is a beautiful, absolutely wonderful thing, but I don't think they consider people with disabilities and deaf and hard of hearing people as part of the diversity mandate."

Marlee Matlin



I love being deaf.



ABLEISM

Disability justice activist and educator
Lydia X Z Brown:

1. The oppression, prejudice, stereotyping, or discrimination against disabled people on the basis of actual or presumed disability.
2. The belief that people are superior or inferior, have better quality of life, or have lives more valuable or worth living on the basis of actual or perceived disability.

Throughout his life, David constantly faced ableist biases. Seeing a diagnosis of “developmental disability,” medical teams would incorrectly assume he was nonverbal, incontinent, and unable to ambulate independently.

I once posted signs in his hospital room listing his favorite discussion topics, such as country music and recently released comedic movies, hoping that if we humanized him, his team would provide better care.

Morris MA. Death by Ableism. N Engl J Med. 2023 Jan 5;388(1):5-7. doi: 10.1056/NEJMp2212109. Epub 2022 Dec 31. PMID: 36592337.

ABLEISM

AUDISM

- Discrimination or prejudice that is based on a person's ability, or lack of ability, to hear

THAT DEAF GUY



Medical Model Understanding of Disability



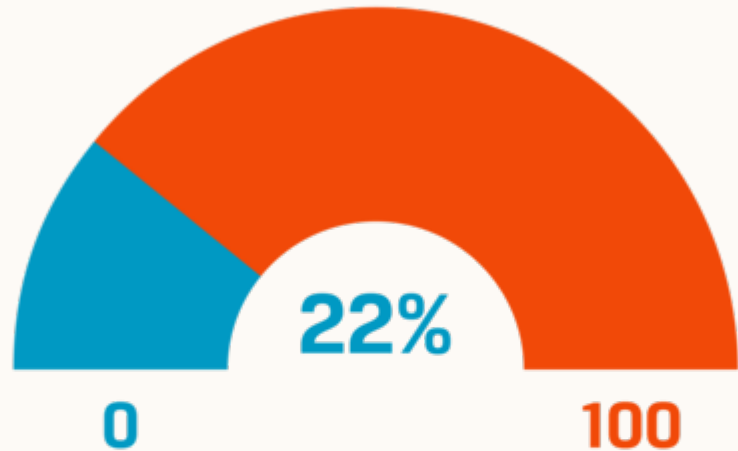
The problem is
the disabled person

IDENTITY: HOW IS DEAFNESS PERCEIVED?

Disability vs
Linguistic
minority

Medical model
vs cultural
model

IDENTITY: BORN DEAF IN A HEARING WORLD



Only 22% of hearing parents with deaf children learn sign language

- > 90% of deaf children are born to hearing parents (Mitchell, Karchmer 2004)
- Family's communication ability varies
- Fear that learning ASL will hinder English acquisition

IDENTITY: BORN DEAF IN A HEARING WORLD



Avoiding "Dinner Table Syndrome"

- Reduce background noise
- Ask your child questions about their day and things that interest them.
- Practice good turn-taking skills. Don't interrupt. Avoid "side bar" conversations.
- Use lots of body language, gestures, and facial expressions.
- Avoid phrases like "never mind" or "it's not important".
- Consider incorporating sign language into your family's communication system.

JOHN EAR CENTER
Hearing & Balance
Ear & Skull Base Surgery

- Limited accessibility to conversations
 - Family dinner syndrome
- Medical appointment
 - accessibility
 - Understanding
 - Agency
- knowledge of family medical history

IDENTITY: BORN DEAF IN A HEARING WORLD

language deprivation:
insufficient access to direct
child–caregiver
communication during the
critical period of language
development

communication neglect: is
used to indicate that a child
who is DHH always or often
feels ignored or excluded from
family conversations

Adverse Childhood Experiences

Traumatic events that can have negative, lasting effects on health and wellbeing

Abuse

- Emotional abuse
- Physical abuse
- Sexual abuse

Household Challenges

- Domestic violence
- Substance abuse
- Mental illness
- Parental separation / divorce
- Incarcerated parent

Neglect

- Emotional neglect
- Physical neglect

People with 6+ ACEs can die

20 yrs

earlier than those who have none



1/8 of the population have more than 4 ACEs



www.70-30.org.uk
@7030Campaign

4 or more ACEs

3x the levels of lung disease and adult smoking

11x the level of intravenous drug abuse

14x the number of suicide attempts

4x as likely to have begun intercourse by age 15

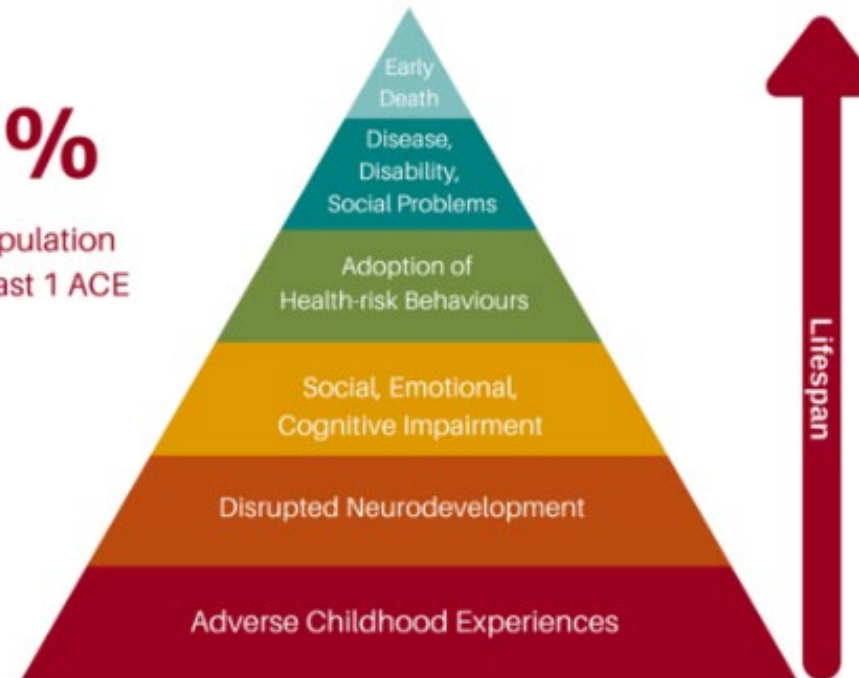
4.5x more likely to develop depression

2x the level of liver disease

“ Adverse childhood experiences are the single greatest unaddressed public health threat facing our nation today ”

Dr. Robert Block, the former President of the American Academy of Pediatrics

67%
of the population have at least 1 ACE



IDENTITY: BORN DEAF IN A HEARING WORLD

1,524 Deaf adults	Hearing parents (1,101, 72%)	DHH parents (417, 27%)
Spoken language	539, 49%	50, 12%
Sign language	341, 31%	42, 82%
Other modalities: gestures, written, cued speech	220, 20%	25, 6%

Kushalnagar P, Ryan C, Paludneviciene R, Spellun A, Gulati S. Adverse Childhood Communication Experiences Associated With an Increased Risk of Chronic Diseases in Adults Who Are Deaf. *Am J Prev Med.* 2020 Oct;59(4):548-554.

Table 2. RRR Estimates, ARI, NNH, for Each Medical Condition by PROMIS-Deaf Profile_ELCEs Domain

Medical condition	PROMIS-Deaf Profile_ELCEs					
	Direct child–caregiver communication			Indirect family communication/inclusion		
	RRR ^a (95% CI)	ARI (95% CI)	NNH (95% CI)	RRR ^a (95% CI)	ARI (95% CI)	NNH (95% CI)
Diabetes	1.12 (1.01, 1.24)	0.08 (0.06, 0.10)	13 (10, 17)	1.05 (0.95, 1.17)	0.04 (0.02, 0.06)	24 (16, 42)
Hypertension	1.10 (1.03, 1.17)	0.13 (0.10, 0.15)	8 (7, 10)	0.94 (0.88, 1.01)	0.04 (0.02, 0.06)	25 (16, 59)
Heart condition	1.61 (1.39, 1.87)	0.07 (0.05, 0.08)	15 (12, 20)	1.07 (0.92, 1.24)	0.02 (0.007, 0.04)	49 (29, 138)
Lung disease	1.04 (0.93, 1.16)	0.02 (0.001, 0.04)	52 (26, 797)	1.19 (1.07, 1.33)	0.04 (0.02, 0.06)	25 (17, 44)
Cancer	0.87 (0.75, 1.01)	0.02 (0.003, 0.03)	56 (29, 402)	1.11 (0.97, 1.26)	0.04 (0.02, 0.05)	26 (18, 44)
Arthritis	1.00 (0.92, 1.09)	0.09 (0.07, 0.11)	11 (9, 15)	0.99 (0.91, 1.08)	0.05 (0.03, 0.07)	19 (13, 30)
Depression	0.92 (0.84, 1.01)	0.05 (0.03, 0.07)	20 (14, 35)	1.34 (1.25, 1.44)	0.07 (0.05, 0.10)	13 (10, 19)
Anxiety disorder						

Note: Boldface indicates statistical significance ($p < 0.05$). Adequate access is the reference group.

^aAdjusted for age, sex, race, education, parent hearing status, and health status.

ARI, absolute risk increase; ELCE, Early Life Communication Experience; NNH, number needed to harm; PROMIS, Patient-Reported Outcomes Measurement Information System.

COMMUNICATION: ASL VS ENGLISH

Variable English literacy amongst Deaf high school graduates (Traxler 2000)

Knowledge of English medical terminology is similar to that of non-English-speaking immigrants to the United States (McEwen 1988)

Deaf participants were 6.9x significantly more likely than hearing participants to have inadequate health literacy (McKee et al, 2015)

Traxler, C. B. (2000). The Stanford Achievement Test, 9th edition: National norming and performance standards for deaf and hard-of-hearing students. *Journal of Deaf Studies and Deaf Education*, 5, 337–348.

McEwen E, Anton-Culver H. The medical communication of deaf patients. *J Fam Pract*. 1988 Mar;26(3):289-91.

McKee MM, Paasche-Orlow M, Winters PC, et al. Assessing Health Literacy in Deaf American Sign Language Users. *Journal of health communication*. 2015;20(02):92-100.



ASL Interpreter 3



Ms. Stacy Abrams



ASL Interpreter 1



Dr. James Huang



ASL Interpreter 2



Dr. Poorna Kushalnagar



Dr. Gigi El-Bayoumi

zoom

COMMUNICATION: DEAF ASL USERS



[doctors] have no idea how frustrating and dehumanizing it is for deaf and hard-of-hearing patients when they are forced to:



write back and forth about their stroke symptoms



lip-read the doctor who is about to perform surgery on them



be told by their family member (and not the doctor) that they had a heart attack and will be undergoing a cardiac catheterization and possible stent placement”

COMMUNICATION: DEAF ASL USERS

Lip readers at best can understand 30-45% of spoken English (Iezzoni et al 2004)

accents can make it more difficult to read lips

facial hair can obscure

In situations where the Deaf person is familiar with the speaker or the conversation is easily predictable comprehension goes up to 60%



COMMUNICATION: DEAF ASL USERS

1

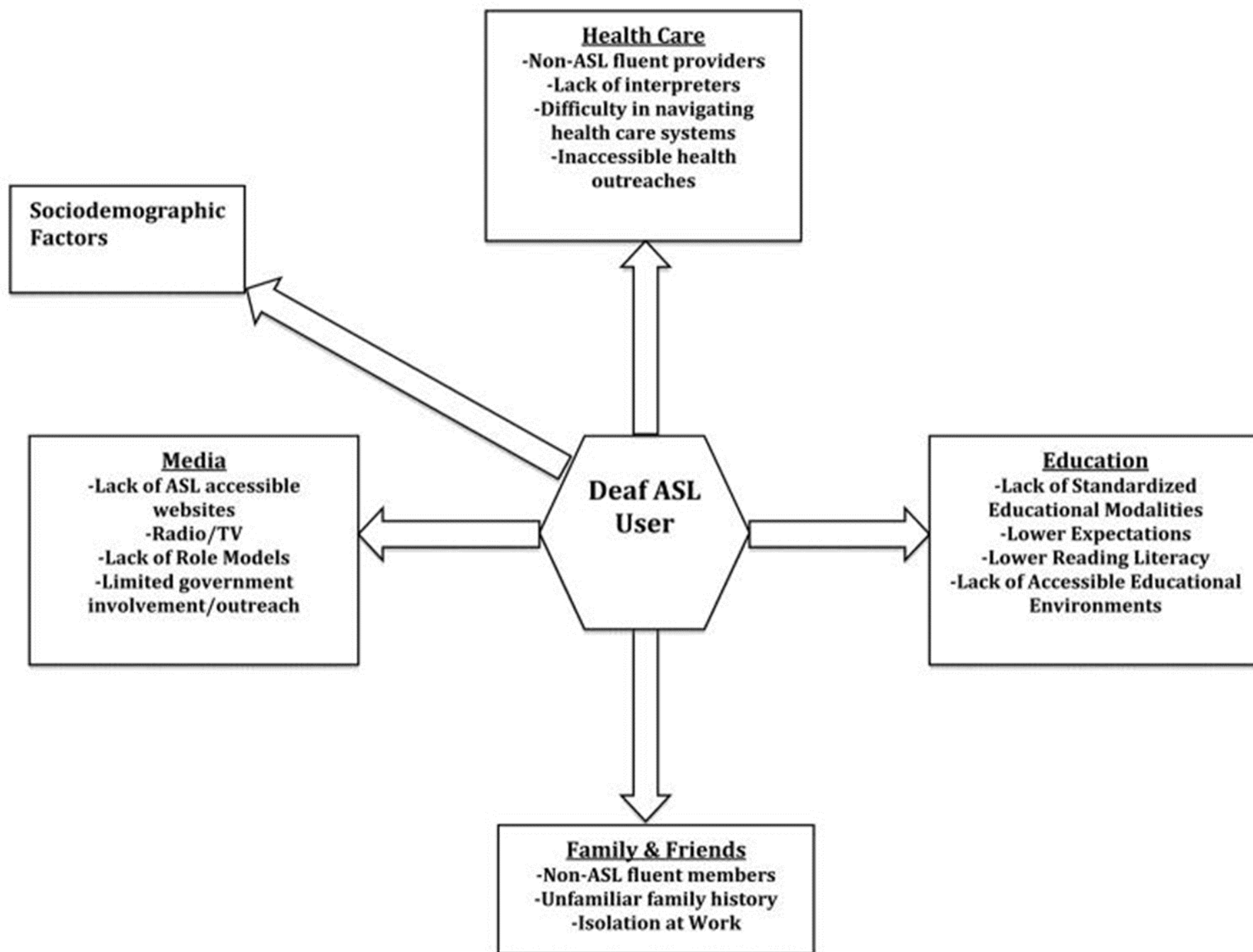
Untrained professionals can misread social and cultural differences in deaf patients

2

Mental health symptoms are present but misattributed to deafness and ignored

3

Normative Deaf behavior is interpreted as a mental health symptom (overpathologizing)



DEAF HEALTH DISPARITIES

- Fewer doctor visits in the preceding year (Barnett, 2002)
- Decreased preventive health care services (McKee et al, 2011)
- Deaf Health Survey (Barnett et al, 2011)
 - more likely to be obese (34 % vs 26 % in the general population)
 - 5x more likely to report attempting suicide in the past year
 - Rates of partner violence and forcible sex were higher

Barnett S, Franks P. Health Care Utilization and Adults Who Are Deaf: Relationship with Age at Onset of Deafness. *Health Services Research*. 2002;37(1):103-118.

McKee MM, Barnett SL, Block RC, Pearson TA. Impact of Communication on Preventive Services Among Deaf American Sign Language Users. *American journal of preventive medicine*. 2011;41(1):75-79.

Barnett S, Klein JD, Pollard RQ, et al. Community Participatory Research With Deaf Sign Language Users to Identify Health Inequities. *American Journal of Public Health*. 2011;101(12):2235-2238.

EQUALITY:

Everyone gets the same – regardless if it's needed or right for them.



EQUITY:

Everyone gets what they need – understanding the barriers, circumstances, and conditions.



ADA – AMERICAN WITH DA ACT

requires public and commercial entities – including doctor’s offices and hospitals – to provide equal access and “**effective communication**” to those who have vision, speech or hearing loss.

Applies to other individuals who may not be “patients” of health care provider (i.e., deaf parent of hearing child, deaf husband with sick wife).

BEST PRACTICES: COMMUNICATION

Knowledge of Deaf culture

Fluency in sign language or access to interpreting services

Ability to be expressive in non-verbal behavior and facial expressions

Respectful and curious attitude, open-mindedness to cultural differences

COCHLEAR IMPLANTS

- use electrical stimulation to provide hearing
 - moderate to severe bilateral sensorineural hearing loss
-
- Varied outcomes: noisy vs quiet environments
 - Limits of the cochlear implant
 - CIs positively help social, but they do not guarantee age-appropriate socialization experiences with hearing peers (Christiansen & Leigh, 2005)
 - Bilingual approach (Paludneviciene & Leigh, 2011)



THE BRIGHT & DARK SIDES OF MY COCHLEAR IMPLANT

@adventuresindeafed

 BLUETOOTH TECHNOLOGY

 THE BITTER PATTERN OF MY DOGS' FEET

 MUSIC

 NO MORE RUNNING OR DRIPPING WATER

MIGRAINES & HEADACHES



SPORADIC BUILD UP OF PRESSURE AROUND THE IMPLANT SITE



LISTENING FATIGUE



HEARING DOES NOT EQUAL UNDERSTANDING

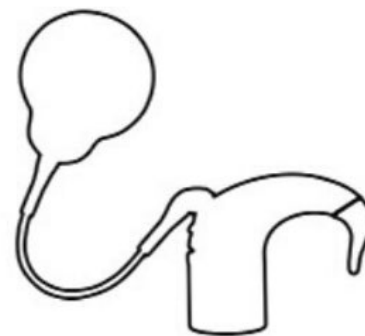


REMINDER

@ADVENTURESINDEAFED


THIS IS NOT A CURE FOR DEAFNESS...

(IT IS SIMPLY A TOOL.)



COCHLEAR IMPLANT

BEST PRACTICES: COMMUNICATION

Type of sign
language

Oral Interpreter

Cued Speech
Interpreter

Tactile
Interpreter
(Deaf/Blind)

Certified Deaf
Interpreter
(CDI)

BEST PRACTICES: COMMUNICATION ⁴¹



- Maintain eye contact with the Deaf person and not with the interpreter
- Address the Deaf person directly
- Avoid phrases such as “ask her this...”, or “tell him to...” Talk to the Deaf person through the interpreter.
- Be prepared to pause while you are speaking

BEST PRACTICES: COMMUNICATION

- Allow a brief silent time for reading if you hand out written material. Wait until the Deaf person looks up before you start to speak again.
- The interpreter is bound by a Code of Professional Conduct which means the interpreter will interpret everything that is either signed or spoken in the room (i.e. phone calls, private conversations, environmental sounds, etc.) Everything communicated in the room will be kept confidential.



COMMUNICATION: VRI

- Intermittent internet connection
- Screens are not appropriate size
- Deaf patients who have cognitive, psychiatric or linguistic difficulties
- in certain physical positions
- under the influence of medication or who are tired
- Deaf patients using regional sign language dialects, which require the use of a local interpreter;
- Equipment or technical difficulties
- Insufficient training of hospital or clinic staff



Characteristics	Satisfied with VRI ^a service quality (n=228)	Not satisfied with VRI service quality (n=327)	Chi-square value
Age (years), mean (SD)	46 (19)	44 (17)	0.8 ^{b,c}
Gender, n (%)			5.0 ^c
Male	114 (50.2)	129 (40.6)	
Female	113 (49.8)	189 (59.4)	

COMMUNICATION: VIDEO RELAY INTERPRETING



Photo used courtesy Sorenson Communications

BEST PRACTICES: SYSTEM

EMR alerts for preferred method of communication – i.e ASL interpreter

Advocate for in-person ASL interpreters

How does your clinic / hospital arrange interpreters?

Educate Deaf patients on their rights

Additional aids: visual alert systems in hospitals/clinics, non-auditory cues

VRI should not be the sole option

- ▲ Global Alerts
- Arrange Sign Language Interpreter

BEST PRACTICES: SYSTEM

- Develop appropriate literacy educational materials for deaf patients:
 - captioned videos
 - ASL-interpreted videos
 - Translate written materials into ASL



M | MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

Depression Screening Quiz

This free 9-question screening quiz is for informational purposes only and is not intended to replace a consultation with a doctor. Please consult your doctor if you believe you may have depression/anxiety. If you are in crisis or think you may hurt yourself or someone else, please seek help immediately. Call 911 or your doctor's office immediately.

To begin, please watch this short introduction for more information about the depression screening quiz:



Watch on  YouTube

BEST PRACTICES

Deaf ASL users who had access to full-time interpreter services were more likely to report receiving preventive services than a comparison group of deaf ASL users who sought care elsewhere (MacKinney 1995)

BEST PRACTICES: WORKFORCE DEVELOPMENT

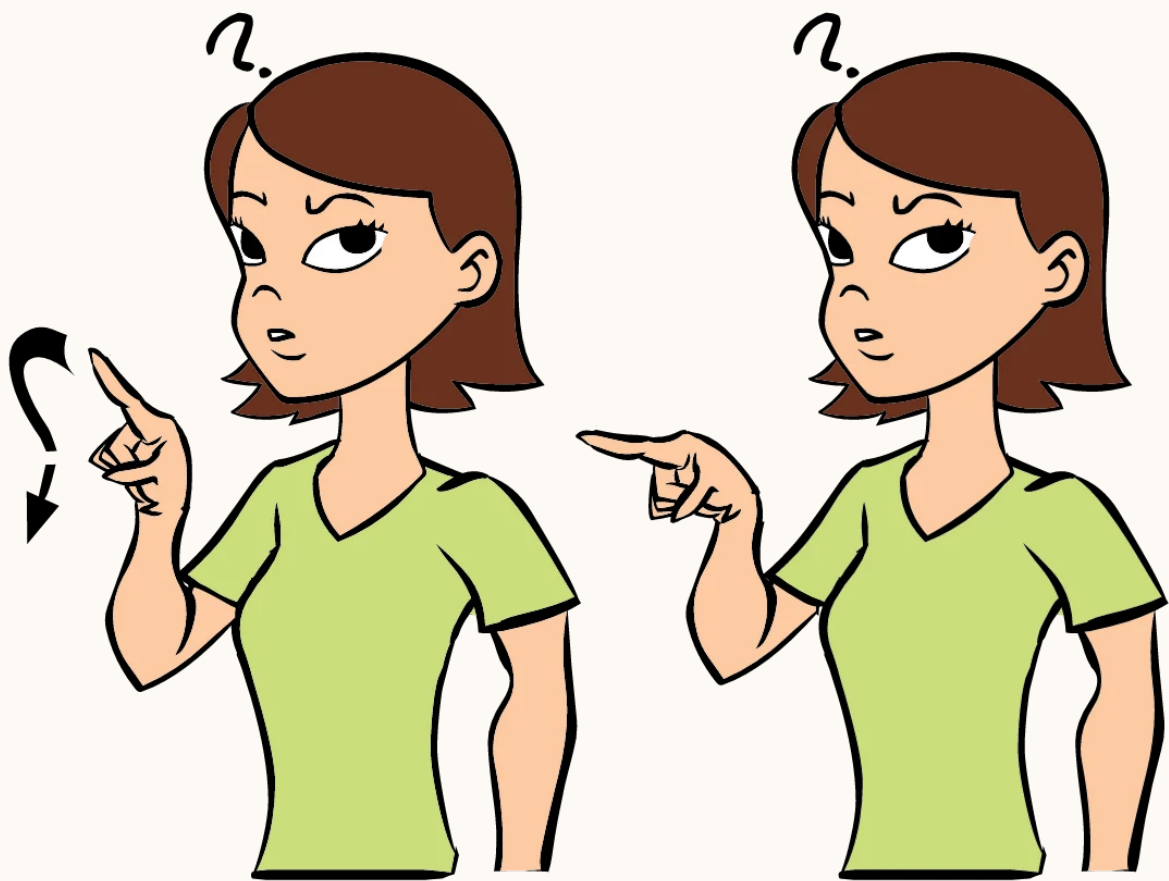
Early exposure and training in health care programs

- lectures
- Standardized patients
- Deaf pathways elective

Increase Deaf healthcare workers

- American Medical Professionals with Hearing Loss: <https://amphl.org/>
- Stanford Medicine Alliance for Disability Inclusion and Equity (SMADIE)
- Docs with Disabilities





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