

Addressing Barriers in Health Literacy Within the Deaf Community

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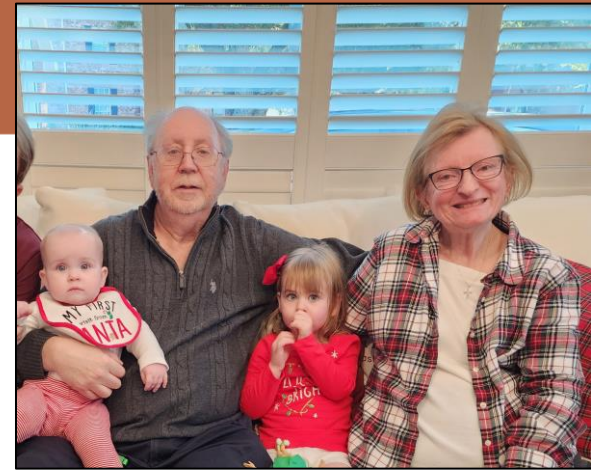
Learning Objectives

- Identify aspects of Deaf culture that impact health literacy
- Identify communication/language barriers that hinder health literacy among the Deaf
- Name at least one communication method or technique that can be used to improve communication with Deaf people/patients



My Story

- I am a CODA – Child of Deaf Adults
- Mother – born Deaf to hearing parents
- Father – born hearing to Deaf parents, moderate-severe hearing loss due to measles at age 2, uses hearing aid
- Mixed education – hearing public schools (no accommodations) and private Deaf schools (oral school)
 - No sign language in their Deaf schools, focus was on speech
 - Sign language learned from Deaf peers/family



ASL



Defining 'Deaf'

- Deaf – individuals who self-identify with Deaf culture, have severe to profound hearing loss (congenital or acquired)
- Deaf community (DC) – distinct cultural and linguistic minority group that uses American Sign Language (ASL) to communicate
- Identity is fluid and can change over time or with setting
- Deaf people do not view deafness as a disease or a disability, only as a difference

‘Deaf’ versus ‘deafness’



- Hard of Hearing (HH) – hearing loss varies (mild-severe)
 - Some wear hearing aids or cochlear implant(s)
- These devices do not restore hearing to “normal” nor enable deaf people to hear at “normal” hearing levels
- Some can use a telephone or recognize music; others can only pick up environmental sounds
- Not all HH individuals self-identify as being part of the DC
 - Adults with age-related hearing loss

Deaf Population



- Statistics concerning the number of people who identify as members of the DC, are not well captured (Morisod et al., 2022)
- “Across all age groups, in the United States, approximately 1,000,000 people (fewer than 1 in 20 Americans) over 5 years of age are “functionally deaf;” more than half are over 65 years of age.” (Mitchell, 2005)
- More than 90 percent of deaf children are born to hearing parents (Quick Statistics About Hearing, 2021)

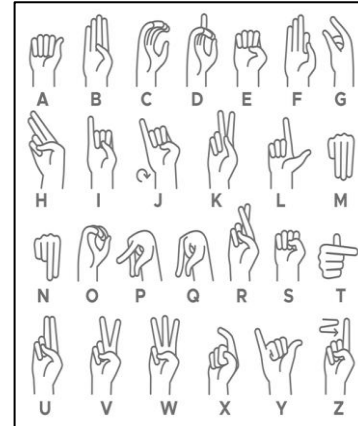
American Sign Language (ASL)



- American School for the Deaf – established 1817 in Hartford, Connecticut
- ASL is the native and preferred language, all other languages including English are viewed as a second language (Pollard et al., 2009)
- Visual language – shape, placement, and movement of the hands; facial expressions and body movements
- Majority learn ASL, health information, and even culture via peers rather than family

American Sign Language (ASL)

- Separate and distinct language from English, unique rules of grammar and syntax
- Not universal, different sign languages are used in other countries
 - ASL – one hand alphabet
 - BSL – two hand alphabet
- Regional variations based on where you live in the US



American Sign
Language (ASL)



British Sign
Language (BSL)

Deaf Education & Literacy Level

- Educational background is diverse
 - 49 residential & day schools for the Deaf
- 2017 American Community Survey
 - 83.7% Deaf adults completed *high school*, 18.8% completed a *bachelor's degree* or more
 - 89.4% hearing adults completed *high school*, 34% completed a *bachelor's degree* or more (Garberoglio et al., 2019, Figure 1)
- The average Deaf ASL user reads English at or below a 6th grade level (McKee et al., 2015)



Limited English Proficiency (LEP)



- ASL is a visual language, does not have a written form
- Deaf & Hard of Hearing (DHH) individuals may lack proficiency in written English
- Majority of DHH grow up in a hearing family and often experience 'dinner table syndrome'
- The loss of incidental learning opportunities and information marginalization occurs daily regardless of work, schools, friends, families, government, media, and health care situations

Health Inequities & Health Literacy

- DHH individuals are significantly more likely to be publicly insured, unemployed, less educated and have lower family incomes
- According to the Institute of Medicine (IOM, 2011), Health Literacy: A Prescription to End Confusion, each of these factors are independently associated with inadequate health literacy

Health Inequities & Health Literacy

- Multitude of barriers in accessing and receiving high-quality healthcare and achieving optimal health outcomes
- Health literacy barriers and lack of appropriate communication results in ineffective communication and understanding
- Lack of access to ASL interpreters, lack of awareness and training in culturally appropriate communication with Deaf people among healthcare professionals

Low health literacy status is driven by a host of factors centering around ***communication and language barriers***

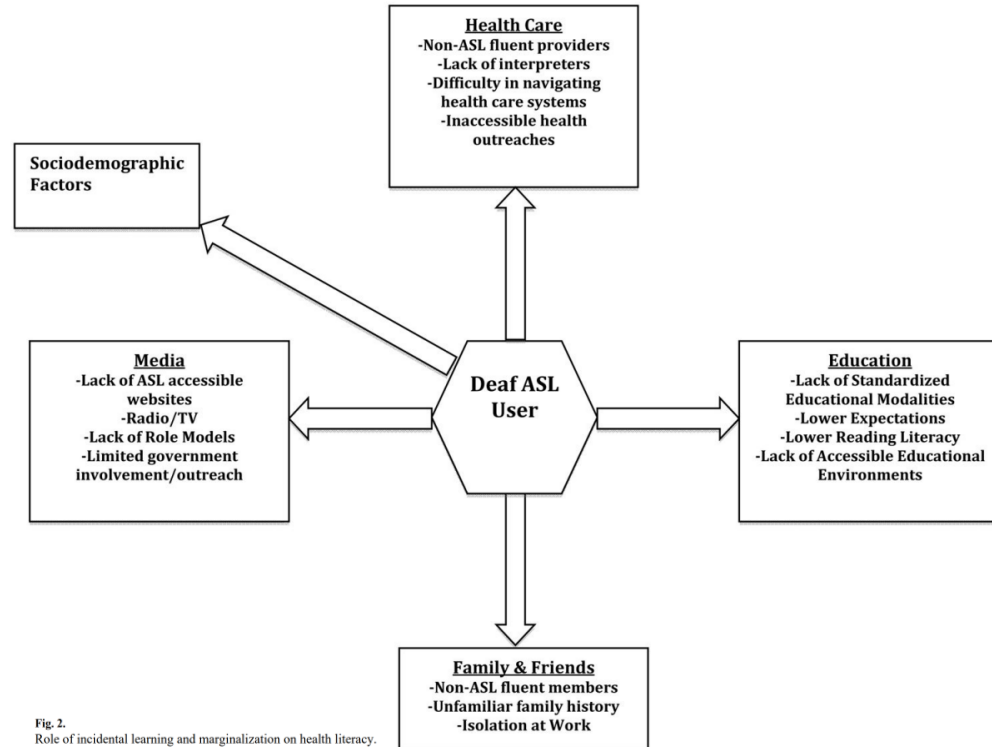


Fig. 2.
Role of incidental learning and marginalization on health literacy.

American with Disabilities Act (ADA)

- ADA provides protection from discrimination for individuals based on disability as it relates to employment (public and private sector), transportation, public accommodations, services provided by state and local government, and telecommunication relay services
- “Person with a disability” – anyone with a physical or mental impairment that substantially limits one or more major life activities, such as hearing



ADA - Aids and Services

- The goal is to ensure that communication with people with disabilities is *equally effective* as communication with people without disabilities
- Provide auxiliary aids and services for people who are DHH when needed or upon request
- The type of auxiliary aid or service provided will depend on what is needed for a specific situation

ADA - Aids & Services for Deaf

- Qualified sign language interpreters, real-time captioning, written materials
- Use a variety of telecommunication technologies
 - Videophones, captioned telephones, smartphones, other voice, text, and video-based relay services
 - Open captioning, closed captioning, real-time captioning
 - Assistive listening systems and devices (amplifiers), hearing-aid compatible telephones, teletypewriters or text telephone (TTY or TTD)



Role of the Electronic Health Record

- The Disability Equity Collaborative (DEC) – The Documentation workgroup seeks to develop standards for documentation of patients' disability status in Electronic Health Records
 - Addressing disparities and improving care and assists with provision of disability accommodations
- How does your workplace assess and assist with accommodations for the Deaf?
 - Technology

Sign Language Interpreter



- Specialized training and credentials to develop the skills and expertise needed to mediate meanings across languages and cultures
- Passed a state or national level of certification, bound by a strict Code of Professional Conduct - established by the Registry of Interpreters for the Deaf (RID)
 - Online database www.rid.org or 703-838-0030
- Many employed by local agencies or work remotely

Use of Accompanying Adults/Children

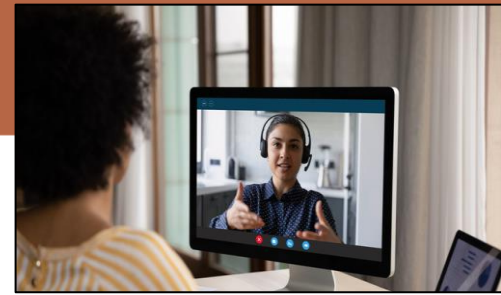
- ADA places responsibility for providing effective communication, including interpreters, directly on covered entities
- Cannot require a person to bring someone to interpret
- When a covered entity can rely on a companion to interpret
 - Emergency – imminent threat to the safety or welfare of an individual or the public
 - Non-emergent situation – a) the individual requests this, b) the accompanying adult agrees, and c) reliance on the accompanying adult is appropriate under the circumstances

Use of Accompanying Adults/Children

- Can be applied to all languages that require interpretation:
 - Lack specialized vocabulary needed to interpret effectively and accurately
 - Lack of impartiality, impropriety or discomfort with personal issues
 - Lack of medical understanding
 - Stress on relationships
 - HIPPA/privacy laws



Telecommunications Services



- Telecommunication Relay Service (TRS) – free nationwide, dial 7-1-1
 - Uses communications assistants who serve as intermediaries between Deaf person using a TTY and those who use standard voice telephones
- Video Relay Service – free subscriber-based internet service
 - Subscribers (Deaf persons) use a videophone, smart phone, tablet, or personal computer to place and receive calls
 - Mainly used for personal use

Video Relay Service (VRS)

- All subscribers are issued an individual video phone number
- For all calls, an interpreter serves as an intermediary between the subscriber and standard voice telephone user
- Many VRS providers also have apps



Video Remote Interpreting (VRI)

- VRI is a fee-based service, allows DHH individuals to communicate with a hearing person via live videoconferencing
 - If VRI is chosen, all specific performance standards must be met
- Used in a wide variety of settings: hospitals, outpatient clinics, mental health settings, legal sector, police stations, schools/university, financial institutions, and workplaces
- Entities may contract for VRI services “on demand” or by appointment



VRI Challenges & Controversy

- VRI in the health care setting has exploded, often used as the sole auxiliary aid option (lower cost/convenience)
- DC is concerned about the over-reliance of this newer technology and their lack of involvement in deciding how to best provide this service
- Many report adverse experiences in healthcare settings
 - A study from Kushalnagar et al., found that only 41% out of 555 VRI users in the US were satisfied with the quality of the service used in healthcare (2019)

Closing the Health Literacy Gap

- Communication - ask DHH persons for *their* communication preferences and list those in the record
- Access to an ASL interpreting service
- Be respectful of Deaf culture values – visual access is key
 - Face the patient, maintain good eye contact, avoid obscuring your face whenever possible
- Optimal visual-based information sources help address health literacy gaps (McKee et al., 2015)

Effective Communication Techniques

- ID badge clearly displayed
- Reduce background noise
- Well lit room, minimize visual distractions
- Speak clearly to the patient not the interpreter, moderate pace
- Avoid exaggerating words, confuses lip readers
- If the patient does not understand or appears confused, rephrase rather than repeat the same words or sentences
- Inform you are changing topics or context

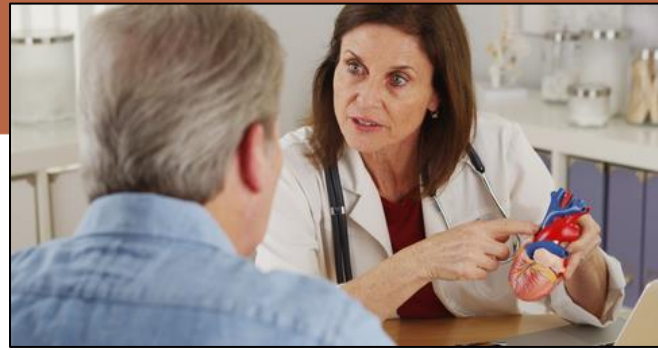


Impact of Masks on DHH

- Major communication barrier
 - Seeing the entire face is crucial because facial expressions are critical in ASL and convey meaning
 - Lip readers are also severely impacted
- Unavoidable in surgical & procedural settings
 - Consider leaving your mask off for effective communication with Deaf patients until it is necessary to wear
- COVID-19 mask mandates were vital in preventing spread of the virus but left some of the most vulnerable communities even more isolated



Visual Aids/Handouts

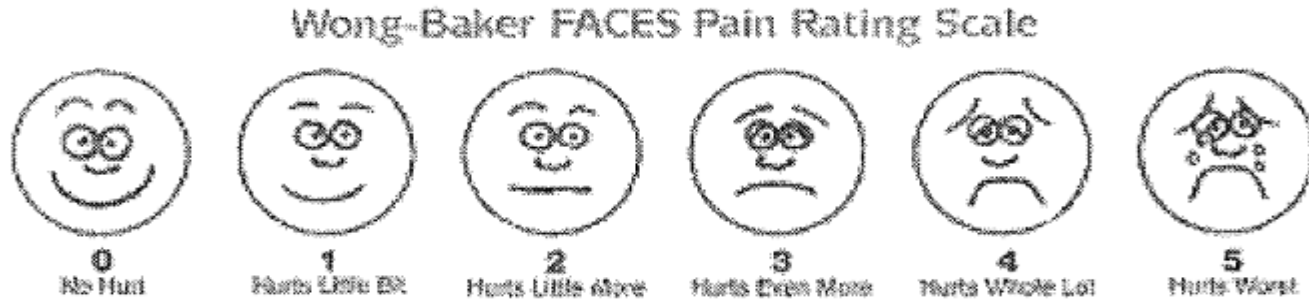


- ASL is a visual language – using diagrams, models, illustrations, and other visual aids will assist communication and understanding
- Educational handouts/resources should be in plain language, around 4th-6th grade reading level
- MedlinePlus Easy-to-Read Information & Health Education Materials Assessment Tool:
 - https://medlineplus.gov/all_easytoread.html#D

Lost in Translation

- The facial illustrations below are facial components of ASL signs for: happy, glad, surprise, depressed, sad, and cry

Figure 1: FACES Pain Rating Scale



Teach-back Strategies

- Research-based health literacy intervention that promotes adherence, quality, and patient safety
- Teach-back tools/strategies
 - A way to ensure that we explained the information clearly
 - Ask patient to explain what they need to know or do
 - A way to confirm patient understanding, re-explain if needed, check again
- Helpful way to double-check the accuracy of the interpretation and to encourage questions

Communicating *with* Deaf Individuals

- Not a “one size fits all” approach, nor is there a “typical” deaf person
- Each DHH person is unique with their own set of communication needs and preferences
 - Type of communication should also be *based on setting and purpose of the interaction*
 - Determine how to communicate effectively *with* the deaf individual, not *for* the individual
- Providers of care need to understand that they are responsible for any accommodations, including cost, to ensure effective communication



Helpful Websites

- The National Registry of Interpreters for the Deaf <https://rid.org/>
- National Association of the Deaf <https://www.nad.org/>
- ADA.gov <https://www.ada.gov/topics/effective-communication/>
- Telecommunications Relay Service <https://www.fcc.gov/trs>
- Video Relay Service Providers <https://www.fcc.gov/vrs-providers>
- VRI service providers can be found by using any search engine
- AHRQ Health Literacy <https://www.ahrq.gov/health-literacy/about/index.html>
- MedlinePlus Easy-to-Read Information & Health Education Materials Assessment Tool: https://medlineplus.gov/all_easytoread.html#D

References

- Ada quick tips - sign language interpreters*. (n.d.). ADA National Network. Retrieved April 19, 2023, from <https://adata.org/factsheet/sign-language-interpreters>
- Ada requirements: Effective communication*. (2020, February 28). ADA.gov. Retrieved April 19, 2023, from <https://www.ada.gov/resources/effective-communication/>
- Allen, B., Meyers, N., Sullivan, J., & Sullivan, M. (2002). American sign language and end-of-life care: Research in the deaf community. *HEC Forum*, 12(3), 197–208.
- American sign language*. (2021, October 29). National Institute on Deafness and other communication disorders. Retrieved April 19, 2023, from <https://www.nidcd.nih.gov/health/american-sign-language>
- Americans with disabilities act*. (n.d.). Gallaudet University. Retrieved April 19, 2023, from <https://gallaudet.edu/academic-career-success/students-with-disabilities/disability-law/americans-with-disabilities-act/>
- Communicating with deaf individuals*. (n.d.). National Deaf Center. Retrieved April 19, 2023, from <https://nationaldeafcenter.org/resource-items/communicating-deaf-people/>
- Garberoglio, C. L., Palmer, J. L., Cawthon, S., & Sales, A. (2019). *Deaf People and Educational Attainment in the United States: 2019* [PDF]. Washington, DC: U.S. Department of Education, Office of Special Education Programs, National Deaf Center on Postsecondary Outcomes. https://nationaldeafcenter.org/wp-content/uploads/2019/07/Deaf-People-and-Educational-Attainment-in-the-United-States_-2019.pdf
- Hearing Loss Associates of America. (2018). *Communicating with Hard-of-Hearing and Deaf patients - providers* [PDF]. https://www.hearingloss.org/wp-content/uploads/HLAA_HC_Providers_Communicating-with-Patients.pdf
- Hladek, G. (2009). *Cochlear Implants, The Deaf Culture, And Ethics A Study Of Disability, Informed – Surrogate Consent, And Ethnocide*. The Institute for Applied & Professional Ethics Archives; Ohio University. <https://www.ohio.edu/ethics/tag/deaf-culture/index.html#:~:text=The%20Deaf%20culture%20is%20a,the%20world%20as%20the%20norm.>
- Kushalnagar, P., Paludneviciene, R., & Kushalnagar, R. (2019). Video remote interpreting technology in health care: Cross-sectional study of deaf patients' experiences. *JMIR Rehabilitation and Assistive Technologies*, 6(1), e13233. <https://doi.org/10.2196/13233>
- McKee, M. M., Paasche-Orlow, M. K., Winters, P. C., Fiscella, K., Zazove, P., Sen, A., & Pearson, T. (2015). Assessing health literacy in deaf American sign language users. *Journal of Health Communication*, 20(0 2), 92–100. <https://doi.org/10.1080/10810730.2015.1066468>
- Mead, A. (2019, October 9). *Enhancing services for Deaf, Hard of Hearing, and Deafblind patients in rural America*. The Rural Monitor. <https://www.ruralhealthinfo.org/rural-monitor/enhancing-services-for-deaf/>
- Minimum standards for video remote interpreting services in medical settings*. (n.d.). National Association of the Deaf. Retrieved April 19, 2023, from <https://www.nad.org/about-us/position-statements/minimum-standards-for-video-remote-interpreting-services-in-medical-settings/>
- Mitchell, R. E. (2005). How many deaf people are there in the united states? estimates from the survey of income and program participation. *Journal of Deaf Studies and Deaf Education*, 11(1), 112–119. <https://doi.org/10.1093/deafed/enj004>
- Morisod, K., Malebranche, M., Marti, J., Spycher, J., Grazioli, V. S., & Bodenmann, P. (2022). Interventions aimed at improving healthcare and health education equity for adult d/deaf patients: A systematic review. *European Journal of Public Health*, 32(4), 548–556. <https://doi.org/10.1093/eurpub/ckac056>
- Murphy, J. (2022, October 5). *More Than 90% of Deaf community struggled after initiation of mask mandate during COVID-19 pandemic*. Contemporary Clinic. Retrieved April 19, 2023, from <https://www.contemporaryclinic.com/view/more-than-90-of-deaf-community-struggled-after-initiation-of-mask-mandate-during-covid-19-pandemic>
- Pollard, R. Q., Dean, R. K., O'Hearn, A., & Haynes, S. L. (2009). Adapting health education material for deaf audiences. *Rehabilitation Psychology*, 54(2), 232–238. <https://doi.org/10.1037/a0015772>
- Quick statistics about hearing*. (2021, March 25). National Institute on deafness and other communication disorders. Retrieved April 19, 2023, from <https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing#:~:text=More%20than%2090%20percent%20of%20deaf%20children%20are%20born%20to%20hearing%20parents.%26text=Approximately%2015%25%20of%20American%20adults,over%20report%20some%20trouble%20hearing.>
- Welcome to the always use teach-back! (training toolkit)*. (n.d.). Always use teach-back!. Retrieved April 19, 2023, from <http://www.teachbacktraining.com/home>
- What is American sign language*. (n.d.). National Association of the Deaf. Retrieved April 19, 2023, from <https://www.nad.org/resources/american-sign-language/what-is-american-sign-language/>

Questions



THANK YOU

