

REDIRECTING HEALTH LITERACY EFFORTS TO BRIDGE EXISTING HEALTH INFORMATION AND HEALTH LITERACY GAPS AMONG PEOPLE WITH DISABILITIES

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OBJECTIVES

1. Provide an overview of health literacy and health information gaps and needs of people with disabilities
2. Discuss principles of universal design and inclusion
3. Review principles of disability competency
4. List examples of successful programs for people with disabilities

Disability Impacts **ALL of US**

COMMUNITIES



HEALTH

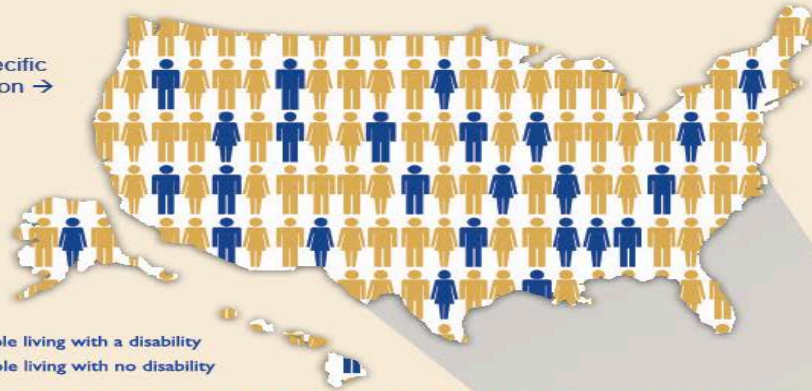




ACCESS



61 million adults in the United States live with a disability

Click for
state-specific
information →



 People living with a disability
 People living with no disability

26%
(1 in 4)

of adults in
the United States
have some type
of disability

The percentage of people
living with disabilities is
highest in the South



Percentage of adults with functional disability types

13.7%

MOBILITY

Serious difficulty
walking or
climbing stairs



10.8%

COGNITION

Serious difficulty
concentrating,
remembering, or
making
decisions



6.8%

INDEPENDENT LIVING

Difficulty doing
errands alone



5.9%

HEARING

Deafness or
serious difficulty
hearing



4.6%

VISION

Blindness or
serious difficulty
seeing



3.7%

SELF-CARE

Difficulty dressing
or bathing



HEALTH CARE DISPARITIES

People with disabilities are ten times more likely than non-disabled people to report low satisfaction with their health care!

The more serious the disability, the less satisfied patients are with their health care.

NATIONAL HEALTHCARE DISPARITIES REPORT, 2010. AVAILABLE ONLINE:
[HTTP://WWW.AHRQ.GOV/RESEARCH/FINDINGS/NHQRDR/NHDR10/CHAP10A.HTML](http://www.ahrq.gov/research/findings/nhqrdr/nhdr10/chap10a.html) (ACCESSED 17 DECEMBER 2014).

HEALTH CARE QUALITY

- According to the *2013 National Healthcare Disparities Report*:
 - >60% of quality indicators, such as measures of patient-centered care and access to care, had improved for non-disabled people yet. . . Only 20-35% had improved for PWDs

LIVING WITH A DISABILITY

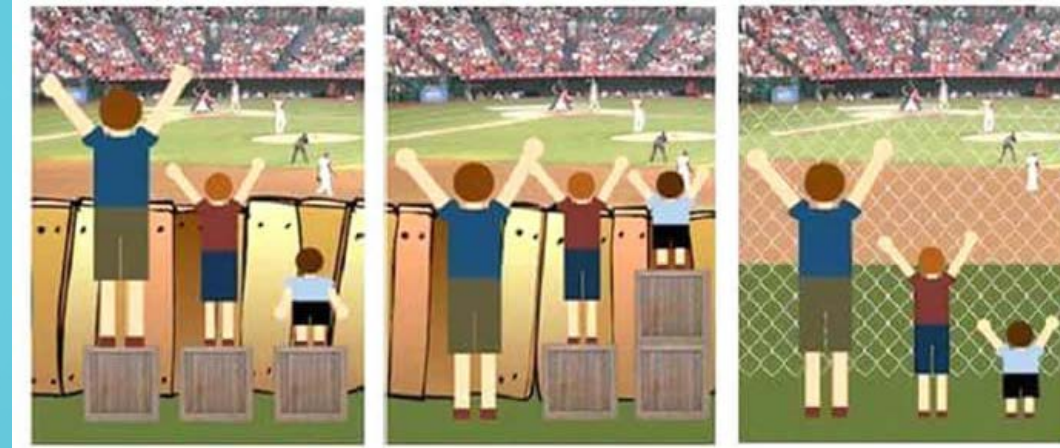
Adults with disabilities are:

- Less likely to have private insurance, received preventive services including cancer screenings, report met health care needs
- More likely to be readmitted to the hospital due to complications, report lower provider-patient communication quality, suffer higher burdens of health conditions.
- Some examples:
 - Obesity rates are 58% higher among adults with disabilities than their nondisabled peers
 - New cases of diabetes is almost three times as high among adults with disabilities relative to adults without disabilities (19.1 per 1,000 vs 6.8 per 1,000).
 - Disability status is a high risk factor for early onset cardiovascular disease, with rates of 12% vs 3.4% among 18 to 44 year olds with and without disabilities.

HEALTH LITERACY & HEALTH INFORMATION

- The Program for the International Assessment of Adult Competencies found that only 29% of PWDs demonstrated general literacy proficiency compared with 50% of persons without disabilities (Goodman et al., 2013).
- Large gap in health literacy research among PWD
 - Disability is rarely looked at in detail (binary responses) limiting the opportunity to develop useful interventions
 - Less clear are the mechanisms driving these gaps
- PWD struggle with decreased access to health information
 - Universal design principles rarely used in health information media and exchanges
 - Role of low expectations, loss of independence, stigma

WHAT CAN WE DO?



Equality

Equity

Justice

- Ensuring that PWDs are included in health literacy research
 - Including standard disability questions with branching questions as needed
 - Ensure the questions are accessible and easily comprehended
 - Consider oversampling similar to what is done for other racial/ethnic groups
 - Include representatives with disabilities on research and community advisory boards
 - Inclusion of PWDs on research team
 - Prioritize grant funding for disability related conditions
- Ensure health information is both accessible and equitable
 - Emphasize universal designs with information (e.g. websites, videos, patient portals)



CREATING A HEALTH LITERACY BRIDGE FOR DEAF AND HARD OF HEARING INDIVIDUALS

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Understanding and Promoting Health Literacy

Mechanisms of Health Literacy and Information Accessibility in the
Deaf

Health Info Lab is a collaboration of the following organizations



LEARNING OBJECTIVES

- Review of health literacy and how it applies to deaf and hard of hearing individuals
- Provide an update on the role of language discordance and health information access
- Identify the information needs of deaf and hard of hearing individuals and their known best practices to address them

New Study of Hearing Loss Among U.S. Adults Aged 20 to 69

Who has hearing loss?



14% of adults aged 20 to 69 in 2011–2012

Prevalence of hearing loss has **declined slightly** from about **16%** in 1999–2004.

Who is most at risk for hearing loss?

Older Age Groups



Prevalence of hearing loss increases with age.

Men



Men are about twice as likely as women to have hearing loss.

Hearing loss is defined as when the average threshold across four speech frequencies (0.5–1–2–4 kHz) is greater than 25 decibels hearing level. The statistics above are for hearing loss that may occur in one or both ears.
Source: National Health and Nutrition Examination Survey, 2011–2012. Analysis reported in JAMA Otolaryngology—Head & Neck Surgery, December 2016.



NIH

National Institute on Deafness and Other Communication Disorders

<https://www.nidcd.nih.gov/>

<https://twitter.com/nidcd>

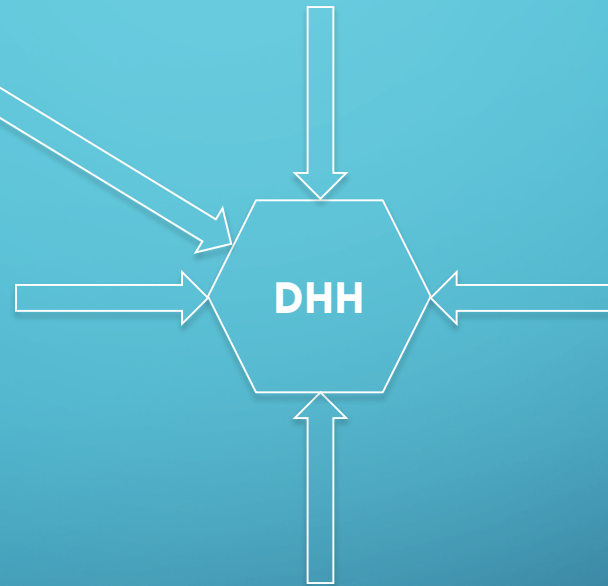
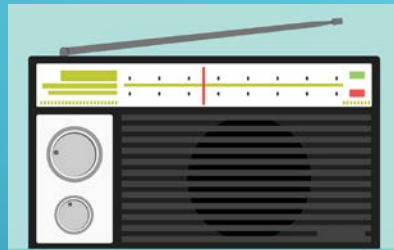
HEALTH LITERACY & HEARING LOSS

- Very few health literacy studies known for individuals with hearing loss
 - None known for the general hearing loss population
 - Deaf were 6.9 times more likely than hearing to have inadequate health literacy (McKee, et al. 2015)
 - Unpublished data (pilot work) shows that those with hearing loss still struggle with health literacy
 - Mechanistic studies are needed to determine ideal targets for intervention

McKee M, et al., 2015. Assessing health literacy in Deaf American Sign Language users. *Journal of Health Communication*. 20:92–100



Role of Incidental Learning and Marginalization on Health Literacy



Newest Vital Sign Health Measure

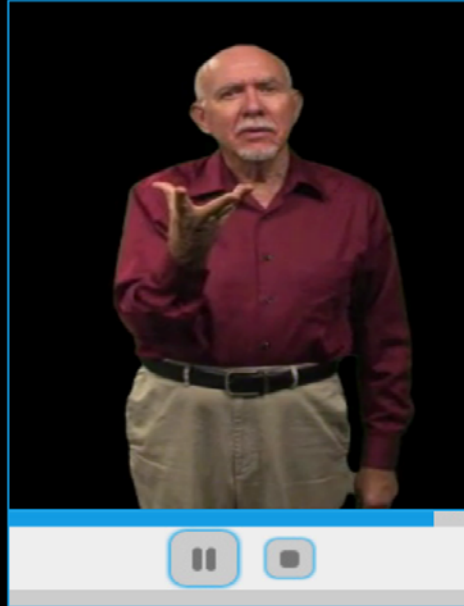
Standard Contrast

Nutrition Facts

Serving Size	1/2 cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
%DV	
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

* Percent Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.



Question 1

If you eat the entire container, how many calories will you eat?

Next »

Deaf Health Literacy Study

Deaf individuals (n=383) were more likely to have inadequate health literacy than hearing individuals (n=406) (45.9% vs 19.5%; $p < 0.001$)

HEALTH LITERACY PREDICTORS (AD INTERIM)

Predictors for adequate health literacy were similar for both Deaf and hearing but the magnitude differed.

- 4 + college was a stronger predictor for Deaf (OR 95% CI: 3.65 vs 2.54; $p < 0.001$)
- Role of reading and language fluency were also significant predictors but were strongly correlated with educational attainment

Focus should be on ensuring communication and language access first before addressing health literacy (Sudore, et al. 2009)

ONLINE ACCESS/ABILITY

DHH use and access the Internet more often than hearing (95% vs 78%) yet their ability to use and assess online resources was poorer than hearing

Key Interim Findings:

- Lower e-literacy (eHeals) scores despite higher ownership/use
- Superficial queries and searches



SO, IN THE MEANTIME. . .

- No one approach fits all
 - Deaf signers prefer videos in ASL and social media as ways to share information
 - Hard of hearing prefer captioned videos and easy to read online health information.

Yet. . .



UNIVERSAL DESIGN PRINCIPLES

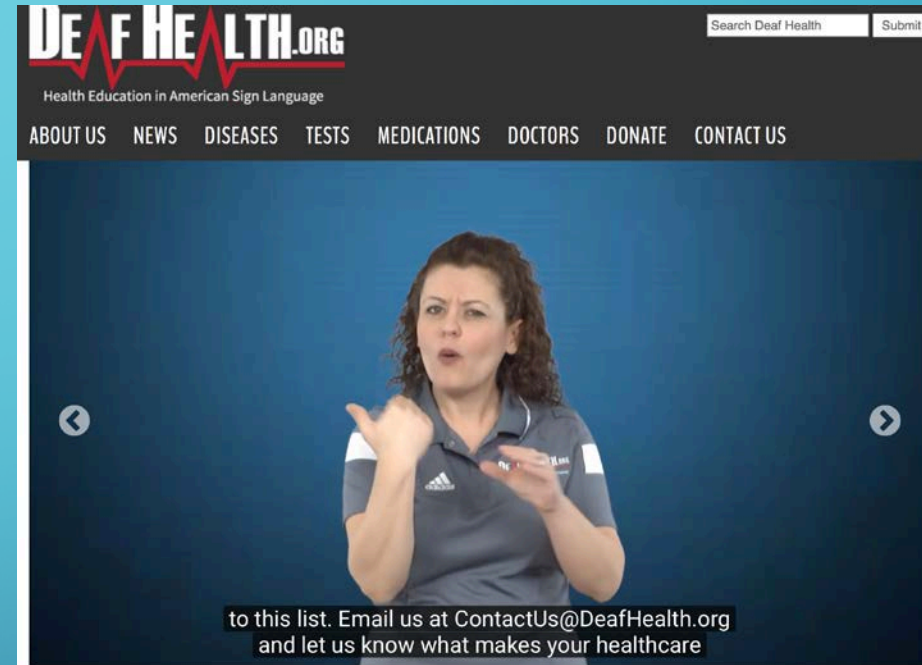
Story et al, 1997 developed the Seven Principles of Universal Design

- *Equitable: Useful and marketable to people with diverse abilities.**
- *Simple and Intuitive: Easy to understand for any user.**
- *Perceptible Information: Communicates information effectively.**

UNIVERSAL DESIGN PRINCIPLES FOR DHH

- Health Videos

- Captioning (auto vs manual)
- Signing videos



Use automatic captioning

- Go to your Video Manager by clicking your account in the top right > Creator Studio > Video Manager > Videos.
- Next to the video you want to add **captions** or subtitles to, click the drop-down menu next to the Edit button.
- Select Subtitles and CC.



UNIVERSAL DESIGN PRINCIPLES FOR DHH

50,000 to 90,000 Adult Deaths a Year Caused by Vaccine-Preventable

📌 Infectious Disease, Prevention



- Print Media

- Know your audience (strengths and weaknesses)
- Tailored messages
- Community feedback
- Clear Communication Tools

CDC Clear Communication Index Score Sheet

UNIVERSAL DESIGN PRINCIPLES FOR DHH

- Health Care Communication Protocols
 - Ensure effective communication
 - Electronic health record charting and flagging
 - Patient room designs
 - Move the laptop/computer to the side
 - Use of teach back or teach to goal
 - Recognize hearing loss signs and cues
- Recognize when communication is breaking down and ask for help
 - Interpreters, assistive technologies, etc.
 - Visual aids
 - Longer appointments

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