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

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

- **Mobility**: 13.7%
  - Serious difficulty walking or climbing stairs

- **Cognition**: 10.8%
  - Serious difficulty concentrating, remembering, or making decisions

- **Independent Living**: 6.8%
  - Difficulty doing errands alone

- **Hearing**: 5.9%
  - Deafness or serious difficulty hearing

- **Vision**: 4.6%
  - Blindness or serious difficulty seeing

- **Self-Care**: 3.7%
  - Difficulty dressing or bathing

[Diagram showing the distribution of disabilities across different categories]
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.

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.

Source: IOM Report
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?

• 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
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

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGED 40–49</td>
<td>8%</td>
</tr>
<tr>
<td>AGED 50–59</td>
<td>23%</td>
</tr>
<tr>
<td>AGED 60–69</td>
<td>39%</td>
</tr>
</tbody>
</table>

Prevalence of hearing loss increases with age.

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

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

Role of Incidental Learning and Marginalization on Health Literacy
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)
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
Universal Design Principles for DHH

Print Media

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