



Better Health through Accessible Communication

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Goals of Presentation

- Introduction
- Health Literacy Issues
- Impacts of Poor Communication
- Access Issues
- Solutions
- Discussion Time

Deaf ASL Users

- Linguistic minority community:
 - Share language and culture (same as other minority communities (Padden & Humphries, 2005))
 - Deaf group communicates in American Sign Language (ASL)
 - Deaf group shares the values of Deaf Culture
 - Hearing loss is a cultural identity not a disability
 - Medically underserved due to language barriers

Deaf Individuals

- Among individuals with hearing loss (Blanchfield, et al, 2001), they were more likely to be:
 - Publicly insured
 - Poorer (lower family incomes)
 - Less educated
 - Higher unemployment rate
- Same seen with other minority groups
- Deaf ASL users???

Deaf ASL Users

- One exception to other minority groups → Family history
- Deaf ASL users struggle with family history due to (Hauser, O'Hearn and McKee, in press):
 - Vertical vs Horizontal cultural sharing
 - *Dinner table syndrome*
 - Hearing family with no ASL fluency (95 percent of deaf people grow up in a hearing family)
 - Loss of incidental learning

Poor Health Literacy

- **Health Literacy:** ability to obtain, process and understand health information that is necessary to make suitable health care decisions (HHS, 2001; Nutbeam, 2000; Zarcadoolas, et al., 2002)
 - >33% of English-speaking patients and >50% of primarily Spanish-speaking patients at U.S. public hospitals have low health literacy (Marcus, 2006)
 - Deaf ASL users???

Literacy Concerns

- ASL has no written language- English is a foreign language
- Lack of good educational systems for the deaf
 - Low English reading results (Allen, 1986; Traxler, 2000)
- Low English literacy (or reading) places deaf individuals at risk for medical complications or medication errors.
 - A random sample of 40 potentially harmful medications' guidance pamphlet revealed that they are typically written between the 11th and 12th reading levels (Wolf et al, 2006)
 - Incomplete understanding of medication labels may cause ~ 2% to 11% of hospital admissions in the United States (Davis, et al, 2006)

Deaf Health Literacy

- No assessment tool for health literacy on deaf ASL users exist
- Limits health educational or interventional programs for linguistic minority
- Healthy People 2010
 - Removing disparities among minorities and disabilities
- Few existing health educational programs target deaf ASL users
 - www.deafmd.org
 - www.deafdoc.org

Health Information in ASL

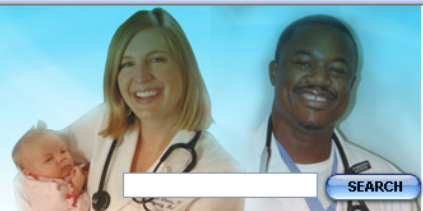

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IN YOUR AREA
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Deaf Health Knowledge

- Deaf ASL users have poorer knowledge of:
 - Dangers of sexual contacts with drug users and multiple sexual partners (Woodruffe, et al., 1998)
 - Deaf students had significantly lower knowledge scores pertaining to HIV/AIDS (Heuttel et al, 2001)
 - Swartz (1993) found that 23% of the hearing individuals learned about sex primarily from their mother while only 2.9% of deaf individuals did the same
 - Depended on family and friends for information on HIV/AIDS (Heuttel et al, 2001) – can lead to distorted information

Prevention

- Deaf and hard of hearing were less likely to learn preventive information from their doctor or the media (Tamaskar, et al., 2000)
- Preventive health counseling and screening procedures were thought to be less important (Tamaskar, et al., 2000)
- Cancer prevention and intervention knowledge was poor (Zazove, et al., 2009)
- Children with hearing loss had twice the injury rate as hearing peers (Mann, Zhou, McKee, & McDermott, 2007)

Cardiovascular Health

- Cardiovascular disease (Margellos-Anast et al., 2006)
 - 40% of deaf were unable to list a single symptom of heart attack (<10% for hearing)
 - 60% of deaf unable to do the same for stroke (30% for hearing)
 - Only 61% reported that they would call 911 if they had any acute cardiovascular symptoms
 - Knowledge of risk factors for heart disease:
 - Hypertension (59% of deaf respondents reporting this as a risk factor versus 97% of hearing respondents reporting the same);
 - High cholesterol (52% versus 92%)
 - Diabetes (40% versus 75%)

Deaf Health

NCDHR



National Center for Deaf Health Research



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MELIORA
Ever Better

- 1st Deaf Health Research Center
- Deaf Health Survey
- Located at Rochester, NY
- Mission:
 - To promote health and prevent disease in deaf and hard-of-hearing populations through community-based participatory research

<http://www.urmc.rochester.edu/ncdhr/about/mission.cfm>

Health Data



	White	African Americans	Deaf	
Cancer	193.9 per 100,000	243.1 per 100,000	No data	
Diabetes	23.0 per 100,000	49.2 per 100,000	No data	
Infant Mortality	5.7 per 1,000 live births	13.3 per 1,000 live births	No data	
Adult Immunizations	70.2 %	52%	No data	

Source: www.cdc.gov

*http://www.urmc.rochester.edu/ncdhr/information/documents/GallyPresentation11-7-07REV_000.pdf

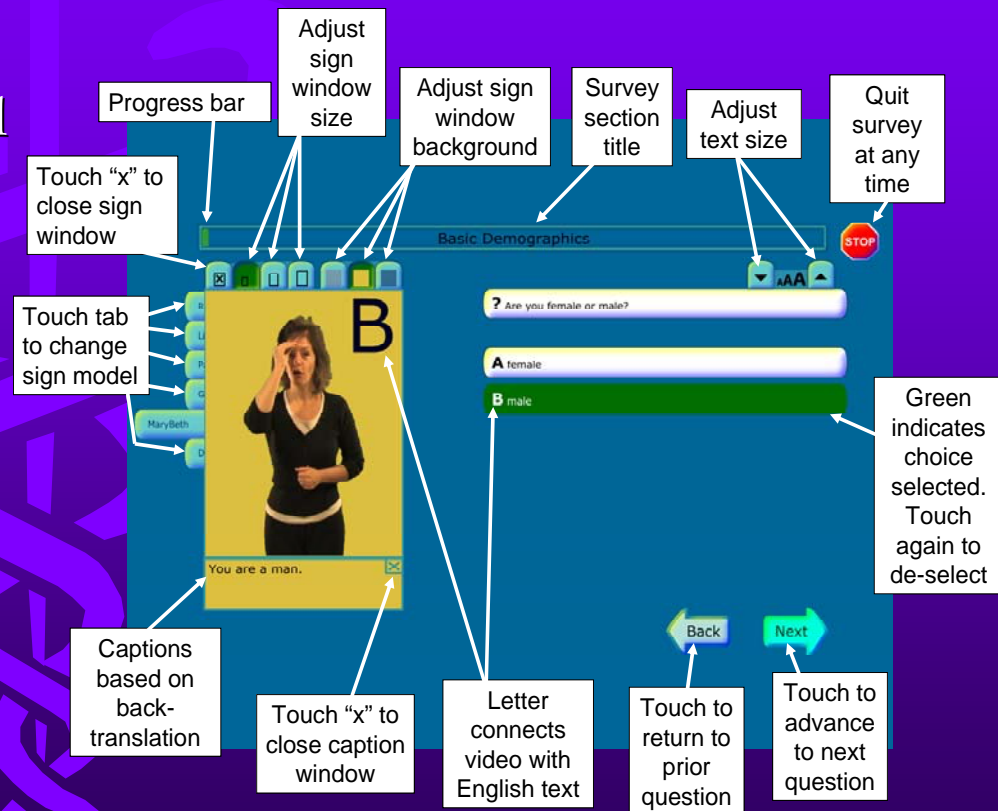
Deaf Health Survey

- Deaf Health Survey

- Adapted from Behavioral Risk Factor Surveillance System (BRFSS) from CDC

Measures:

- Health risk behaviors
- Preventive health practices
- Health care access
- Demographic data



Poster: Barnett, McKee and Samar (2008)

Health Disparities

- Why Seen:
 - Communication Barriers
 - Language Barriers
 - Low Education
 - Low Income/Poverty
 - Poor Knowledge of Family History
 - Public Insurance
- These factors are “Access” issues!

Communication Access Issues

- Refusal to provide interpreters
 - Lack of awareness on ASL/Deaf Culture by medical staff
 - Lack of awareness of legal rights
- Interpreter issues
 - Poor Interpreter Qualifications
 - Lack of interpreters
- *Goal→ Ensure effective communication to provide good medical care!

Communication Access Issues

- Alternative strategies:
 - Writing
 - Usage of family members or friends as interpreters
- Cost cited as number one reason for refusal to provide interpreters

What You Need to Know

Americans with Disabilities Act (1990)

- Civil rights law to address discrimination among individuals with disabilities (40 million +)
- Protect rights of individuals with disabilities in employment, public accommodations, state and local government and telecommunications
- Title II - applies to hospitals not clinics
- Title III - public accommodations and services operated by private entities (clinics)

What You Need to Know

- ADA specifies that accommodations must be made to ensure effective communication
- This can be done through auxiliary aids and services (qualified interpreters, assistive listening devices, notetakers, etc.)
- Department of Justice enforces ADA
- Exceptions to ADA:
 - Undue financial burden
 - Accommodations would fundamentally alter the nature of the service provided

Accommodations

- Must be provided by the health care provider not the patient (grants / tax credits available)
- Health care provider can choose any methods of accommodations as long as effective communication is obtained with the patient
- Department of Justice expects the provider to consult with the patient to choose optimal accommodation

What Can You Do to Help?

- Inform medical staff ahead of time of your accommodation needs
- If necessary, educate the medical staff
- Be patient if you are refused
- Don't threaten
- Find ASL fluent medical staff
- Legal advice

Legal Help

- Department of Justice
- Protection and Advocacy Services
 - Minnesota Disability Law Center
(<http://www.mndlc.org/>)
- Private attorneys

Lack of Medical Knowledge

- Poor Medical Knowledge due to:
 - Loss of family contact/communication
 - Confusing medical words
 - Lack of knowledge of personal medical history
 - Few health education programs in ASL

What You Can Do to Help- Personal Level

- Email or ask your family members about family history- write this down
- Keep a copy of your medical history
- Request early for medical records to be sent to your new doctor if switching doctors
- Write down what diseases or surgeries you have had
- Look for health information in ASL
 - Community health educators
 - ASL friendly health educational videos or websites

What You Can Do to Help

- Contact your government, community and medical leaders to increase support
- Vote!
- Look for health centers with more resources
- Increase community awareness about this problem

Questions?

- **Research:**

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