

Measuring Health Risk Behaviors of Deaf and Hard-of-Hearing Young Adults

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U.S. Deaf Population

- 16.4% of adults experience some hearing difficulty (NHIS '04)
- 1 million people are functionally deaf (Mitchell, 2006)
- Of U.S. adults who are deaf:
 - 17.1% lost their hearing before age 19
 - 6.6% lost their hearing before age 3
(NHIS 1990-1991)

U.S. Deaf Population (2)

- English vs. American Sign Language (ASL)
- Literacy limitations
- Health disparities
- Frequently overlooked/not included in research
- Little is known about health behaviors and health services use

National Center for Deaf Health Research

- In response to these issues, NCDHR was developed
- CDC Prevention Research Center, funded 2004
- Partnership between University of Rochester and National Technical Institute for the Deaf
- Community participatory research
- Core project: development of sign language video surveys

Objective

- To develop a linguistically accessible written English survey instrument to assess health risk behaviors of deaf and hard-of-hearing young adults

4 Stages of Survey Development

- I. Building the item pool
- II. Adapting the language
- III. Cognitive interviews
- IV. Fielding the instrument

I. Building the Item Pool

- Pooled > 300 items from YRBS, BRFSS, National College Health Assessment
- Developed new items to assess hearing level, language preferences, mode of communication
- 71 items selected by consensus

Survey Topics

- Demographics
- Safety and violence
- Physical health
- Mental Health
- Sexual behavior
- Substance use
- Health care use
- Hearing Level
- Language
- Communication

II. Adapting the Language

- 5 English language and deafness experts modified survey items
- Adjusted words, phrases, and syntax
- Maximized comprehension while retaining item integrity

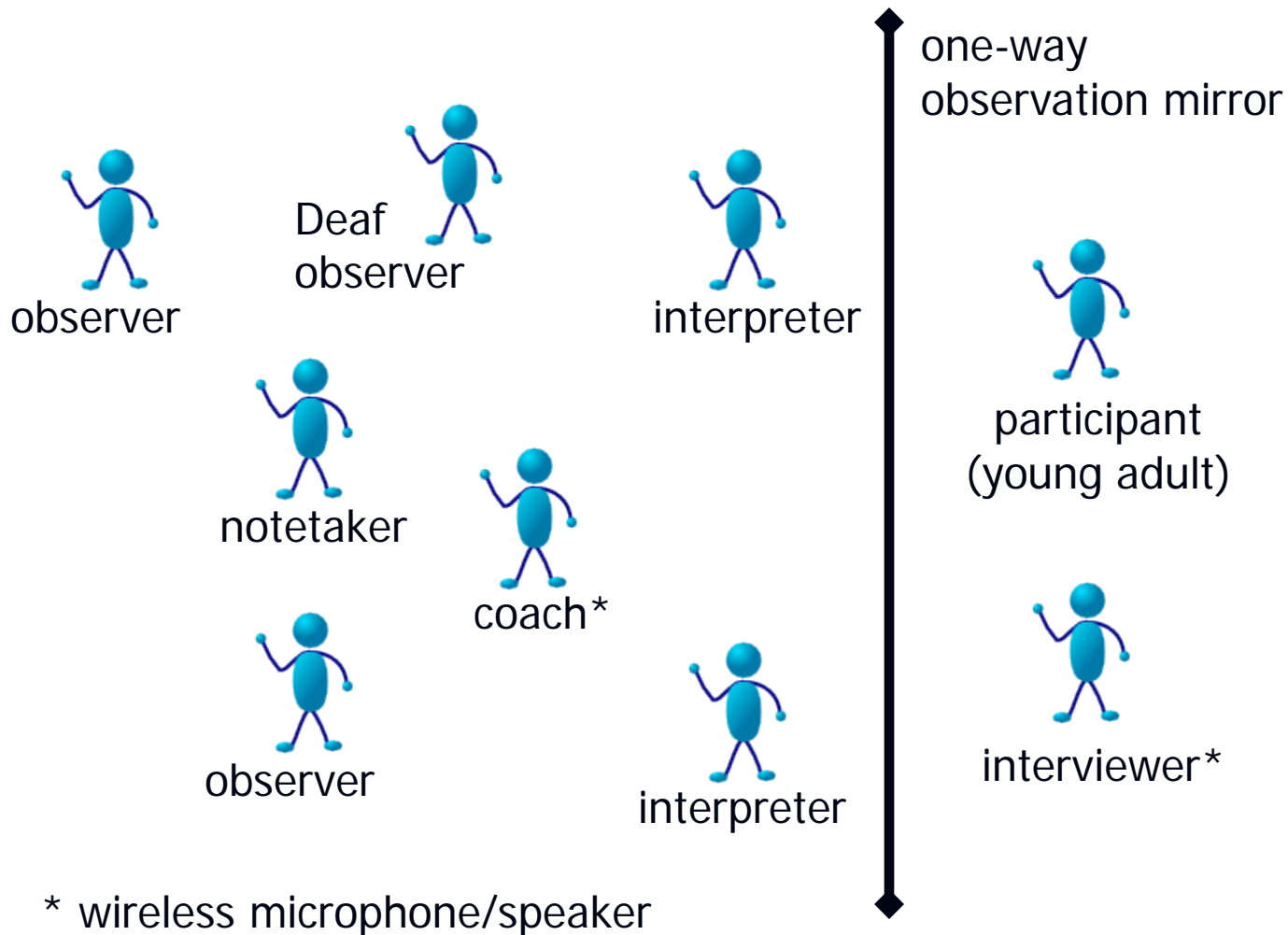
Examples of Language Modification

| Original Item | Modified Item |
|---|---|
| Have you ever become pregnant or gotten someone else pregnant? | <i>Did you ever get pregnant or get another person pregnant?</i> |
| Have you ever taken medication for depression? | <i>Did you ever take medicine for depression?</i> |
| During the past 12 months, how many times did you actually attempt suicide? | <i>During the past 12 months, how many times did you really try to kill yourself?</i> |

III. Cognitive Interviews

- Purpose of cognitive interview testing
- 18 deaf and hard-of-hearing diverse young adults
- Varied reading levels and sign proficiencies
- Interview process

Cognitive Interview Setup



Cognitive Interview Findings

- Some vocabulary terms were questioned
- Participants thought critically about their behaviors in order to select their answers
- Health care items were less often understood than behavioral items
- Participant feedback was incorporated to produce a more accessible English instrument

IV. Fielding the Instrument

- 168 deaf and hard-of-hearing young adults
- 578 hearing young adults – comparison group

Findings from Field Testing

- Significant differences in answer patterns between deaf and hearing respondents
- Inconsistent responses were more common among deaf respondents
- Deaf respondents were more likely to choose the “don’t know” response when it was available
- Survey modalities preferred by deaf respondents varied
- Some prevalence estimates for behavioral risks and health service use were similar between groups; others showed disparities

Limitations

- Inability to validate self-reported behaviors and health services use
- Deaf and hard-of-hearing young adults in the sample had high levels of education – may not be representative of total population

Conclusions

- Process used for developing a modified English survey was effective
- Modified paper and pencil surveillance methods yield estimates of health behaviors for this population
- Methods for surveillance of cultural or linguistic minority groups may require use of instruments in respondent's preferred language
- Disparities in health care access and use require further exploration
- ASL and English-based sign language surveys are in development

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