

DEVELOPMENT OF A LINGUISTICALLY ACCESSIBLE HEALTH SURVEY FOR DEAF AND HARD-OF-HEARING YOUNG ADULTS

Erika Sutter, MPH, Elizabeth G. Finigan, MD, Vincent Samar, PhD, Gerald P. Berent, PhD, Steven Barnett, MD, Robert Q Pollard, Jr., PhD, Caryn Havens, MPH, MBA, Jonathan D. Klein, MD, MPH, and the Research Committee of the National Center for Deaf Health Research

Rochester Prevention Research Center: University of Rochester School of Medicine and Dentistry and National Technical Institute for the Deaf, Rochester, NY



BACKGROUND

- Deaf and hard-of-hearing populations are frequently overlooked or not included in health research.
- Research has shown health disparities among deaf and hard-of-hearing populations, including differences in health knowledge, attitudes, and access to health care.
- One of the challenges of health research with these populations is creating surveys that are linguistically and culturally appropriate.
- Use of standard English language health risk surveys poses serious validity problems for surveillance with these populations, due to:
 - Inaccessibility of text-based English phone surveys
 - Limited English language literacy levels
 - Sometimes culturally inappropriate survey content
- The National Center for Deaf Health Research (NCDHR) aims to develop methods that include deaf and hard-of-hearing populations in surveillance and research.

OBJECTIVES

- To develop a linguistically accessible written English survey instrument to assess health risk behaviors and health services use among deaf and hard-of-hearing young adults.
- To help clinicians, community members, and researchers learn more about the health and behaviors of these populations.

STAGE 1: BUILDING THE SURVEY ITEM POOL

- 300+ items were pooled from the Youth Risk Behavior Survey (YRBS), Behavioral Risk Factor Surveillance System (BRFSS), and American College Health Association's National College Health Assessment (NCHA).
- New items were developed to assess self-described hearing level, language preferences, and mode of communication used with a health provider.



The final paper-and-pencil written English survey contained 71 items.

Survey topics: demographics, safety and violence, health, sexual behavior, substance use, health care use, hearing level, language use, and communication

STAGE 2: ADAPTING THE LANGUAGE OF SURVEY ITEMS

- Five English language and deafness experts from NTID adapted survey language: Gerald Berent, PhD, Research & Teacher Education; Karen Christie, PhD, EdD, Cultural & Creative Studies; Kathleen Crandall, PhD, Kathryn Schmitz, MS, NTID English; Susan Keenan, Liberal Studies Support
- Language modifications maximized comprehension while retaining item integrity.
- Adjusted words, phrases, and syntax of items for college-age deaf population; changes were consistent with teachers' experiences and research on relative difficulties in processing English text during reading comprehension.
- Ensured language usage consistent with Deaf cultural norms.



Examples of Language Modification

Have you ever become pregnant or gotten someone else pregnant?
Have you ever taken medication for depression?

*Did you ever get pregnant or get another person pregnant?
Did you ever take medicine for depression?*

During the past 12 months, how many times did you actually attempt suicide?

During the past 12 months, how many times did you really try to kill yourself?

STAGE 3: PILOTING THE SURVEY: COGNITIVE INTERVIEWS

- Cognitive interviews focus on the cognitive processes that respondents use to answer survey questions, to evaluate and minimize sources of response error in the survey.
- 18 deaf or hard-of-hearing young adults completed the survey and were interviewed about item content, grammar, vocabulary, comprehension of concepts, and cognitive processes used to answer items.
- Interviewers were fluent in American Sign Language (ASL), but accommodated each participant's preferred communication style.



Participant feedback was incorporated to produce a more accessible English survey.

- Participants thought critically about their behaviors in order to select their answers
- Some vocabulary terms were consistently questioned
- Health care items were less often understood than items about behaviors

STAGE 4: FIELDING THE SURVEY

- The revised survey was administered to:
 - 168 deaf and hard-of-hearing young adults
 - 578 hearing young adults (comparison group)
- Data analysis is in progress; preliminary results show some differences in responses between deaf and hard-of-hearing and hearing respondents.



- Significant differences in answer patterns were found between deaf/hard-of-hearing and hearing respondents
- Inconsistent responses and "don't know" responses were more common among deaf/hard-of-hearing respondents
- Some estimates of behaviors and health care use were similar between groups; others showed disparities
- Findings will inform development of computer-based ASL and English-based sign language surveys