

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

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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.

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.

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.

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.

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

Examples of Language Modification

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

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

*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 really try to kill yourself?

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

- 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