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

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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

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

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.

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.

For more information, visit www.urmc.rochester.edu/ncdhr or TTY: (585) 276-2120. Supported by a Prevention Research Center grant from the Centers for Disease Control and Prevention.