Surveying Adults Deaf Since Childhood: Identifying and Addressing Disparities Through Community-Based Participatory Research

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Learning Objectives

1) List successful approaches to adapting a survey for adults deaf since birth/childhood

2) List the benefits of using a collaborative approach to designing and implementing health research measures

3) List reasons to include Deaf people in health research
33 Prevention Research Centers (PRCs)
NCDHR

A CDC-Funded Prevention Research Center

Mission

Health Promotion & Disease Prevention with Deaf people & families through CBPR
The Challenge

• LACK OF DATA
  • Health Disparities in Minority Communities
  • 2010 Healthy People

• LACK OF COHESIVENESS
  • How to collect information from the Deaf Community?
Contribution to understanding context & collaboration planning

• Creating collaborative partnerships for community engagement & Deaf health needs

• Working together to analyze health-identified priorities & goals (e.g., BRFSS)
Contribution to understanding context & collaboration planning (cont’d)

• Transforming ideas into action plan

• Seeking feedback from Deaf Health Community Committee (DHCC) and community partners
CBPR Approach to Survey Design and Implementation

- Involve Deaf & hearing members of the research team in survey development

- Create a framework for participation & influence in decision making

- Meet weekly to discuss and make decisions about survey implementation & design
METHODS

- Translated English items into ASL & Signed English
- Developed new items in ASL & translated into English
- Adapted English for captions
- Added Deaf specific items
METHODS (cont’d)

- Worked with community partners to prioritize topics
- Designed a computer-based survey interface
- Developed a survey dictionary
- Carried out in-depth cognitive interviews
- Developed recruitment strategies
Translation Work Groups (TWGs)

- ASL Team
- English-based Team

The Translation Process

- Back translated
- Addressed linguistic, cultural, medical & survey methodology challenges
The Collaborative Process of ASL Translation Work Group

- Discussed & analyzed each question item
- Reached mutual agreement on ASL translations relating to semantics and survey intent
- Filmed TWG Deaf members signing translated ASL items
- DHCC selected 6 sign models for the survey
Survey Development

Adjust sign window size
Adjust sign window background color
Survey section title
Adjust text size
Quit survey at any time

Progress bar
Touch “x” to close sign window
Touch tab to change sign model
Touch “x” to close caption window
Captions based on back-translation
Letter connects video with English text
Touch to return to prior question
Touch to advance to next question
Green indicates choice selected. Touch again to de-select

You are a man.

? Are you female or male?
A female
B male

Quit survey at any time
NCDHR Evolution: The Collaborative Process

Deaf Health Community Committee (DHCC)

Executive Committee – a DHCC representative

Research Committee – DHCC representatives

Interface Working Group

Cognitive Interviews

Deaf Researchers, Interns & Fellows in Training

Full Time Staff Interpreter
Reasons to Include Deaf People in Health Research

• Culture as a way of describing the lives of Deaf people: beliefs and practices
• Important role of ASL
• Long history of interacting with the world (Padden & Humphries, 2005)
• Deaf perspective
• Deaf experience from childhood to adulthood
• Knowledge of ASL and Deaf culture
• Advice on how to work with Deaf people in health settings
Survey Development Results

Shared Collaboration

First Comprehensive Health Survey in ASL

Prioritized List of Health Issues for Intervention

Future Research: More favor for computer-based ASL surveys
NCDHR is supported by Cooperative Agreement U48 DP000031 from CDC. The contents of this presentation are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

Steven Barnett is supported by grant K08 HS15700 from the Agency for Healthcare Research and Quality.

Thank you to all the research participants, community partners, and researchers.
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