

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

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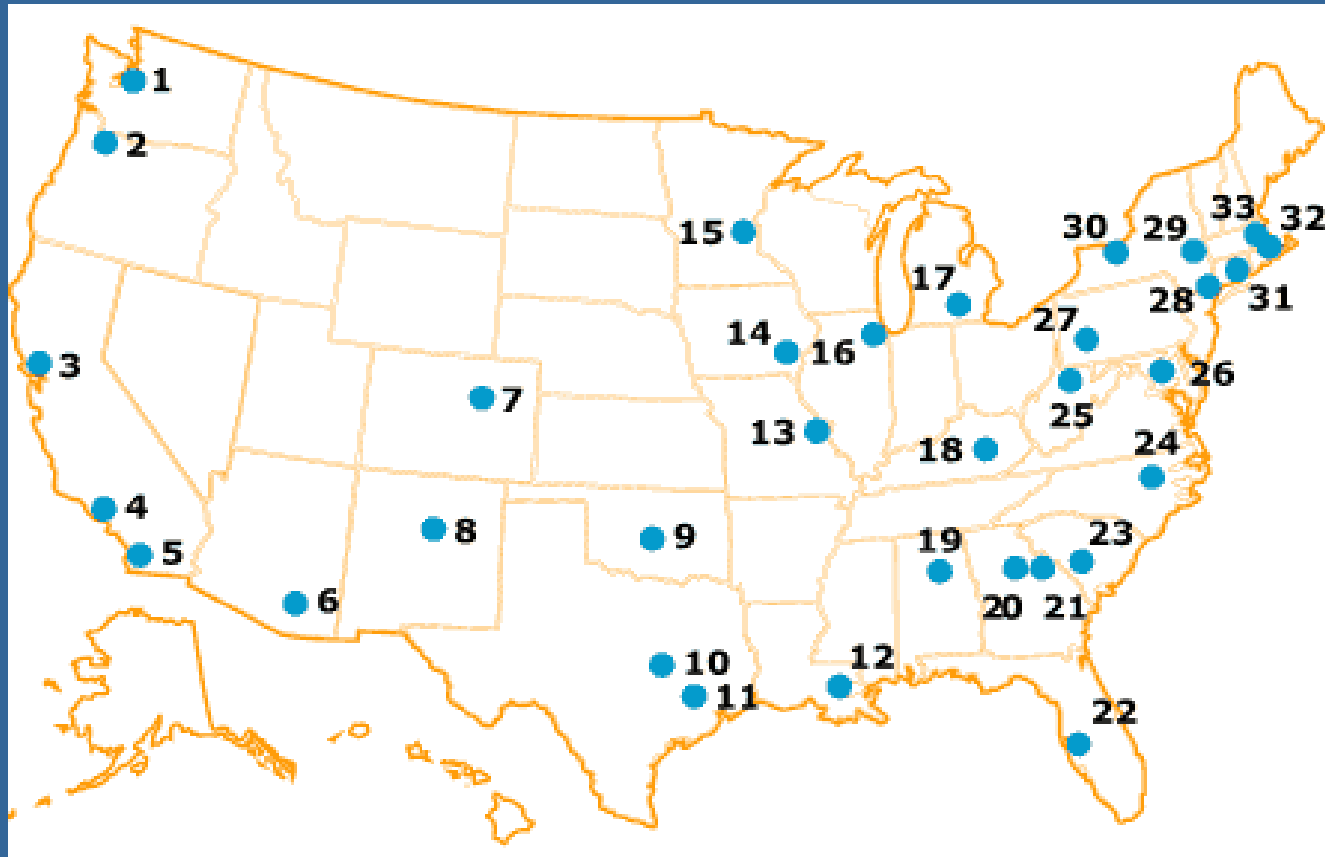
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National Center for Deaf Health Research



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)

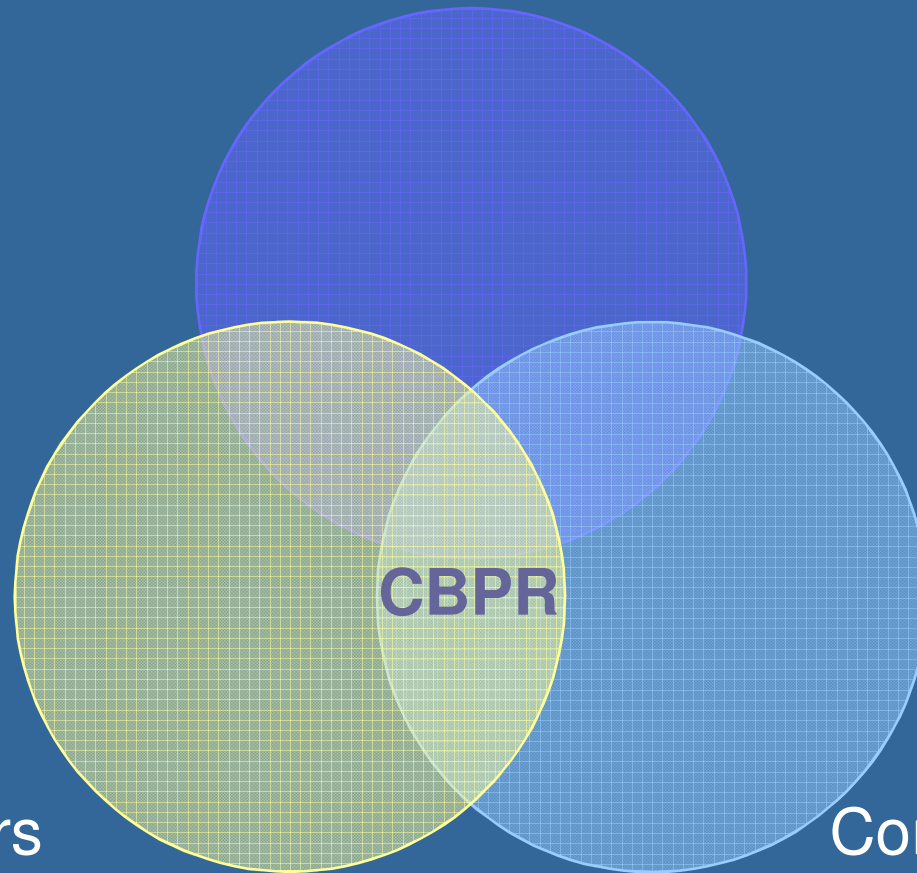
Contribution to understanding context & collaboration planning (cont'd)

- 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

Partners



Researchers

Community members

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

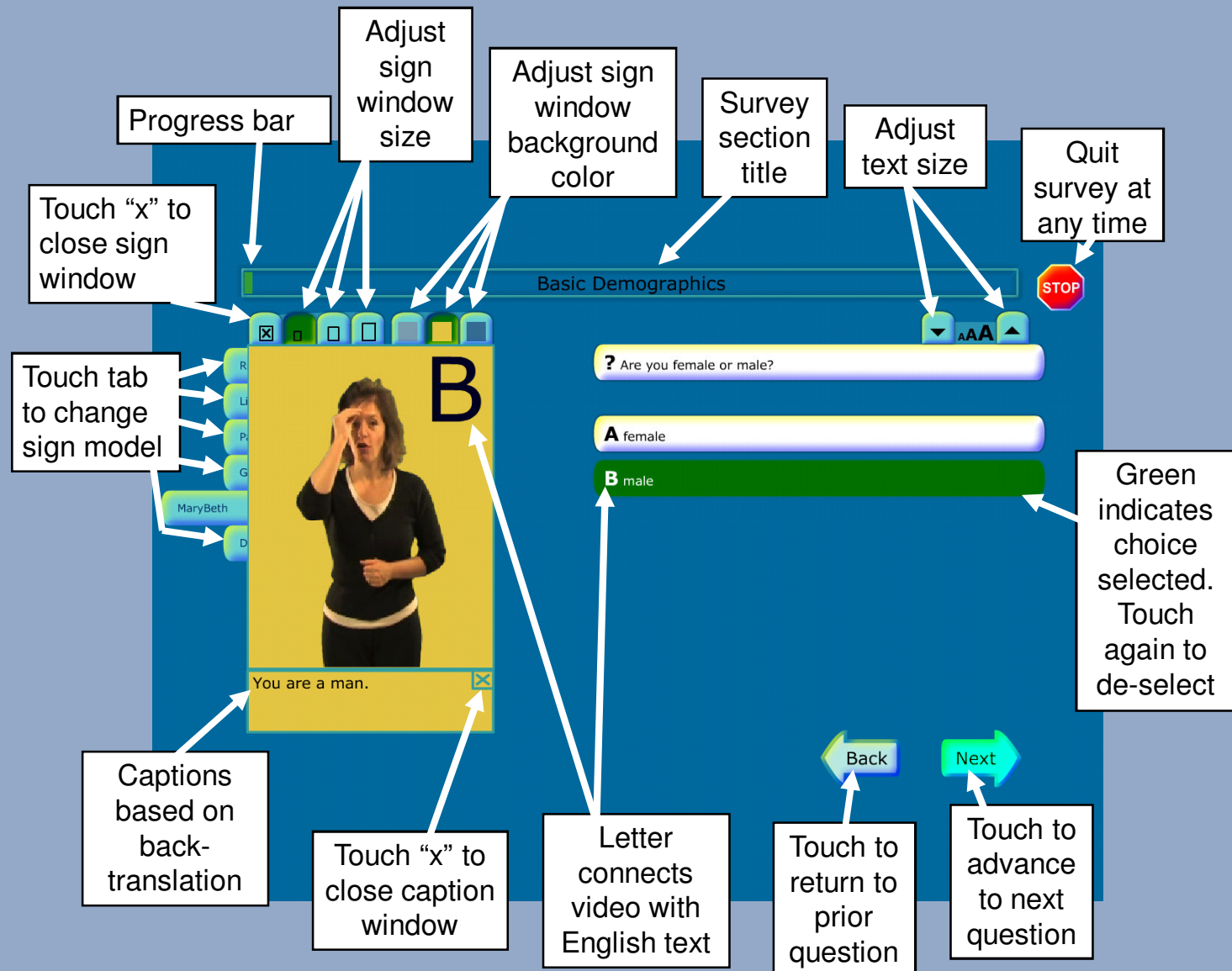
The Translation Process

- 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



NCDHR Evolution: The Collaborative Process

Deaf Health Community Committee (DHCC)

Executive Committee – a DHCC representative

Research Committee – DHCC representatives

Interface Working Group

Cognitive Interviews

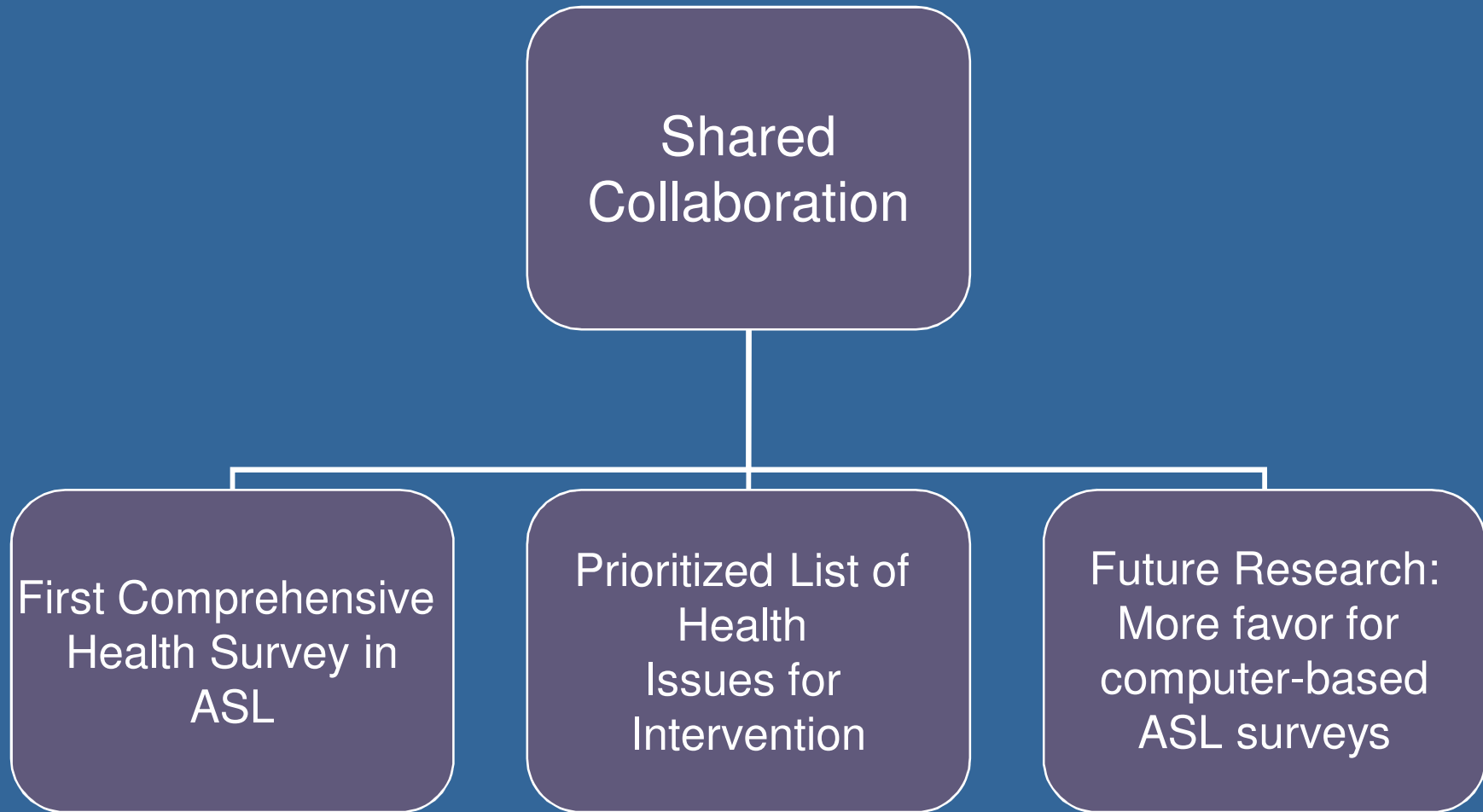
Deaf Researchers, Interns & Fellows in Training

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



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