

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

Deirdre Schlehofer, MPhil

Steven Barnett, MD

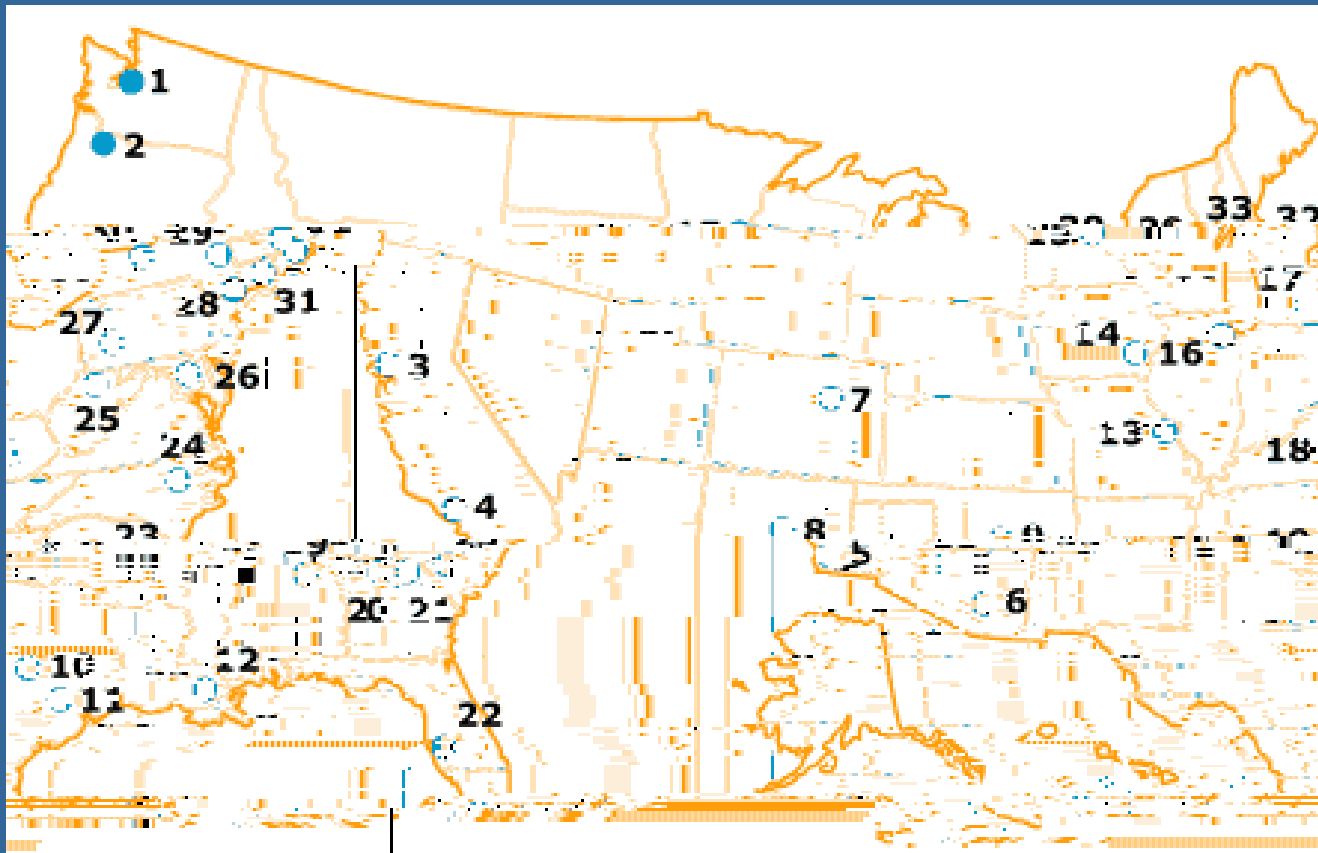
Rochester Prevention Research Center  
National Center for Deaf Health Research



# 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 problems & goals (e.g., BRFSS)

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

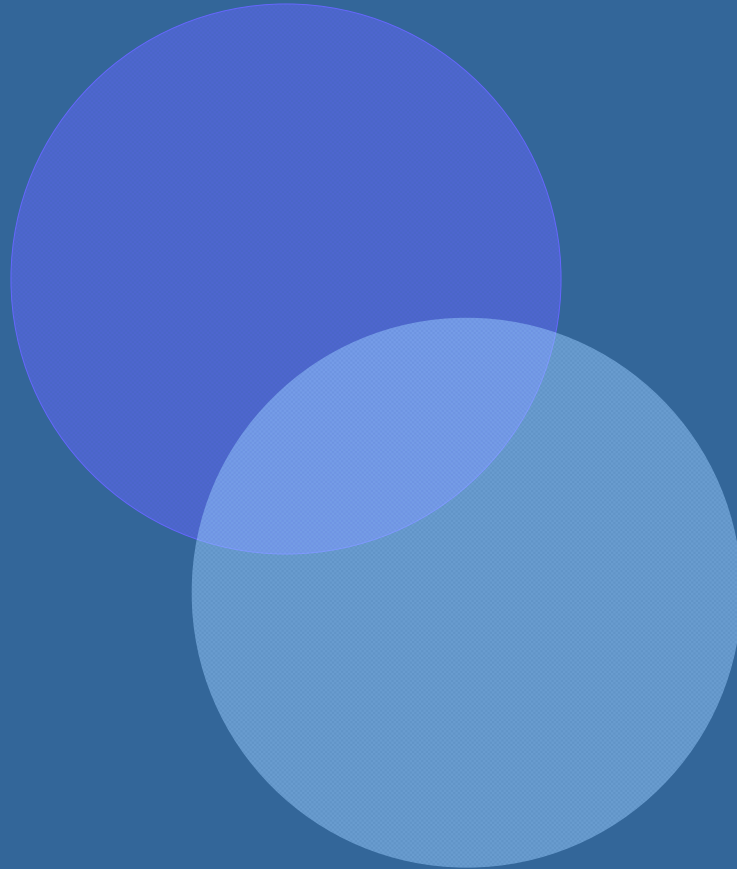
- Transforming ideas into action plan
- Seeking feedback from Deaf Health Community Committee (DHCC) and community partners

# 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



# 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 Translation Work Group

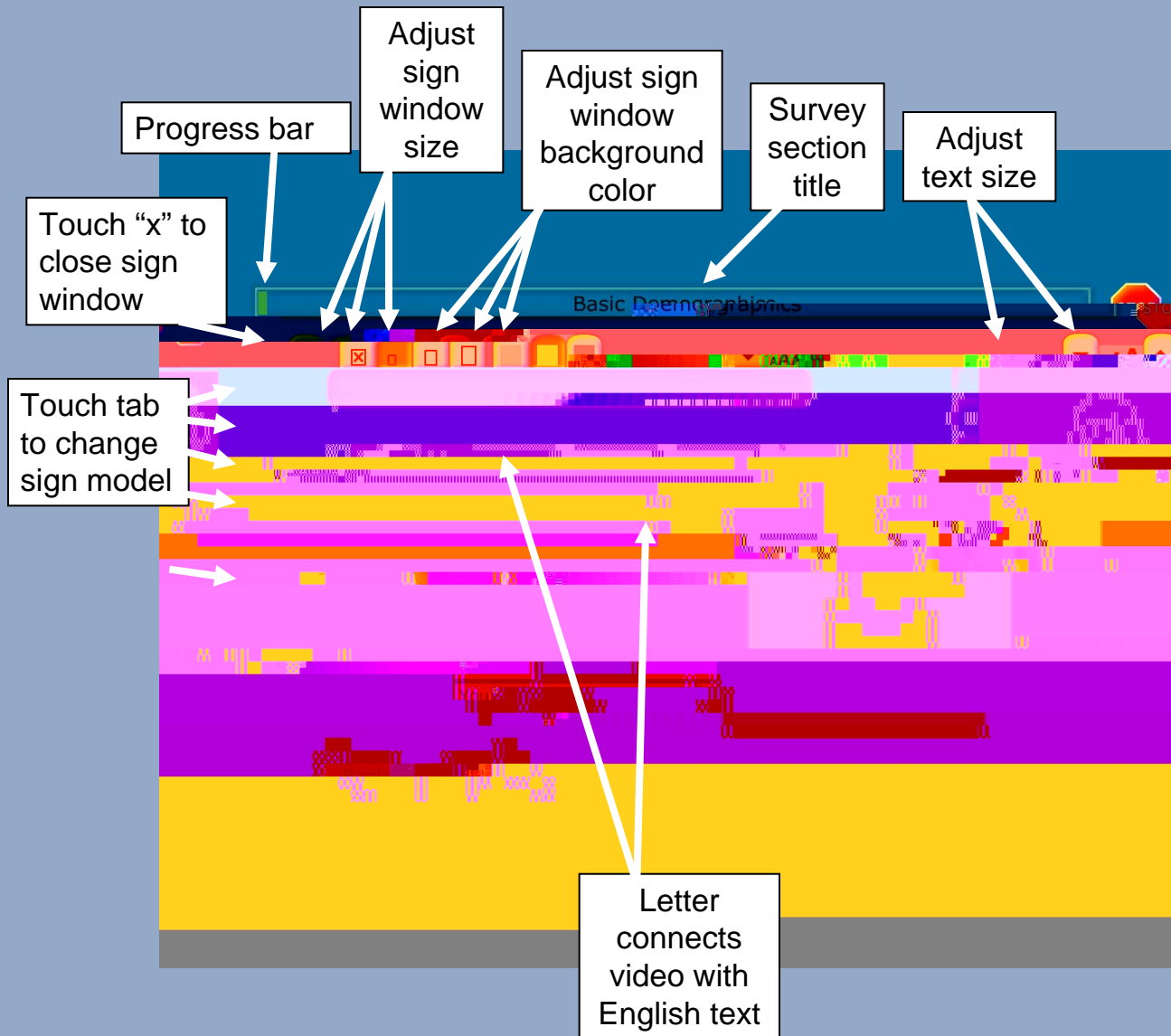
Discussed & analyzed each question item

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 – a DHCC representative

Interface Working Group

Cognitive Interviews

Deaf Researchers, Interns & Fellows in Training

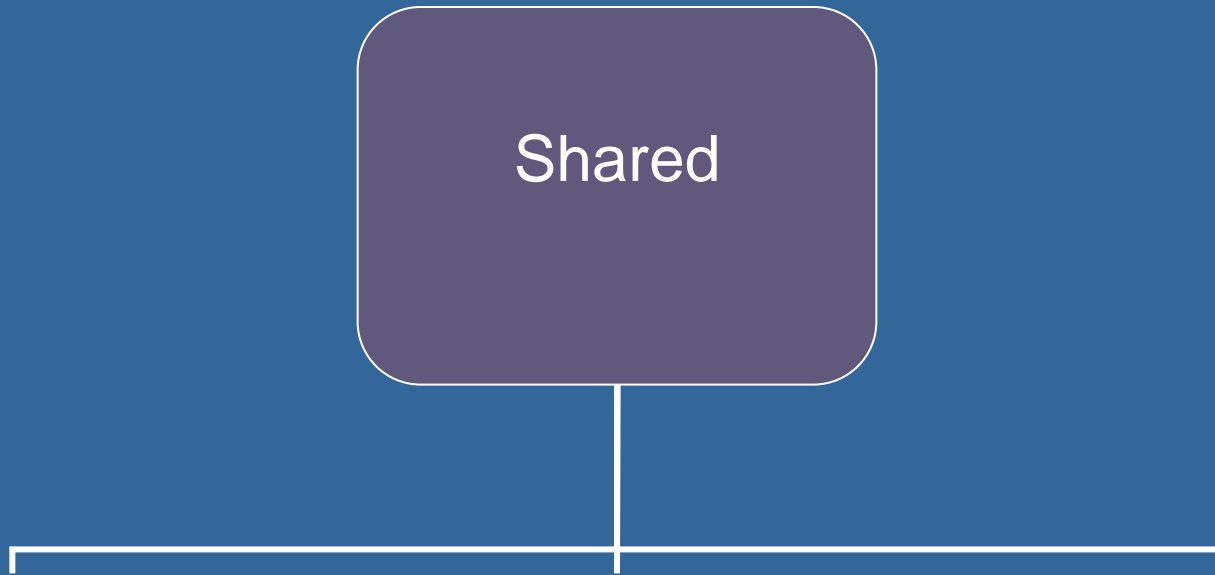
Full Time Staff Interpreter

# Reasons to Include Deaf People in Health Research

- Culture as a way of describing the lives of Deaf people: beliefs



# Survey Development Results



Rochester Prevention Research Center  
National Center for Deaf Health Research  
University of Rochester  
Medical Center

[NCDHR@urmc.rochester.edu](mailto:NCDHR@urmc.rochester.edu)  
[www.urmc.edu/ncdhr](http://www.urmc.edu/ncdhr)

This presentation was supported by Cooperative Agreement Number U48-DP-000031 from the Centers for Disease Control and Prevention (CDC). The findings and conclusions in this newsletter are those of the author(s) and do not necessarily represent the official position of the CDC.