Identifying and addressing disparities through community-based participatory research with deaf people: Experiences of a Prevention Research Center

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Rochester Prevention Research Center: National Center for Deaf Health Research (NCDHR)

Introduction

Deaf people who communicate with American Sign Language (ASL) comprise a linguistic minority population that is frequently excluded from health research.

Many adults deaf since birth or childhood use ASL, which is different from English and has no written form.

For complex reasons, many deaf adults have low English literacy.

Health surveys are often inaccessible to deaf people. Issues include:

- -Survey modality
- -Survey language
- -English literacy
- -Language fluency
- -Fund of information
- -Mistrust
- -Prior survey experience

The lack of health research data limits the ability of the community and public health system to identify & address health priorities.

The mission of the CDC-funded Rochester Prevention Research Center: National Center for Deaf Health Research (NCDHR) is health promotion and disease prevention with deaf people and their families through community-based participatory research (CBPR).

An initial NCDHR research project is to adapt the Behavioral Risk Factor Surveillance System (BRFSS) for use with deaf adult ASL-users in order to collect baseline data on health & health risks.

Methods

To create an accessible survey, we:

(a) translated the English BRFSS items into sign language (and back-translated),

(b) adapted the English for captions,

(c) added deaf-specific items,

(d) worked with community partners to prioritize topics,

(e) designed the computer-based survey,

(f) developed a dictionary to address fund-of-information deficits,

(g) conducted in-depth individual cognitive interviews to evaluate the survey,

(h) developed recruitment strategies for further field-testing.

The research was approved by the University of Rochester Institutional Review Board.

Translation/Adaptation

In addition to translation, we adapted some items to preserve clarity. An example:

English

What is the highest grade or level of school that you have completed?

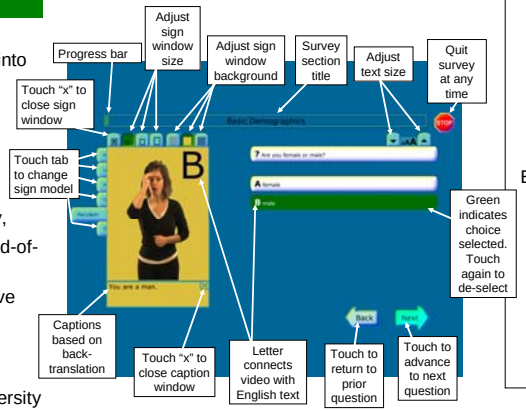
__ 8th grade or less
__ Some high school, but did not graduate
__ High school graduate or GED
__ Some college or 2-year degree
__ 4-year college graduate
__ More than 4-year college degree

ASL format

Did you graduate high school or get your GED?
-If Yes: After HS, did you go to college?
--If Yes: What degree do you have?
-If No: Did you go to high school?
--If No: Did you finish 8th grade?
---If No: Did you finish Kindergarten?
-If Don't know: Did you go to high school?
--If No: Did you finish 8th grade?
---If No: Did you finish Kindergarten?

Instrument

We developed a survey that worked on a touch-screen computer kiosk. We designed the survey to be accessible to a broad segment of the population. We tested the survey design with members of the deaf community, and adjusted the design based on feedback.



Data Collection

We administered the NCDHR Deaf Health Survey in Rochester to 302 non-institutionalized adults from March to September 2008. Approximately half took the survey at the NCDHR office, either by appointment or as a walk-in. Others took the survey at community sites, such as the Rochester Recreation Club for the Deaf (RRCD), often during a community event. For a few individuals with limited transportation, NCDHR staff brought the survey to their home.

We also administered the NCDHR Deaf Health Survey to 215 of the more than 700 adults who attended the 40th Anniversary Reunion of the National Technical Institute for the Deaf (NTID) in Rochester June 26-28, 2008.

Demographics

Below are demographics for the first 283 adults from the Rochester Metropolitan Statistical Area (MSA) who took the survey.

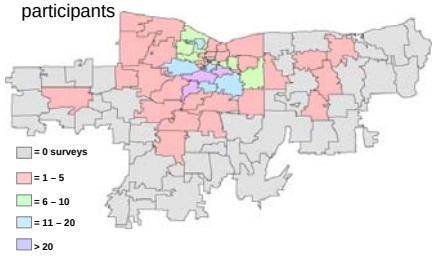
Age range……	18 – 88 yo
Age mean ……..	46 yo
Female	50.4%
Married	48.9%
Hispanic/Latino	2.6%
Race	
White	85.6%
Black/African-American	4.9%
Asian	2.7%
American Indian	1.1%
Other/Multi-racial	5.7%
Education (highest level)	
Some HS	5.3%
HS grad	11.5%
Some college	11.8%
Two-yr degree	22.9%
Four-yr degree	20.6%
Graduate degree	27.9%

Deaf Demographics

Deaf parent or sibling	29.3%
Usher syndrome	2.2%
Education (type attended)	
Only deaf schools	43.5%
Never a deaf school	20.8%
Deaf school & other	35.8%
Age-at-onset of deafness	
Birth	70.2%
< 1yo	9.5%
1 - 7yo	14.9%
Don't know	4.2%

Geography

Home ZIP code of Rochester MSA survey participants



Discussion

Even with collaboration, recruitment challenges remain in reaching certain groups (race, education level, geography).

We do not know how representative our sample is of the Rochester deaf population because there are no data.

Informed consent in health research has not been studied with deaf ASL-users. Discussions amongst community members, researchers & members of the Institutional Review Board (IRB) helped develop relationships & protect participants.

Traveling to take a survey at a kiosk location is fundamentally different than taking a survey at home via telephone.

The Rochester deaf community is not representative of other US deaf communities. It is likely that findings from the Rochester Deaf Health Survey will underestimate health disparities experienced by deaf people.

Conclusions

Deaf people and their families are at risk for unrecognized health disparities because of lack of data.

Community-based participatory research (CBPR) is essential for adapting surveys.

Our computer-based BRFSS enhances access to a difficult-to-reach understudied health disparity population.

Next Steps

Work with partners to:

1) Interpret survey findings.

2) Compare results with those from the local BRFSS of the general population.

3) Collaboratively identify health priorities.

4) Develop & evaluate linguistically and culturally appropriate health promotion interventions.

5) Continue to develop accessible surveys.

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Contact

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