

NCDHR Core Research Project, 2004-2009

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).

The Deaf Health Community Committee (DHCC) is NCDHR's main interface with the Rochester Deaf community. DHCC members are involved in all aspects of the research.

The NCDHR Research Committee is a multidisciplinary team of deaf and hearing people, including faculty from National Technical Institute for the Deaf (NTID).

A challenge is that we have no baseline health data that we can use to identify and address health priorities with the Rochester Deaf community.

Existing public health surveys are inaccessible for deaf people who communicate with American Sign Language (ASL) for a number of reasons.

NCDHR's initial core research project is to collect baseline data by first adapting a health survey to be accessible and culturally & linguistically appropriate for use with deaf adult ASL-users.

Deaf and hearing people worked together to

- Prioritize survey topics
- Choose survey items (questions & response options)
- Add deaf-specific survey items (e.g. age-at-onset, attended a deaf school, ...)
- Assign translation teams
- Translate the survey items into ASL and an English-based signing
- Video-record the survey items (ASL has no written form)
- Back-translate the survey items to check for accuracy
- Develop the computer-based survey interface
- Evaluate the computer-based survey interface (hardware & software) through beta-testing
- Evaluate the sign language items through a series of in-depth cognitive interviews
- Develop recruitment strategies, including through collaboration with community organizations, such as the Rochester Recreation Club of the Deaf (RRCDD)
- Conduct exit interviews with some survey participants, and adjust our methods based on the feedback

In 6-months in 2008, 302 deaf adults took the survey in the Rochester region.

Our Monroe County comparison data is from the telephone Adult Health Survey conducted by the Monroe County Department of Public Health.

Survey topics include: health & healthcare, preventive services, diabetes, heart disease, weight, tobacco & alcohol, sex, violence and mental health.

In preliminary analyses, we identified some Deaf community strengths as well as areas for health concerns.

