

Welcome to the NCDHR **a member of the Prevention Research Centers Program**

NCDHR Mission:

To promote health and prevent disease in the Deaf population through community-participatory research.¹

Our research includes identification and prioritization of the Deaf community's health needs, development of effective and inclusive interventions, communication and dissemination of the Center's findings, and evaluation of the Center to assure its contribution to the local, state, national and international Deaf communities and the national Prevention Research Center Program.

PRC Program:

In 1984, Congress authorized the Secretary of the U.S. Department of Health and Human Services (HHS) to create a network of academic health centers to conduct applied public health research. The CDC was selected to administer the Prevention Research Centers (PRC) network and to provide leadership, technical assistance, and oversight (www.cdc.gov/prc).

Today, CDC supports 33 centers, including NCDHR, associated with schools of public health, medicine, or osteopathy throughout the country. Each center conducts at least one core research project with an underserved population that has a disproportionately large burden of disease and disability.

Guiding Principles for the NCDHR:

Our Center's goals, activities and objectives are guided by the premise of the "Cultural Model" (i.e., Deaf people share a common language and a common culture), not the "Clinical-Pathological Model" (Deaf people who are not "normal" because they cannot hear). As a result, community buy-in and interest by Deaf Americans has been tremendous.

Problem Statement:

"Little is known about disease trends, underlying attitudes, or health behaviors among Deaf or hard-of-hearing people," says Thomas A. Pearson, M.D., Ph.D., MPH, FACPM and Principal Investigator/Director of NCDHR. "This population is woefully understudied and underserved."

Leadership:

Thomas A. Pearson, MD MPH PhD (thomas_pearson@urmc.rochester.edu) – Program Director
Steven Barnett, MD (steven_barnett@urmc.rochester.edu) – Associate Director
Julia Aggas, MS – Chair, Deaf Health Community Committee

Partners:

Deaf Health Community Committee²
Finger Lakes Health Systems Agency
Monroe County Department of Health
National Technical Institute for the Deaf at Rochester Institute of Technology
Rochester School for the Deaf

Mission of Deaf Health Community Committee:

The Deaf Health Community is a partnership between Deaf Communities, researchers and health care providers to promote an understanding of the health needs of culturally Deaf people (American Sign Language users), to identify issues essential to creating parity between the Deaf and general population, across the nation.²

Rochester’s Deaf Community:

Rochester, NY is the home of one of the largest concentrations of Deaf people in the country. It is estimated that there are 10,000 to 15,000 residents whose primary language is American Sign Language (ASL). ASL American Sign Language is a visual-gestural language with its own unique grammar.

Core Research Project: Determinants of Risk and Risk Behaviors in the Deaf Population

This project is meant to assess the levels and determinants of risk behaviors and disease in the Deaf population, and contrast these findings with local and national comparators as well as Healthy People 2010 objectives, in order to better define health disparities in the Rochester Deaf population. Also, this core project is meant to develop generalizable measures and methods that are applicable to research and health surveillance in Deaf populations in other locations and institutions.

Adaptation of segments of the BRFSS, YRBS, and NCHA to be accessible to “various populations of Deaf people” such as those who use ASL and those who do not but have low English literacy skills are now in progress.

NCDHR’s Cross-Cultural Research Training Curriculum:

Opportunities are available for researchers to conduct cross-cultural research, involving culturally Deaf participants, that is of high ethical and scientific quality, which responds to Deaf community priorities and perspectives, that results in new and valid knowledge, and that yields meaningful benefits for researchers and community members alike.

Setting National Deaf Health Agenda (pending):

A Consensus Conference on Health Research with the ASL population will be conducted. NCDHR will work with local and national collaborative partners to bring together from across the country Deaf community leaders, clinicians, researchers, interpreters and representatives of community service organizations and government agencies. Because the conference participants represent all the stakeholders related to health and Deaf people, the resulting research agenda will have broad acceptance and will guide efforts to address disparities in health and health services research. This will help us achieve Healthy people 2010 goals related to health of people with disabilities.

Other Principle Activities of the NCDHR:

Training and Education:

The Center will develop and provide health education to Deaf students at the elementary, high school and college levels, and to adults in community settings. It will train health professionals to better serve Deaf patients. It will train researchers in the methods necessary for research in the Deaf community; educate them in the issues of concern in the community; and provide mentored research experiences.

Dissemination:

The Center will publish research findings for the benefit of the Deaf community worldwide, and for possible application in other cultural, linguistic or disability communities.

Long-term Goals:

Over time, NCDHR will work with other community committees for hard-of-hearing, late-deafened and other deaf and hard-of-hearing groups who are not members of the ASL community. Furthermore, health promotion and disease prevention will be expanded to include Americans with disabilities, a community which has largely been inconspicuous in Healthy People 2010.

¹ “...we adopted the convention of using the capitalized “Deaf” to describe the cultural practices of a group within a group. We used the lowercase “deaf” to refer to the condition of deafness, or the larger group of individuals with hearing loss without reference to this particular culture. Using this distinction, Deaf people range from those who are profoundly deaf to those who hear nearly well enough to carry on a conversation in spoken English and use the telephone, called hard of hearing.” (Padden and Humphries, 1988).

² At least 51% of committee members are Deaf individuals who currently use ASL as a primary means of communication.

