



## **Welcome to the Rochester Prevention Research Center: National Center for Deaf Health Research (NCDHR)**

### **NCDHR Mission:**

To promote health and prevent disease in the Deaf population through community-based participatory research (CBPR).<sup>1</sup> 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 (PRC) 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.

Today, CDC supports 37 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.

### **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."

### **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).

### **Guiding Principles for the NCDHR:**

Our Center's goals, activities and objectives are guided by the premise of "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.

### **Partners:**

Deaf Health Community Committee<sup>2</sup>  
Local Partner Advisory Board (includes Monroe County Department of Public Health)  
National Technical Institute for the Deaf at Rochester Institute of Technology  
Rochester School for the Deaf  
Hearing Loss Association of America – Rochester (NY) Chapter  
National External Advisory Committee  
Deaf Health – Pathways: a medical humanities program of the University of Rochester School of Medicine and Dentistry

### **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.

### **Core Research Projects: Deaf Health Survey and Deaf Weight Wise Project**

This 2004 – 2009 core project was 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. NCDHR adapted the BRFSS<sup>3</sup> for use in sign language in a kiosk computer with touch-screen interface. The adaptation process included translation to ASL, transliteration to English-based signing, back-translation by independent reviewers who had never seen the BRFSS, computer interface design and testing, cognitive testing and exit interviews. Over 6 months, 339 Rochester deaf adults took the **Deaf Health Survey** (DHS). We used the Monroe County BRFSS telephone survey as our general population comparison group.

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Following the principles of CBPR, the topic of obesity prevention was selected by consensus with the Deaf community through a series of Town Hall meetings in which the first-ever DHS results were shared, a number of disparities were identified and prioritized, components of an intervention program were proposed, and an intervention with peer-reviewed publication of evidence for efficacy was selected.

The 2009 – 2014 core research project will test an overall hypothesis that an evidence-based, comprehensive program to modify health behaviors in hearing persons will be effective in Deaf persons who have heretofore had limited access to such programs. This project involves taking an existing obesity program to help people lose weight and be more active, and adapting it for the Deaf community. The existing program, developed by North Carolina PRC, has worked well there, and NCDHR wants to find out if it can be adapted to benefit the Deaf community. The first step for **Deaf Weight Wise Project**, which will start in October 2009, will be to take written program materials and convert them into ASL. Next, Deaf community members will be trained as program “coaches.” Finally, program participants will be recruited from the Deaf community to be involved in a test of this program. The Deaf community coaches will lead the program. Half of the community members will start the program right away. The other half will start 6 months later. NCDHR researchers will collect data throughout to find out if the program works as intended. The center hopes to begin the test sometime in 2011.

**Data-Sharing:** Investigators who are interested in learning more about NCDHR’s Deaf Health Survey and other research findings should contact NCDHR. Requests for data analyses and access to datasets are subject to review by the NCDHR Research Committee and the Deaf Health Community Committee. The NCDHR Executive Committee reviews and manages data use agreements with investigators who are interested in conducting their own hypothesis-driven analyses using an NCDHR dataset.

### **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.

### **Other Principle Activities of the NCDHR:**

#### **Training and Education:**

The Center will develop health education guidelines for teachers of Deaf students at the elementary, high school and college levels, and to adults in community settings. It will train deaf and hearing health professionals to better serve Deaf patients. It will train deaf and hearing 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. The NCDHR sponsors Deaf Strong Hospital, an experiential learning program for medical students in which they navigate through a simulated “hospital” staffed by Deaf volunteers.

#### **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. Its website ([www.urmc.edu/ncdhr](http://www.urmc.edu/ncdhr)) provides contents in ASL and English. ASL, which is a visual-gestural language, is conveyed by means of video blogging (“vlogs”).

<sup>1</sup> “...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).

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

<sup>3</sup> Behavioral Risk Factor Surveillance System ([www.cdc.gov/brfss](http://www.cdc.gov/brfss))