An Overview of Deaf Health Research Organization at University of Rochester

What is NCDHR?
National Center for Deaf Health Research.

What is the mission of NCDHR?
To promote health and prevent disease in the Deaf populations through community-based participatory research (CBPR).

What is CBPR?
It is a collaborative process of research involving researchers and community representatives; it engages community members, employs local knowledge in the understanding of health problems and the design of interventions, and invests community members in the processes and products of research.

Who are NCDHR’s partners?
The NCDHR maintains a close partnership with the local Deaf Community, primarily through the Deaf Health Community Committee (DHCC). The DHCC is closely involved in all phases of NCDHR research, from the development of research project proposals, to carrying out the research, to interpreting and disseminating research findings. Other important partners include the National Technical Institute for the Deaf at Rochester Institute of Technology, the Rochester School for the Deaf, the Rochester Recreation Club for the Deaf, and many other local and national organizations.

What NCDHR does?
NCDHR identifies and prioritizes health needs of Deaf-and-hard of hearing people, develops and evaluates interventions to improve health, and disseminates findings.

How is NCDHR supported?
The NCDHR is part of the University of Rochester Medical Center. Core funding for the Center is provided through the Prevention Research Centers (PRC) Program of the Centers for Disease Control and Prevention (CDC). The Center recently received a second five-year (2009—2014) grant to continue its work.

What is 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 35 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.

Does CDC have a website about the PRC Program?
Yes. The website address is: www.cdc.gov/prc

Why do Deaf Health Research?
Little is known about disease prevalence among Deaf people, their health literacy, attitudes toward health-related issues or health risk behaviors. Many, if not most, health interventions are not accessible to deaf people.

Does NCDHR do research on hearing loss?
No. The Center espouses a “cultural model” of Deafness, meaning that it considers Deaf people to be members of a cultural and linguistic community, rather than a set of people with a medical condition (hearing loss) that should be treated.

What is Deaf Health Survey?
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 BRFSS3 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 DHS. We used the Monroe County BRFSS telephone survey as our general population comparison group.

I am interested in doing research on Deaf Health. How can I access your data?
Researchers 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 researchers who are interested in conducting their own hypothesis-driven analyses using an NCDHR dataset.

What is Cross-Cultural Research?
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.

What are NCDHR’s research plans for 2nd funding cycle?
The Center’s core research project in its second five-year grant cycle will be the development and testing of an intervention to reduce obesity and increase physical activity in the Deaf community. The first step, 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.

I am a community member and I would like to become involved with Deaf Health Community Committee. Who should I contact?
You may contact Chad A. Ludwig, Vice-Chair of DHCC. He is responsible for recruiting new members of DHCC. His e-mail address is ludwigdhcc@gmail.com.

Who should I contact for more information about NCDHR?
Matthew Starr, MPH
National Center for Deaf Health Research
University of Rochester Medical Center
120 Corporate Woods, Suite 350
Rochester, NY  14623
585-286-2721
matthew_starr@urmc.rochester.edu

I am interested in participating in future surveys and research projects with the Deaf Community. Who should I contact?
Matthew Starr (see above).

I am hard of hearing person. How can I become involved with NCDHR?
A health Task Force comprised of hard-of-hearing partners will be convened during first quarter of this year. Contact Matthew Starr (see above) for more information.

I am a student (High School or college undergraduate) and I am interested in internship or summer research opportunities, who should I contact?
Kim Kelstone at kim_kelstone@urmc.rochester.edu
For more information, check out www.urmc.edu/ncdhr.

I am a health care professional and I am interested in learning about Deaf Health. Who should I contact?
Nancy Chin, MPH, PhD, chair of the NCDHR’s Training & Education. NCDHR 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.

Does NCDHR have a website?
Yes, the website address is www.urmc.rochester.edu/ncdhr.

Does NCDHR have a Fan Page in Facebook?
Yes.

What else can I become involved with NCDHR?
NCDHR has an e-mail listserv for people that care about NCDHR. It is called NCDHR News.

What is a listserv?
A long list of e-mail addresses. When we send a message to the listserv, it goes to everyone on then list. NCDHR will send news and announcements.

How can I sign up to be on NCDHR News listserv?
Just ask us at NCDHR@urmc.rochester.edu