We made it! Historic Milestone in Deaf Health Research! Tom Pearson

The Rochester Deaf Health Survey (DHS) is truly a milestone in Deaf Health Research in a number of ways. First, it is by far the largest and most comprehensive survey of health and health behaviors in deaf persons to date. Prior surveys have been limited to fewer than 150 persons; the DHS had over 300. Second, it used ASL translation of standard questions that are asked annually in 49 of the 50 states by health planners to assess the health of communities. The results for deaf persons can be compared to the rest of the U.S., or to Monroe County, to look for disparities between deaf and hearing people. Third, the use of ASL greatly helps the reliability of the information collected, rather than relying on a person’s knowledge of their second language (English). Fourth, the use of computer-based videoclips made sure that each question was asked by the ASL interpreter in the same way. All prior surveys used ASL interviewers who may give and receive translations differently from one to the next. The participant, using the DHS, could provide answers in a confidential and anonymous setting. Finally, and perhaps most importantly, the Rochester Deaf Community played a huge role in the survey from planning, development of questions, modeling on film, recruiting participants, and interpreting and prioritizing the data. All these ways make the DHS truly a milestone in Deaf Health Research.

Town Hall Meetings for 2nd Deaf Health Research Thomas Fogg

NCDHR thanks everyone who participated in our Town Hall Meetings! The goal of the meetings was to get community input and ideas regarding the grant application that we submitted to the Centers for Disease Control and Prevention (CDC) on October 8. With your help, we wrote a wonderful grant application, and we have high hopes that it will result in continued funding for our center.

We hosted five meetings at our offices in Corporate Woods. The dates were August 26 and 27, and September 2, 3 and 25.

During the first meeting, NCDHR faculty and staff described the history of the NCDHR, and presented preliminary analyses of the Deaf Health Survey. We then discussed the community’s health priorities based on the survey data. During the next three meetings, NCDHR presented preliminary ideas regarding the grant application, especially research plans, and got feedback. At each meeting, we presented improved plans based on the feedback we got at the previous meeting. The last meeting took place after 3 weeks of writing the grant. It was a final opportunity for community members to give advice and feedback before we finalized the application.

In spite of busy schedules and other demands, 28 community members attended at least one meeting. Two community members attended all 5 meetings! We appreciate everyone’s participation during a very busy time of year that included the Labor Day holiday and Deaf Awareness Week. In between the Town Hall Meetings, several members of the Deaf Health Community Committee (DHCC) met with NCDHR investigators to discuss details of our plans.

Meeting highlights: The community members that attended our meetings thought that the upcoming grant should focus on public health programs to reduce obesity.

Community members believed that the mission of the NCDHR is still good: to promote health and prevent disease in deaf and hard-of-hearing populations through community-based participatory research.

Community members suggested that NCDHR training programs should include plans to attract young deaf people into research careers.

Next month’s edition of Healthy Signs will describe the grant application. CDC and reviewers from outside the CDC will now read our grant, and all the others that were submitted. The CDC will announce their funding decisions in February or March of next year. Stay tuned!
Focus Groups on Deaf Perceptions of Heart Health

A focus group is an interview done with a group of people on a particular topic. A moderator guides the conversation and takes notes on what is said or signed. Focus groups are one way researchers and community leaders learn more about the communities with whom they collaborate.

Four focus group sessions were completed in September to learn how much Deaf people understand about cardiovascular disease (CVD). CVD involves the heart and blood vessels, and may result in heart attacks or strokes. Risk factors for CVD include high cholesterol levels, high blood pressure, and diabetes. Deaf moderators and assistants from NCDHR ran the four sessions. Twenty-two people from the Deaf community participated. Two sessions were held at the Rochester Recreation Club for the Deaf and two at NCDHR. All participants were given $25 Wegmans Gift Cards for their time.

NCDHR Happenings

Susan Demers Postlethwait, who served on the Deaf Health Task Force in 2003, led the DHCC as its first Chair for three years and worked as a full time NCDHR Coordinator, will be returning to her home roots in Boston. She committed nearly five years of her time in supporting Deaf Health Research. We wish her the best of luck with her new job at the Massachusetts Commission for the Deaf and Hard of Hearing!

The leadership for Deaf Health Community Committee has changed “hands.” Jessica Cuculick will now serve as its Chair for a one-year term.

Julia Aggas, who previously served as the Chair now holds the title of “Past Chair.” She will offer mentoring to the new officers. Jessica and Julia will be attending the annual retreat of the National Community Committee, hosted by the community committee of West Virginia University Prevention Research Center (PRC) on October 19 - 22. Each of the 33 PRCs throughout the country sends at least two representatives of their community committees to NCC. All attendees will learn and exchange information on how to foster community-based participatory research.

NCDHR has been awarded supplemental funding to hire a full-time staff ASL interpreter. The job posting has just been placed on the University of Rochester’s Human Resources website: www.rochester.edu/working.

Additionally, NCDHR will be hiring for an Administrative Assistant position. For more information, contact NCDHR at 585-276-2120 VP or 866-634-7863 Voice.

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Cathie Armstrong, Mistie Creamer and Diane Williams have joined DHCC as new members.

Deaf Strong Hospital 2008

We had a successful annual Deaf Strong Hospital (DSH) event last September at the Medical School. Over 100 medical students took part of this once-in-a-lifetime role-playing experience as hearing patients in a Deaf world where doctors, pharmacists, receptionists and others are Deaf and communicate in ASL. The day kicked off with volunteer training then the role reversal activities for students began in the afternoon. They tried to communicate with others who do not speak their language. After their journey into the Deaf world, the students attended an eye-opening lecture on Deaf Culture delivered by Jessica Cuculick. The day wrapped up with small group discussions where they shared their experiences.

Exclaimed one of the medical students, “I absolutely loved this experience. Seeing the barriers from the other side make it so clear that we need to work on the field of communication.” The event is made possible by over 30 Deaf volunteers. “I enjoy coming here every year. It is on-going fun throughout the day for me,” says one of the volunteers.

Volunteers received DSH scrub shirts to wear throughout the day and as a souvenir.

NCDHR looks forward to DSH 2009!

Focus Groups on Deaf Perceptions of Heart Health

Nancy Chin

All sessions were videotaped for data analysis. All information about participants is kept confidential and no one’s name is associated with their comments. The videotapes are destroyed after the analysis is completed.

One of the early findings from the analysis is that social support offered by the Deaf linguistic community is a key factor in obtaining health knowledge and in using that knowledge. Many of the participants also identified stress as a major cause of poor health, generally. These participants have expressed strong interest in learning more about their health, especially heart health, if the information is made available in a culturally and linguistically appropriate way.

NCDHR will soon collaborate with other Prevention Research Centers in other states (Colorado, North Carolina and West Virginia) to set up additional focus group sessions with the Deaf people living in their communities.