

## Completed Research Projects With CDC-EHDI Funding

### ***Deaf People and Health Measures: Is a Database Feasible? - University of Rochester, Department of Family Medicine***

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**Background:** Adults deaf since childhood are understudied in terms of their health and health care experiences. Evidence suggests that adults deaf since childhood make up a medically underserved community, although they are not frequently recognized as such. The health care experiences of adults with childhood onset deafness differ from those of adults in the general population, as well as those of people who became deaf as adults.

**Purpose:** The overarching goal of this project was to facilitate participation in health services research by members of the deaf community by fostering partnerships between health care, academic, and deaf community organizations. This formed an essential part of exploring the feasibility of a database to help monitor the health of members of this underserved group. A secondary goal was to explore attitudes and beliefs regarding health services research among members of the deaf community.

**Methods:** Focus groups were conducted in American Sign Language (ASL). Through these focus groups members of the deaf community participated in current health services research and helped direct future health services research. The Rochester Deaf Health Task Force (RDHTF), a board comprising members of the deaf, health care, and academic communities, was established. The RDHTF partnered with the Finger Lakes Health Systems Agency (FLHSA), a community health planning agency, to conduct the focus groups.

**Summary of Results:** Through the focus groups, the RDHTF identified and prioritized barriers to health care experienced by deaf people and their families. The RDHTF report summarizes these barriers and priority ratings and made recommendations regarding future research and health system changes.

Based on what was learned about the importance of trust and collaboration, the relationship amongst researchers, health care systems, and deaf people was determined to be too tenuous to begin establishing a health services database. This relationship is essential for the development of a health database for the deaf community. Instead, information gathered from the focus groups helped to form the basis for other collaborative research projects. These projects will help build the foundation of trust necessary to establish a successful health services database that collects information on deaf people and their families. These collaborative research projects will address some of the barriers and recommendations listed in the RDHTF report.

Importantly, the results from this study formed the basis for the establishment of the Rochester Prevention Research Center: National Center for Deaf Health Research (NCDHR). The University of Rochester Medical Center received an unprecedented \$3.5 million grant from the Prevention Research Center Program, which is managed by the National Center for Chronic Disease Prevention and Health Promotion at CDC, to conduct the nation's first comprehensive health studies of people who are deaf or hard of hearing. The goal is to prevent disease and improve overall health in these populations. In the first 5 years, working with many community partners, the Deaf Health Community Committee, and the National External Advisory Committee, the NCDHR will focus on the community of deaf ASL-users to develop and administer a health behavior survey that is accessible to this population. More information on the NCDHR can be obtained from the NCDHR website at: [www.urmc.rochester.edu/ncdhr](http://www.urmc.rochester.edu/ncdhr) (Updated 10/2006)