

Healthy Signs

December 2010

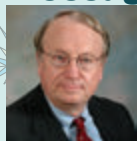
National Center for Deaf Health Research

Mission of NCDHR:

To promote health and prevent disease in the Deaf and hard of hearing populations through community-based participatory research.

Working for a Healthy Deaf Community

Message from the Director



NCDHR is now approaching the 7th year of growing collaborative relationships with its community partners, including the Deaf Health Community Committee (DHCC). These partnerships continue to grow tremendously. As I pointed out in my message in the December 2009 issue of Healthy Signs newsletter, "2000-2010: Ten Years Retrospective of Deaf Health Research," our community-based participatory research (CBPR) collaboration has opened a multitude of new doors for everyone with an interest in working for a healthy Deaf community. The stakeholders of NCDHR are exceptionally diverse: community leaders and members, applied public health researchers, academic leaders, health care providers, policy-makers and governmental entities. Our accomplishments often have invoked remarks such as, "...this was non-existent during my time," and "...unprecedented and highly beneficial knowledge." (See slide presentation posted in NCDHR website, "What have we accomplished?"). It is unequivocally astonishing that NCDHR has reached so many milestones in the face of limited resources and constraints.

The pace of our ground-breaking Deaf health research projects has been fast, and we have quickly built many collaborative relationships. It is wise to "pause" and "reflect" from time to time. Our achievements were not without some growing pains. While progress has been substantial, important issues emerged requiring further dialogue involving our evolving CBPR processes. Last Saturday, over 36 participants, both from NCDHR and the community, were engaged in our 2nd center-wide consensus-building retreat. During the first retreat in 2006, four themes emerged: (1) ensuring bilingual communication, (2) streamlining the Center, (3) improving communication within and between committees and (4)

redefining and embracing the role of DHCC. The latest retreat was guided by two "outside" facilitators, Dr. Robb Adams, Associate Dean for Student and Academic Services at the National Technical Institute for the Deaf (NTID) and Scot Atkins, NTID Deaf faculty member from NTID's Business Studies Department, who previously served as Senior Vice President of Human Resources in a large nonprofit agency with over 2,600 employees at 32 locations. All participants were engaged in a structured participatory process of issue identification, solution generation and prioritization. Discussion centered around 5 themes identified by DHCC members: transparency, communication, trust, respect and partnership. Four main ideas emerged from discussion: (1) regular orientation sessions for DHCC; (2) 100% full-time "chief operating officer" for NCDHR; (3) improve internal/external communication; and 4) regular evaluation. Specific action steps were identified for most of these ideas.



Implementing all of these ideas will prove to be challenging with current economic and political constraints. However, during the early days of the NCDHR, I heard from skeptics about whether we could achieve such ambitious expectations. Indeed, we have accomplished the nearly impossible, with the help of over 60 staff, faculty and volunteers, community leaders, committee members, the University of Rochester and Centers for Disease Control and Prevention. With that in mind, I have every confidence working together, we will find a way to conquer these challenges to bring our Center to yet another higher level. In closing, I look forward to another productive year in 2011 and wish to every one of you a safe and healthy holiday!



P.O. Box 278990 · Rochester, NY, 14627 · 120 Corporate Woods · Suite 350 · Rochester, NY 14623
Phone: (585) 758-7832 · TTY: (585) 758-7804 · VP: (866) 901-0727 · Fax: (585) 424-1469
www.urmc.edu/ncdhr · ncdhr@urmc.rochester.edu

This newsletter was supported by Cooperative Agreement Number U48-DP-001910 from the Centers for Disease Control and Prevention (CDC). The findings and conclusions in this newsletter are those of the author(s) and do not necessarily represent the official position of the CDC.

Behind the Scenes of Deaf Weight Wise

Outreach

- Provide information to the community about DWW.
- Develop plans to recruit 220 Deaf adults to participate.
- Build relationships with local organizations, clubs, and agencies to help recruit participants.

Curriculum Workgroup

- Prepare curriculum for each session including participant materials, activities, and hand-outs.
- Prepare manuals and training sessions for the deaf counselors.

Materials Adaptation Group

- Review the weight wise intervention developed by University of North Carolina - Chapel Hill
- Make recommendations for adaptations to original weight wise materials to be culturally and linguistically appropriate for Deaf people.

Film Development Group

- Develop ASL videos for recruitment, enrollment, and intervention activities including exercise.
- Prepare scripts, coordinate Deaf actors, and edit films.

Survey Measures Group

- Chose surveys that will assess each participant's health status and health behaviors.
- Some surveys will be adapted into ASL and English-based sign language videos on a computer and some surveys will be done in

ASL Translation Workgroup

- Translate all written English surveys into ASL videos.

English-Based Sign Language Translation Workgroup

- Translate all written English surveys into English-based sign language videos.

Studio Filming Group

- Using RIT studio space, sign models are filmed signing each survey item. These video clips are used in the computer survey on a touch-screen computer.

Cognitive Interviews

- We will test the surveys with about 50 people.
- Input from participants will help us improve the surveys before we use them for DWW.

Begin DWW! Summer 2011

Materials Adaptation: Tamala David, FNP, PhD, Robyn Dean, CI, CT, Mike McKee, MD, MPH, and Robert Pollard, PhD. **Outreach:** Tamala David, FNP, PhD, Mike McKee, MD, MPH, Scott Smith, MD, MPH, Matthew Starr, MPH, and Denise Thew, PhD. **Curriculum Workgroup:** Kim Kelstone, CI, CT, Mike McKee, MD, MPH, Tiffany Panko, BSS, MBA, Scott Smith, MD, MPH, Matthew Starr, MPH, and Denise Thew, PhD. **Film Development:** Patrick Graybill and Amanda O'Hearn, PhD. **Survey Measures:** Steve Barnett, MD, Poorna Kushalnagar, PhD, Carlene Mowl, MPH, Rachel Noel, BS, Amanda O'Hearn, PhD, Vincent Samar, PhD, Scott Smith, MD, MPH, and Erika Sutter, MPH. **ASL Translation:** Julia Aggas, Robyn Dean, CI, CT, Patrick Graybill, and Robert Pollard, PhD. **English-Based Sign Language:** Donna Gustina, Vincent Samar, PhD, and Pat Sullivan. **Studio Filming:** Eloise Oyzon and Vincent Samar, PhD. **Cognitive Interviews:** Steve Barnett, MD, Kim Kelstone, CI, CT, Poorna Kushalnagar, PhD, Carlene Mowl, MPH, Rachel Noel, BS, Amanda O'Hearn, PhD, Tiffany Panko, BS, MBA, Vincent Samar, PhD, and Scott Smith, MD. **Study Coordinator:** Erika Sutter, MPH. **Research Committee Chair:** Steve Barnett, MD.