

# Healthy Signs

National Center for Deaf Health Research

Winter 2007

## Mission of NCDHR:

To promote health and prevent disease in the Deaf population through community-participatory research.

## Save the Dates!

March 30 - April 1  
66 Biennial  
ESAD Conference  
at NTID/RIT

May 18, 2007  
12:15 - 1:15 PM  
Public Health  
Grand Rounds  
at LeChase  
Assembly Hall  
Carolyn Stern, MD  
Healthcare and the  
Deaf/Hard of Hearing  
Community:  
Case Studies

May 21 - 22, 2007  
External Advisory  
Committee  
Annual Meeting at  
NCDHR

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## Perspectives: Work Matters!

Getting people with disabilities to work without losing health benefits is challenging. Some recipients of Medicaid and/or Medicare opted not to return to paid employment because they feared losing substantial health insurance



coverage or being hit with high health insurance premiums through employer-sponsored health benefits programs.

An estimate from the Government Accountability Office revealed that prior to 1998, less than 1 out of 1,000 Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) recipients returned to regular work (source: <http://www.nasmd.org/issues/legmemos/98-2.htm>). The Work Incentives Improvement Act of 1998 was enacted to counteract this barrier to employment for many SSI/SSDI recipients, thus encouraging them to return to the labor market. Depending on income level and/or other work incentive provisions, there are programs that allow recipients to keep their Medicaid or Medicare while working. Yet, printed information about work incentives are accompanied by a bewildering set of rules, regulations, income eligibility requirements and grace periods, often using language which may be confusing to the

average Deaf reader whose first language is ASL. Deaf SSI and/or SSDI recipients face enormous language and communication barriers to becoming fully informed consumers.

One program which works toward helping people with disabilities return to work is called the Work Incentives Planning and Assistance Project (WIPA). Community Work Incentives Coordinators (CWIC), provide assistance with planning for individuals who are working or considering returning to work. Unfortunately, some agencies that run WIPA programs have difficult time finding qualified interpreters and many Deaf individuals have suffered financially for this lack of accessibility. There appears to be a great need for culturally competent CWICs. Without a complete and clear understanding of the complex work incentive requirements, the consequent outcome can be losing one's health care coverage. For nearly 5 years, Susan Demers Postlethwait, a certified CWIC, provided fully accessible benefits advisements services to the Rochester Deaf community. She was trained by Cornell University's School of Industrial and Labor Relations Program on Employment and Disability.

In June 2006, DeafWorks!, LLC and The Advocacy Center formed a partnership that will continue to provide WIPA services to the Deaf

community. This partnership is administered by Neighborhood Legal Services, based in Buffalo, NY, ([www.nls.org](http://www.nls.org)) one of the regional Social Security Administration contractors. "Work matters!" says Susan, who is currently the Chair of NCDHR's Deaf Health Community Committee and a co-owner of employment-related services, DeafWorks!, LLC ([www.deafworks.net](http://www.deafworks.net)). "Working can improve your health and well-being." The Advocacy Center has provided consumer-driven services to support people with disabilities and their families in achieving their goals for more than 50 years. This partnership covers 16 counties in the Finger Lakes and Erie regions.

If you know of anyone in Western NY who would benefit from counseling about SSI, SSDI, Medicaid and Medicare in ASL, please contact Susan, at [susan@deafworks.net](mailto:susan@deafworks.net) or call (800) 381-8078, voice. For more information about WIPA nationwide services, check out <http://www.socialsecurity.gov/work/ServiceProviders/WIPADirectory.html>



## Message from the Program Director:

The NCDHR stands on the threshold of an exciting new phase of involving the Deaf Community in research that will directly benefit Deaf persons. Over the next twelve months or so, we hope to have reliable data that describes the health and healthcare of our Deaf



Community. Our investigators and our Community Committee will then consider the question: "What should we do next?" This will probably take two forms. If an excess burden of a disease or condition is identified, one obvious question is, "How do we correct the problem?" Another obvious question is, "Why do Deaf persons have this problem?" This would lead to studies both of lifestyle, as well as hereditary factors. The

continued advice from the Deaf Community would be especially important so the right questions are answered in culturally appropriate ways to provide the greatest benefits.

Thomas A. Pearson, MD, MPH, PhD  
Program Director  
NCDHR

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## NCDHR 2006 Retreat



Opening remarks by Tom Fogg, NCDHR Administrator



Delicious dinner from Aladdins.



Retreat facilitators, Lee Twyman and Denise Kavin



Partners doing small group exercises

This newsletter was written and edited by the Communication & Dissemination Subcommittee. Special thanks to:

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Chris Lehfeldt, DDS  
Tim Malia, MD  
Matt Starr, MPH (Chair)  
Carolyn Stern, MD

**Please welcome Anne Steider, PhD as the Editor of our newsletter!**

## NCDHR Happenings

Tamala David, FNP, a candidate in the UR School of Nursing PhD program and a member of the NCDHR Research Subcommittee, was one of 15 awardees for "Up & Coming Businesswomen" from the Rochester Women's Network.

The ASL Translation Work Group (TWG) is now completing its arduous task of translating English-based health survey questions to ASL. This group (Julianna Aggas, Robyn Dean, Betsy Finigan, Patrick Graybill, Robert Pollard and Susan Demers Postlethwait.) represents a *bona fide* partnership between the University of Rochester and the Deaf Health Community Committee who represent the Rochester Deaf community.

## Turning Challenge into Opportunity: The Retreat

Since its inception, NCDHR has experienced growing pains. As the tasks toward accomplishing our center's goals became clearer over time, so did the accompanying joys and frustrations inherent in any novel endeavor. Some sentiments were predictable enough: there are not enough hours in the day, how will we meet our expected deadlines? Other growing pains were less predictable. For example, limited communication between the numerous committees seemed to create a lack of cohesive partnership within the Center. In turn, this problem with effective communication contributed to a frequent complaint by NCDHR

## Community-Based Paper Recognized

NCDHR was selected to present at an October 2006 conference focusing on community-academic collaborations, sponsored by Center for Applied Community Research and Development at Binghamton University.

This interpreted presentation summarized a draft paper called, "Expected and Unexpected Results: Establishment of a New Community-Participatory Research Center." Four NCDHR representatives, Dr. Ann Doizer, Susan Demers Postlethwait, Tom Fogg and Matthew Starr partici-

Over 100 first year medical students attended an enlightening presentation by Jessica Cuculick, MSW entitled "Introduction to Deaf Health" during Deaf Strong Hospital in September 2006. Jessica, a member of the DHCC, is also a PhD candidate at the University of Rochester Warner Graduate School of Education and Human Development.

Two members of the Research Subcommittee gave presentations this past November at the American Public Health Association's 134th Annual Meeting & Exposition in Boston, MA. Elizabeth Finigan, MD presented, "Development of a linguistically accessible health survey for deaf students" and Erika Sutter, MPH outlined, "Measuring health risk behaviors

of deaf and hard of hearing students; considering language difference."

The Agency for Healthcare Research and Quality (AHRQ), a public health service agency in the Department of Health and Human Services, has selected Dr. Steven Barnett as one of several outstanding healthcare researchers to receive the Mentored Clinical Scientist Development Award (K08).

DHCC welcomes its newest members: Angela Hauser and Takeshi Yamaji.

members that the overall direction of the Center was unclear. Fortunately, we were not alone in this process. Renowned organizational behavior researcher, Eric Flamholtz of UCLA, in several of his books, cites similar symptoms in his list of The Ten Most Common Organizational Growing Pains.

The Deaf Health Community Committee recognized the need for improved communication and the Center in turn decided a retreat would be useful to address these concerns. The overarching goal of the retreat was to improve participation/interaction/communication/trust within the NCDHR.

Nearly all Center's staff and partners participated in the 2-part retreat, facilitated by Lee Twyman and Denise Kavin from NTID, during November and December of 2006. From these meetings 28 recommendations for improved functioning of the Center were submitted, and four themes emerged which are the focus for the next year of the NCDHR: (1) ensuring bilingual communication, (2) streamlining the Center, (3) improving communication within and between committees and (4) redefining and embracing the role of DHCC.

pated in the two hour paper presentation and panel discussion.

We were honored to learn that our paper received the conference's best-written paper award called, "New York Campus Compact Excellence Award." New York Campus Compact is a state chapter of a national organization that promotes effective community-academic partnerships throughout the United States.

For more information about Campus Compact, check out [www.nycc.cornell.edu](http://www.nycc.cornell.edu).

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