

The Importance of the Deaf Healthcare Survey

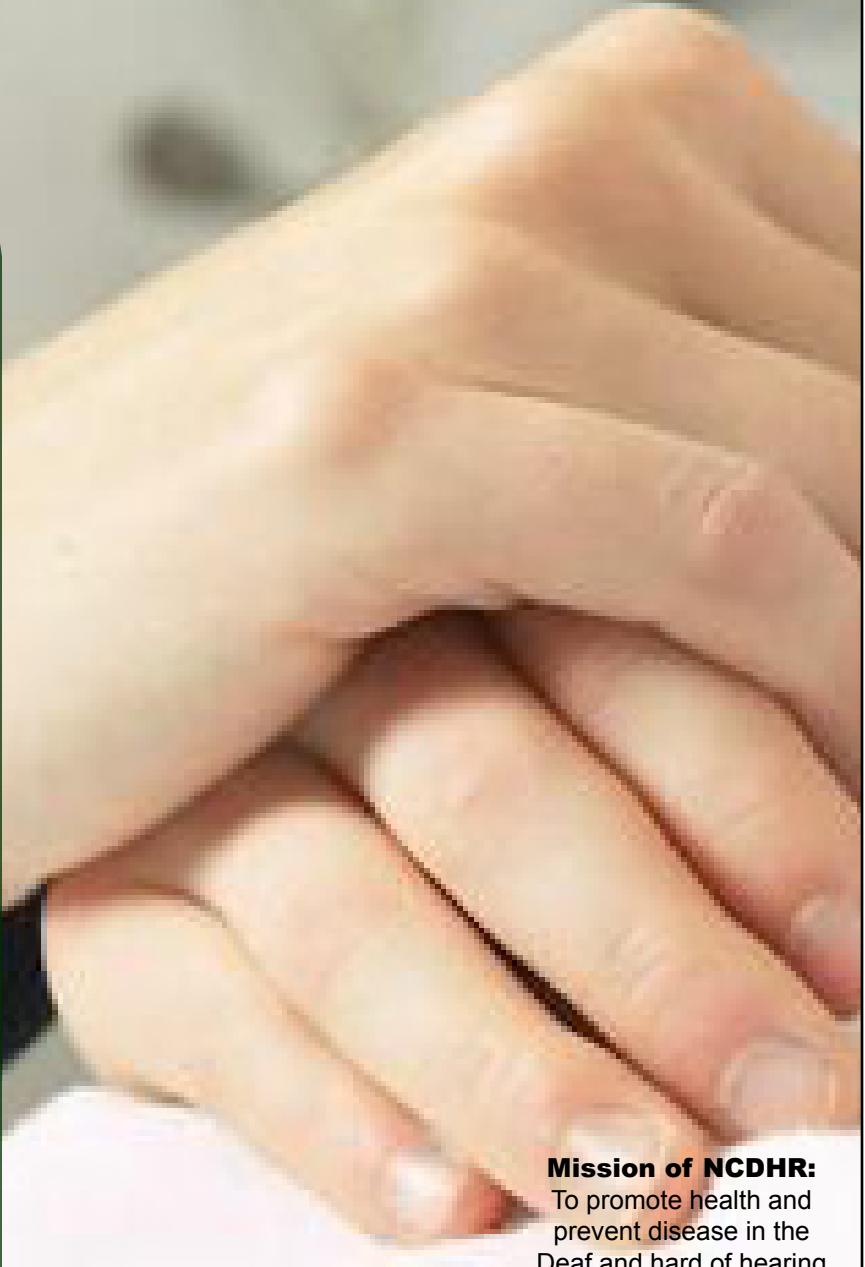
What are the benefits for the Deaf Community?

Where are they now?
Heidi Thompson

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

The Importance of the Deaf Healthcare Survey

What are the benefits for the Deaf Community?

Did you know? If you are 18 or older, you can take the Deaf Healthcare Survey! Why is this so important? What is the Deaf Healthcare Survey?

In this article, we are going to focus on the Deaf Healthcare Survey and what makes this survey so important for the Deaf community!

What is the Deaf Healthcare Survey?

The Deaf Healthcare Survey is adapted from a set of surveys called the Consumer Assessment of Healthcare Providers and Systems (also known as CAHPS). CAHPS is administered to people all over the United States and it asks patients to report about and evaluate their experience with health care including access to services and communication with providers. The CAHPS surveys are typically administered as written surveys that are mailed home to patients after a hospital visit or doctor's appointment. We have taken these written surveys and adapted them into ASL surveys that are given on a touch screen computer.

Why is the Deaf Healthcare Survey so important?

The Deaf Healthcare Survey asks participants about their most recent doctor's appointment (primary doctor, emergency room visit, specialist visit, etc.) as well as about their primary care provider. The survey asks questions about getting an appointment, getting the results of tests, communication, and relationship with the provider. After we collect all of the data, we can analyze it and learn more about the experiences of Deaf people – for example, what challenges do deaf people face when they go to the doctor? This information will be shared with the deaf community, doctors and other researchers. We hope that what we learn from this survey will help improve health care for Deaf people in Rochester! Your participation is important to us! For more information regarding this study, please contact Carlene Mowl at Carlene_Mowl@urmc.rochester.edu or visit our website: www.urmc.rochester.edu/ncdhr.

Take charge of your healthcare experience and make a difference in the Rochester Deaf community!

NCDHR
National Center for Deaf Health Research

UNIVERSITY OF ROCHESTER
UNIVERSITY OF ROCHESTER MEDICAL CENTER

Have you been to a doctor in the past year?

There is a research opportunity at the National Center for Deaf Health Research

Take our new sign language survey called the Deaf Healthcare Survey

Have the option of ASL or English-based sign language or written English

Help us learn more about the healthcare experiences of Deaf people

Deaf adults ages 18 and older only

Interested?

Contact us at ncdhr@urmc.rochester.edu
Or call us at 585-286-5042 (VP) or 585-276-1137 (TTY)
Principal Investigator, Steven Barnett, MD: steven_barnett@urmc.rochester.edu

An Update on Research Opportunities at NCDHR

Two opportunities you can sign up for today!



Deaf Healthcare Survey

Dr. Steven Barnett is recruiting participants for his research project called The Deaf Healthcare Survey. Anyone over the age of 18 can take this survey. The goal is to complete 300 surveys and we have about 70 surveys done to date. So far, NCDHR has set up surveys at various community locations and events like the Rochester Recreational Club for the Deaf and the National Technical Institute for the Deaf. If you are interested in joining the Deaf Healthcare Survey, please contact Carlene Mowl at Carlene_Mowl@urmc.rochester.edu.

A screenshot of a website for a research study. The page is divided into two main sections: "HEALTH LITERACY" and "CARDIOVASCULAR RISK FACTOR".
Health Literacy Section:
- **ELIGIBILITY:** Live near or in Monroe County, ASL proficient, Ages 40-70 only.
- **CONTACT:** Earn \$20 to participate in a survey!
- **Image:** A photo of a smiling older woman.
- **Text:** Researchers are studying the effect of Health Literacy on Cardiovascular Risk Factors.
Cardiovascular Risk Factor Section:
- **ELIGIBILITY:** Live near or in Monroe County, English proficient, Ages 40-70 only.
- **CONTACT:** Earn \$20 to participate in a survey!
- **Image:** A photo of a smiling older man.
- **Text:** Researchers are studying the effect of Health Literacy on Cardiovascular Risk Factors.
- **Image:** A photo of a woman holding a blood pressure cuff.
- **Text:** Martha Tuttle (phone) (585) 296-8454 x450, Martha_Tuttle@urmc.rochester.edu

Health Literacy and Cardiovascular Risk Factors Survey:

Dr. Michael McKee is running a research study called the Health Literacy and Cardiovascular Risk Factors Survey. Only recently starting to recruit, Dr McKee is looking for 250 Deaf participants and 250 hearing participants completed with the survey. Currently, there have been about 60 surveys completed by the Deaf participants and hearing participants equally. Enrollment is still ongoing.

If you are **Deaf between the ages of 40 and 70** and interested in joining this survey, please contact Dr. Michael McKee at Michael_Mckee@urmc.rochester.edu.

If you are **hearing between the ages of 40 and 70** and interested in joining this survey, please contact Martha Tuttle at Martha_Tuttle@urmc.rochester.edu.

An Update on Deaf Weight Wise

Deaf Weight Wise – 104 people are enrolled!

The Deaf Weight Wise (DWW) research program has successfully enrolled 104 participants! The NCDHR research team would like to thank everyone who signed up to join DWW. Your interest and motivation will help us learn more about the DWW 16-week healthy lifestyle group program. The NCDHR team would also like to thank all the community organizations and clubs around Rochester that helped to support DWW recruitment events. We are thankful that you helped us spread the word about this important research!

DWW is a randomized controlled trial. That means that some DWW participants were randomly selected to start their 16-week group sessions this year (spring/summer 2012). Other participants were randomly selected to start their 16-week group sessions next year (spring/summer 2013). (Watch an ASL vlog about randomization [here](#).)

DWW participants will also be coming to NCDHR every 6 months for ASL surveys and bloodwork appointments, from now until 2014. Results from surveys and bloodwork will help the NCDHR team learn about the health of participants throughout the program.

At the end of the research program, NCDHR will share the results with the Rochester Deaf community. We look forward to your participation in community meetings to help the NCDHR research team understand how the results of DWW will impact the Deaf community. Stay tuned!



Do you wish you had signed up for DWW?

Well...NCDHR needs 10 more people to sign up for a videophone (VP) version of DWW. Starting in August 2012, NCDHR will be looking for 10 new people who are interested in trying the DWW program over VP. DWW VP participants will have a 1-hour meeting with a DWW counselor over VP every week for 16-weeks. Help researchers learn whether the same 16-week DWW program can work in a one-one-one format using VP technology!

Email carlene_mowl@urmc.rochester.edu for more information.

You may be wondering . . .

What is a randomized controlled trial?

(Watch an ASL vlog about randomization [here](#).) A randomized controlled trial is considered the most reliable method of determining which medical treatment programs work the best. Research participants are randomized in clinical trials so that bias does not weaken the research results. Each participant had a fair and equal chance of receiving the DWW program either in 2012 (Group 1) or in 2013 (Group 2). The goal of randomization is to produce two similar groups in terms of age, gender, and other key factors that might affect health and healthy living. In this way, the two groups are as similar as possible at the start of the research program. At the end of the program, if one group has a better result than the other group, the researchers will be able to learn whether it was the DWW program itself that was successful in helping participants live healthy and lose weight.

Where are they now? Heidi Thompson



From 2007-2008, Heidi Thompson worked with NCDHR. She attended medical school at the University of Rochester where she did a research internship with NCDHR for one year, instead of taking medical school courses. While she was at NCDHR, she worked with Dr. Nancy Chin on the Rapid Assessment Process (RAP). The “RAP” process involved interviews with NCDHR staff, researchers, and community partners. The interview asked people about NCDHR collaboration, partnership, communication, and trust. Once the interviews were complete, Heidi, Nancy, and the rest of the RAP team wrote a manuscript about their RAP findings. Heidi also helped to develop the 2008 NCDHR Deaf Health Survey.

Currently in her 2nd year in the Family Medicine Residency in Fort Collins, Colorado, Heidi was given the opportunity to do “rotation” (brief internship) for 4 weeks. She decided to take this opportunity to return to Rochester, NY where she worked on completing the “RAP” paper to submit to a scientific journal for publication.

When asked why she decided to return to NCDHR, Heidi simply stated that she was “happy to be back in the Deaf Community again.” In Fort Collins, Colorado, Heidi stated that there are “some Deaf people, but no big Deaf community.” In the past 2 years that Heidi has been in Fort Collins, she has seen roughly 10 Deaf people.

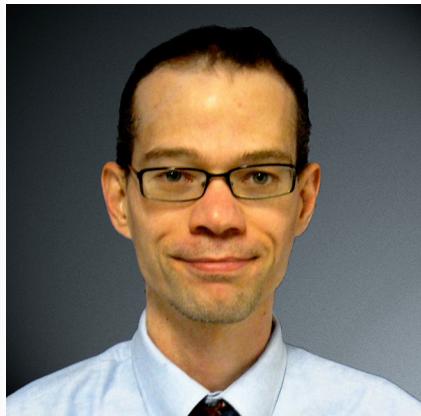
Heidi has one more year of residency left in Colorado. She then plans to take on a fellowship in obstetrics (delivering babies). After completing her schooling requirements, Heidi is considering staying involved with the residency program, teaching other prospective Healthcare professionals along their residency paths.

During her short stay here in Rochester, Heidi worked hard to complete the “RAP” paper that was started nearly 3 years ago. She completed the paper with the help of Nancy Chin, and the paper will be submitted for publication soon.

When Heidi returns to her residency, she will be presenting about her 4-week stay here in Rochester, NY. She plans to talk a little about the “RAP” paper itself and more about what NCDHR is doing now and the resources being used to allow Deaf community partnership and access to healthcare.

An Update from Scott Smith and Denise Thew

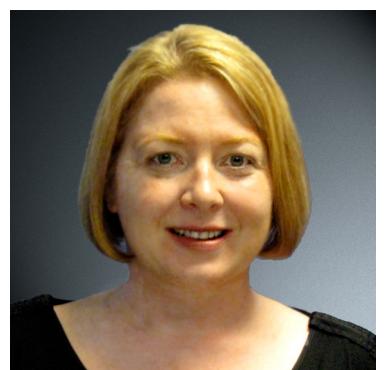
Recruiting for their Research



Scott Smith, MD, MPH

Denise Thew, PhD, Preventive Cardiology fellow and psychologist, and Scott Smith, MD, MPH, assistant professor in the Department of Community and Preventive Medicine and a developmental-behavioral pediatrician, conducted a successful recruitment event at RIT/NTID during the institute's last month of the academic year. Dr. Smith collaborated with Dr. Thew on her thesis project to determine how well Deaf and Hard-of-Hearing college students understood health-related information from the

peer-reviewed article that was published in Preventing Chronic Disease (March 2011), "Deaf Sign Language Users, Health Inequities, and Public Health: Opportunities for Social Justice". Recruited students had the opportunities to review the article in written English and in ASL adapted video, using a health literacy measurement called the Test of the Functional Health Literacy in Adults (S-TOFHLA).



Denise Thew, PhD

Dr. Thew's thesis goal is to learn and find ways to improve how health related information are disseminated to the Deaf and Hard-of-Hearing audience. Dr. Smith's career goal is to improve the health knowledge and health literacy of deaf adolescents and young adults and this project provided an opportunity for the first-ever pilot test of the S-TOFHLA measure with deaf people. More than 115 Deaf and Hard-of-Hearing students at RIT/NTID participated in this study in support of deaf researchers. Congratulations and a heart-felt thank you to all of the RIT/NTID students, staff, and faculty who helped to make this a successful recruitment event!



National Center for Deaf Health Research
Rochester Prevention Research Center



Working for a Healthy Deaf Community



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