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New Staff with NCDHR:
Kathleen Jensen & Tom Coughlan

Retreat 2012:
Solidifying NCDHR Partnerships

The Community Transformation Grant and the Development of HEART
An update

Mission of NCDHR:
To promote health and prevent disease in the Deaf and hard of hearing populations through community-based participatory research.
Solidifying NCDHR Partnerships: What is the Right Glue?

It has become clear, over the years, how much NCDHR has grown. In last year’s retreat, several participants commented that there were so many unfamiliar faces at NCDHR. It was unclear how people were associated with NCDHR and what their roles and responsibilities were inside the quickly growing Center.

On Saturday February 4, NCDHR hosted its 3rd retreat in the new Saunders Research Building on the campus of the University of Rochester Medical Center. Members of every committee, community group, and advisory board, were invited to attend. (to see a list of who is involved with NCDHR, visit www.urmc.rochester.edu/ncdhr/ under Committees and Partners). The retreat focused on two key themes: "enduring partnerships" and "finding the right glue."

The 3rd retreat marked a milestone in the history of NCDHR. This was the first time such a diverse group has gotten together to work towards a common goal of partnership.

Matt Starr (NCDHR Administrator and Community Liaison), Dr. Tom Pearson (Director/Principle Investigator of NCDHR), Patrick Graybill (Chair of the Deaf Health Community Committee) and Mary Chizuk (Chair of the newly formed Exploratory Task Force for people with hearing loss) all provided the welcome and opening remarks. Each laid the groundwork for why everyone had come together that day and the high hopes for strengthening partnerships between NCDHR and its community partners as well as identifying common threads or "glue" between all of NCDHR’s Deaf community members and the people with hearing loss (formerly called hard-of-hearing people).

After the morning welcome, pictures of all committee members and organizational charts were presented to the retreat participants in order to help make "unfamiliar" faces become familiar as well as clarify roles of NCDHR stakeholders.

After the morning’s introduction, the day’s events turned to small breakout sessions. These groups focused on questions such as “What partner strengths can the NCDHR Partnerships utilize?” After each breakout session, all participants came back together to share the findings from their small groups. Each small group reported many similar ideas and recommendations.

Scot Atkins and Bill Moore from NTID, who served as the retreat facilitators, were outstanding in their facilitation of the small breakout groups. Each breakout group was uniquely composed of Deaf community members, people with hearing loss, faculty, staff, and volunteers from NCDHR. Interpreters were provided to all participants, to ensure barrier-free interactions between Deaf, hearing, Deaf Blind, and people with hearing loss. Access to spoken English was provided with assistive listening devices and C-print captioning.

As planned in their original grant proposal, NCDHR invited the community leaders from the local hearing loss organization to start their own community committee (much like the Deaf Health Task Force in 2003 before it became the Deaf Health Community Committee in 2005 to work with NCDHR). The Exploratory Task Force (ETF) is now in the process of creating a mission and vision.

Several members of the ETF were present during the retreat. The 3rd retreat marked a milestone in the history of NCDHR. This was the first time such a diverse group has gotten together to work towards a common goal of partnership. This emerging partnership between Deaf people and people with hearing loss will solidify the NCDHR’s mission:

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

Up until now, all public health research by NCDHR and its partners was focused on cultural and linguistic adaptation from English to American Sign Language, the preferred language of the culturally Deaf community. As NCDHR continues to grow, it will begin to research the health needs of people with hearing loss, as well as continuing to explore and address the identified health needs of the Deaf community, and incorporate those needs into more research to promote health lifestyles for both populations.

NCDHR believes, as an applied public health research center, they have an opportunity to help engage and empower a nationwide working model of how culturally Deaf people and individuals with hearing loss can come together and advocate for their community health needs. NCDHR will use the information from the retreat to help solidify these unique partnerships to benefit the health concerns for all.

. . . Deaf people and individuals with hearing loss can come together and advocate for their community health needs.
In September, 2011, the University of Rochester Medical Center/Center for Community Health, the Monroe County Department of Public Health, NCDHR and its community partner (the Deaf Health Community Committee), Rochester School for the Deaf and numerous other community partners were awarded a 5-year, $3.6 million Community Transformation Grant by the Centers for Disease Control and Prevention (CDC). This grant was the only one out of 68 awards given throughout the country that involves the local Deaf community.

Over the next 5 years, this grant will be used to develop an initiative, called HEART (Health Engagement and Action for Rochester’s Transformation). The main goals of HEART are to improve the health of all Monroe County residents by creating an environment that supports healthy behaviors. By doing this, the ultimate goals are to prevent chronic disease and reduce health care costs.

There are several unique things about this award. Early on in the proposal process, the Deaf Health Community Committee (DHCC) was asked what some major health concerns are for the Deaf Community. These concerns and ideas provided valuable initial feedback on what the Deaf community needs for improving overall health. This process demonstrates the value of including the Deaf community in county-wide collaborations.

Another important factor of this award is HEART’s inclusion of the Deaf Community. While the Deaf Community is normally underserved and left out of different local community initiatives, this award marks one of the first times the Deaf Community is meaningfully involved in a county-wide initiative!

HEART developed several initiatives to improve the health of all county residents, including the Deaf Community. All of these initiatives can be seen on the HEART website. A few of those initiatives have become major foci for NCDHR and the DHCC. These initiatives are:

- **Coordinated School Health Programs**
  Focuses on the Rochester City School district and the Rochester School for the Deaf (RSD). The goal of this program is to improve physical activity and nutrition for the students.

- **Diabetes Prevention Program**
  Recently, obesity has been identified as a health priority in the Rochester Deaf Community. Diabetes is a related health topic to this growing concern for the community. Due to this concern, NCDHR and DHCC will be helping HEART work on the Diabetes Prevention Program.

- **Food Hub**
  Include stations around Monroe County for local residents to go to in order to obtain healthy food in a safe environment. NCDHR and DHCC are also working with HEART to make sure the Rochester Recreation Club for the Deaf will be one of the hubs available for the Deaf Community.

During the HEART initiative, the Monroe County Health Department will administer a general population telephone survey (Behavior Risk Factor Surveillance Survey). NCDHR plans on providing an ASL adapted version of this survey for the Deaf Community, very similar to the previously completed Deaf Health Survey. The goal of these surveys will be to assess the health and health behaviors of the Rochester community (including the Deaf community).

There have already been several meetings to begin working toward an improved Rochester Community. As the HEART initiative starts to take form, and NCDHR and DHCC continue to work diligently to focus on the Deaf community, it will be exciting to see the changes to come. To read more articles about this award and the HEART initiative, click on one of the links below:

- URMC article from September 29, 2011
- Information about HEART and the Initiatives
- Rochester Business Journal article about the grant
New Staff with NCDHR:

Kathleen Jensen

Another new addition to NCDHR is Kathleen Jensen, the Executive Director of Finance and Facilities for the Clinical and Translational Science Institute (CTSI). Kathleen has extensive experience in clinical and research administration. By joining NCDHR, Kathleen will be providing senior administrative guidance and leadership in several areas, including grant management, finance, human resource, and facility issues. Kathleen has become a member of the NCDHR Executive Committee and she may be participating in various committee meetings and events.

Kathleen brings with her many years of financial experience, and expertise inside of the University of Rochester Medical Center and its intricate structure. In her short time working with NCDHR, Kathleen has shown excellent professionalism, support, and has made some great improvements in some internal workings of NCDHR.

Kathleen is very excited to be working with this unique and richly diverse group of NCDHR and the Deaf community and community for people with hearing loss. She looks forward to meeting the many committee and community members and will provide any assistance needed to help NCDHR continue to grow and progress down the path of success. Be sure to say hello to Kathleen and contact her at Kathleen_Jensen@urmc.rochester.edu. It is a great pleasure to have such an experienced and creative employee join the team and NCDHR welcomes her aboard.

Thomas Coughlan

One new addition to NCDHR is Tom Coughlan. Tom is a 12-year veteran of the Xerox Corporation and a part-time faculty member at The College at Brockport - SUNY and Nazareth College where he teaches American Sign Language. Tom also teaches for the Medical Humanities department at the University of Rochester Medical Center. Recently Tom was granted a 1-year paid Social Services Leave (SSL) from Xerox to work with the National Center for Deaf Health Research.

In 1971, Xerox created the Social Services Leave (SSL) program in order to fill the needs of their employees and the communities they work with. Over the years, Xerox learned from their employees that they wanted more out of life than just going to work. This is what originally triggered Xerox to create the program which has now become an annual tradition. Xerox employees, like Tom, after going through a competitive application and review process, are then chosen by a committee of peers to take a paid leave of absence from Xerox in order to work full-time on a social action project of their own design. While there are many companies that do "loan" their employees, the SSL program is different because the entire process does not start with the company, but the employees themselves!

This program allows employees to take a leave of absence for periods of time ranging from three months to one year. Tom Coughlan was awarded a full year for his leave of absence and has chosen to spend the opportunity working with NCDHR.

Tom will be assisting NCDHR in a variety of research projects, but focusing particularly on the Deaf Weight Wise program and community outreach. He will also be contributing his skills to the different core functions of NCDHR including communication and dissemination. It is with great pleasure that NCDHR welcomes Tom and congratulates him on his success with receiving this opportunity. The SSL has sponsored 499 people since 1972 to assist with community-based projects. Being a Deaf community member, Tom Coughlan will be giving back to his community, not only fulfilling his own desires, but contributing to the desires of Xerox, NCDHR, and the Deaf community as well.

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