Page 8

#### North Dakota Center for Persons with Disabilities

#### **Training Events**

Promoting Staff Creativity and Initiative: Gaining Staff Buy-In to Promote a Person Centered Culture by Margaret (Peggy) Gould

September 12 – Development Homes, Inc. Grand Forks

September 13 – Research 1, NDSU, Fargo

September 14 – Comfort Inn, Bismarck September 15 – International Inn, Minot

For more information please contact: Mary Mercer, NDCPD Community Training Coordinator at 1-800-233-1737 or 858-3260.

The North Dakota Center for Persons with Disabilities is a member of the Association of University Centers on Disabilities (AUCD). AUCD is a national network of interdisciplinary centers advancing policy and practice through research, education and services for and with individuals with developmental and other disabilities, their families and communities.

#### The COLLABORATOR

North Dakota Center for Persons with Disabilities at Minot State University

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### North Dakota Real Choice Systems Change Grant Rebalancing Initiative A Summary of Focus Groups and Personal Interviews Conducted in North Dakota



By: Amy Armstrong, NDCPD Project Director

In September of 2004, The North Dakota Department of Human Services, Aging Services Division received a Real Choice System Change Grant from the Centers for Medicare and Medicaid Services of the U.S. Department of Health and Human Services. NDCPD was contracted through Aging Services to facilitate this project called the North Dakota Real Choice Rebalancing Initiative – Choice and Self-directed Resource Delivery for the Elderly and People with Disabilities. The Real Choice Rebalancing Initiative is taking an in-depth look at ways to improve North Dakota's system which provides services that enable seniors and adults with disabilities to stay as independent as possible as they age and as their needs change.

During October, November, and December of 2005, a series of statewide focus groups and inhome personal interviews were conducted as part of the *Real Choice Rebalancing Initiative* research project. This research, in addition to questionnaire mailings, was conducted to identify current perceptions, themes, and suggestions for improving the choice and self-direction, quality and access to long term care supports (i.e. home and community based services [HCBS] and nursing home care) for the elderly and persons with disabilities. This research was also conducted to identify ways to balance state funding resources for these services, and to identify elements for the design and structure of a single point of entry mechanism to all long term care supports.

Combined, a total of 43 focus groups and personal interviews were conducted throughout the eight ND human service regions in rural and urban communities. Focus group and personal interview participants included consumers of HCBS, elderly nursing home residents, younger nursing home residents, family members of consumers of continuum of care services, and providers of continuum of care services. This article gives a summary of the themes of focus group participants' perceptions and suggestions for improving quality and access to long term care supports. Common patterns emerged across all focus groups and personal interviews. One theme identified how North Dakotans currently find out about continuum of care services, which included:

- social workers,
- doctors and hospital staff,
- word of mouth,
- on their own,
- family members

"Had it not been for maybe some neighbors of mine that used some of the services, I would have never known that they [services] existed." Family Member



#### North Dakota Center for Persons with Disabilities

#### (Continued from Page 1)

Another theme identified <u>problems</u> that participants experienced related to continuum of care services. The common <u>problems</u> identified included:

- confusion of the information that people receive,
- high cost of services, both nursing home and HCBS, is a barrier to receiving services,
- lack of information about continuum of care services that are available in the community, lack of quality, comprehensive information,
- no choices available for services in the community,
- lack of flexible funding to support consumer's choice of services
- living in a rural community, isolated from services that are not available in the community,
- no needed services available or not enough workers available to provide the needed HCBS,
- not eligible for needed services

"It would be helpful if there were someone there that could tell you rather than send you on again because that happens so often too. You get to one place and then you go there and then you have to go over there." Elderly Nursing Home Resident

"My mother would be home right now if I could afford the \$8/hour for someone to watch her. But yet I couldn't get the funding to keep her at home. Because [Medicaid] will pay to put her in a nursing home but they won't pay to keep her at home, when it would not cost them nearly as much." Family Member

"Someday I will have to reside in a nursing home because I won't be able to find someone or won't be able to pay for them." Rural Consumer of HCBS

Participants also identified <u>needs</u> in the area of long term support services. They included:

- case management described as assistance with assessment, care planning, provider selection, monitoring, services, and making referrals,
- both functional and financial assessment,
- a reliable, consistent, and knowledgeable "go to person," this person should have access to necessary resources,

- a single point of entry system for streamlined access to services, a simplified service system,
- access to comprehensive, timely information about services,
- HCBS options, including access to HCBS in rural communities.
- public education and media related to available continuum of care services and preventative education,
- flexible funding to pay for the service of choice,
- alternative housing options

"I want[ed] one voice that was nice and that would give me the same answer twice to the same questions and know what they were talking about." Family Member

"They[case management] need to be knowledgeable about what's out there so that they can give you the appropriate information in a great timely manner and say, okay you have this option, this option,[and] this option."

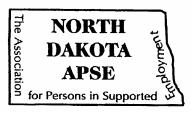
Consumer of HCBS

Consumers of continuum of care services expressed what is <u>important</u> to them, such as: the opportunity to stay at home, the opportunity to live with or near family, and maintaining independence.

"None of us asked to be this way but we can't help it. And if we can live cheaper at home and be a lot happier at home it all makes sense." Consumer of HCBS

With the information gathered from the focus groups and personal interviews as well as future questionnaire reports, the *Rebalancing Initiative* will build a Plan or roadmap for developing improved access to long term care supports that reflects the needs and concerns expressed by the public. As part of the *Rebalancing Initiative*, potential legislation will also be drafted for the 2007 Legislature and will reflect the common concerns expressed by the research participants.

The complete Focus Group & Personal Interview Final Report is available on the ND Department of Human Services website at: <a href="http://www.nd.gov/humanservices/info/pubs/1t">http://www.nd.gov/humanservices/info/pubs/1t</a> ccontinuum.html or contact Amy Armstrong at amy.armstrong@minotstateu.edu.



#### **Resource Mapping**

Page 7

By Karlee Rauschenberger NDCPD Business Analyst and APSE Member

The North Dakota Comprehensive Employment Systems Grant (ND CES) is completing an in-depth statewide strategic planning process to gather

information from a wide variety of consumers, advocates, employers, employment organizations, providers, and many other key stakeholders. The purpose of gathering this information is to develop a comprehensive 5-year strategic plan which will develop a comprehensive employment system for people with disabilities in North Dakota.

A key component to writing this strategic plan is to conduct statewide resource mapping with the goal of understanding the range of employment related services and supports available to individuals with disabilities in North Dakota. Information gathered from the resource mapping process will be used to analyze how the current employment system in the state is working and to identify policy direction for the future.

The ND CES grant is following a 5-step resource mapping process developed by the National Consortium for Health Systems Development:

STEP ONE: Resource Inventory

This step involves taking "inventory" of the employment related services and supports available for individuals with disabilities in North Dakota. Information gathered about each program includes: services/supports provided, disability population served, area/number served, and funding source.

STEP TWO: Evaluative Criteria

In this step, fundamental questions are developed to evaluate how well the current system is working. An example question might be "How useful do participants view the program to be?"

STEP THREE: Information Gathering

This step of the process involves gathering information to see if programs and services meet evaluative criteria. The ND CES staff will be gathering information from regional planning meetings, focus groups, and one-on-one interviews.

STEP FOUR: Summary and Analysis

At this point, data gathered through the resource mapping process will be compiled to take a look at the current employment system and to summarize what is working, what is not working, and what might be missing.

STEP FIVE: Policy Recommendations

The last step of the resource mapping process is to identify where changes need to be made to increase employment outcomes and to make policy recommendations.

The ND CES grant is partnering and contracting with the North Dakota Disabilities Advocacy Consortium and the National Consortium for Health Systems Development to assist in the development, consolidation of information and policy recommendations derived from the resource mapping data collection. The information gathered will be utilized to develop the statewide strategic plan for a Comprehensive Employment System in North Dakota.

For more information please contact: Ms. Karlee Rauschenberger @ NDCPD/Minot State University, 500 University Ave West, Minot, ND 58707 or 1-800-233-1737, or karlee.rauschenberger@minotstateu.edu.

#### **Remote Realtime Online Captioning (RROC)**

Crossing State lines to provide service to People with Hearing Impairments
By: Steve Peterson, NDCPD Community Services Coordinator

RROC is a service designed to translate speech into print as an accommodation for individuals with a wide variety of learning, language, and hearing disabilities. It uses computer and internet-based technology to capture audio and to connect RROC captionists with those we serve. This technology is similar to closed-captioning services seen on television, allowing people with disabilities to access information in a variety of settings such as conferences, workshops, public meetings, and classrooms. Development of this service began nine years ago with a grant from the Department of Education. RROC was funded as a research project for five years and due to its success, and consequent demand, evolved into one of NDCPD's available services.

Presently, we provide RROC services to students from elementary school to graduate school in states from the Midwest to the Atlantic Ocean. The system now provides approximately 300 hours of service per month to 20 students in 7 different states. A key advantage to this technology is that it is not restricted by geography. For instance, we have captionists in Utah providing services scheduled through our server in North Dakota to students in New Jersey. The design of RROC technology results in a relatively low cost compared to other available services and allows the flexibility to provide services anywhere in the world. In fact, we recently signed a service agreement with the New York City Public Schools.

How does this work? It's very complex from the perspective of the designer and programmer, but thankfully, quite straightforward from the user's perception. Think of it as three components: (1) a scheduling server in Minot ND, (2) a client with a computer in any location connected to the internet. Each site uses specially designed software (available from NDCPD); the server with scheduling software, the client with "Viewer" software, and the captionist with "Caption" software. The following is a typical sequence in the process of providing RROC services:

• A client (student, etc.), using their computer and through the internet, connects to the

- scheduling server in Minot and schedules an event (a class). This is often done a week in advance.
- A Captionist, using their computer and through the internet, connects to the scheduling server in Minot and accepts the event. This event is now scheduled and the server will connect the two at the scheduled time.
- At the scheduled time, both parties log in and the scheduling server connects them. They are now connected directly (no longer connected with the server). During this connected period, the audio in the client's room is recorded with a microphone into the client's computer; and passes through the internet to the captionist's computer and out their speakers. The captionist types (provides text for) the audio heard; and it travels back through the internet to the clients computer monitor. All this happens with a delay of just one to two seconds (hence, the term "realtime"). Our client also receives an edited transcript by email shortly after the event.

We, at NDCPD, are pleased that RROC has made a difference in the lives of many students with hearing disabilities. After all, that's what we do; that's why we're here. We help people who help people with disabilities.

We are also proud of the fact that RROC software was researched and developed by NDCPD staff and written by graduates and faculty of Minot State University.

Anyone interested in more information can view our web-site at <a href="https://www.ndcpd.org/realtime.or.call">www.ndcpd.org/realtime.or.call</a> <a href="https://www.ndcpd.org/realtime.or.call">1-800-233-1737</a> and ask for an RROC representative.



#### NDCPD Project receives National Recognition

The "2006 Exemplary Program Award" was presented by the American Council on Rural Special Education (ACRES) to Brent Askvig, NDCPD Associate Director, and Lynne Chalmers, Professor at UND, for their excellence in interagency collaboration for personnel training through the Rural Special Education Strategist (RSES) project. The national award was presented on March 24<sup>th</sup> at the ACRES annual conference in Lexington, KY.

The RSES project is administered through NDCPD at Minot State University, and is supported by a federal personnel training grant from the U.S. Department of Education. Over the past three and a half years, RSES has provided over \$500,000 in student stipends for 90 teachers to receive special education training. Although this is the final year of the RSES grant, MSU special education faculty have developed some strategies to keep the training efforts going. The incorporation of the UND resident teacher model into the MSU special education training program will be critical for continuation.

The Special Education Resident Teacher program at UND has been in operation for nearly nine years and has prepared over 130 teachers. The program prepares teachers who live in rural towns in ND; coursework is delivered through summer training sessions and distance delivery modes during the school year. Federal funding, support from the state special education office, and local contributions have made the program possible.

According to Askvig, "There has been a national shortage of special education teachers

Dr. Chalmers and I have been working within our universities and with local school districts to assure that rural North Dakota Students with disabilities have quality teachers. The local school administrators and our state special education leaders have been instrumental in our success in this area."

Congratulations to Brent and Lynn!



## Kelly Buettner-Schmidt receives National Recognition

Kelly Buettner-Schmidt, assistant professor of nursing at MSU and principal investigator of Healthy Communities
International (HCI) at NDCPD and the Department of Nursing, has been awarded the Lillian Wald Service Award. This national recognition is given to an individual or group who depict exemplary public health nursing practice to the public, especially in political, legislative, professional, or interdisciplinary activism. The award is presented by the American Public Association, Public Health Nursing Section; only one award is given each year. Kelly received this award for her many years in tobacco policy advocacy.

As part of the HCI project, a study was conducted to assess cigarette use, the beliefs related to cigarette use and secondhand smoke, and the level of support for smoke-free policies among Minot State University students, staff, and faculty. Information gathered from the study was used to inform decision makers on issues related to the development of a smoke-free grounds policy for MSU. Minot State University became a smoke-free campus on June 1.

**Congratulations Kelly!** 

#### **New Staff at NDCPD**

# Four new employees joined NDCPD in March. Heather Lee began as a Research Assistant and is currently working on the Part C Data Project and the Region Six Feasibility Study. Teri Aufforth and Cassie Artz jointed the Comprehensive Employment System (CES) project team; Teri as Project Secretary and Cassie as the Strategic Planning Coordinator. Cynthia Billings is a Project Coordinator for the ND Transition Partnership Project and the Job Corps Disability Training & Technical Assistance Resource Center grant.

**Kelly Drevecky** began working with the Flatlands Project at NDCPD in May. Kelly has been providing occupational therapy consultation to the Minot Infant Development Program through NDCPD since 1988. Aside from his work at NDCPD, Kelly also operates Prairie Therapy, a private practice pediatric therapy business.

**Dr. Patrick Moran** joined NDCPD in June as Associate Director for Community Services. He will be involved with grant writing, program development, prospective development, and center representation. Patrick came to Minot from Texas, but has spent many years in Alask. He brings more than 20 years of experience working in the disability field.

**Betty Omvig** is retiring as Coordinator of the Williston Infant Development Program (WIDP) after 24 years of service. Betty will continue providing early intervention services on a part-time basis for the WIDP. Betty plans to visit her two grown sons and enjoy traveling with her husband. **Best wishes to Betty! Erica Turnquist** will take on the role of WIDP Coordinator beginning in July. Erica has been with the WIDP for 5 years as an early interventionist.

#### **WE CARE**

The winner for May, 2006 in the WE CARE drawing is Janice Fuchs from Minot; she won a gift certificate from Charlie's Main Street Café. The June winner is Susie Mack; she won a gift certificate from Wal-Mart.

**Thanks** to all who contribute to NDCPD fundraising efforts by bringing in MarketPlace receipts. Also, special thanks to our sponsors who donate gifts that are used for the WE CARE and other fundraising events. New sponsors include: Herberger's, Dakota Square Hallmark, Scheels, McDonald's, Ground Round, Wal-Mart, Trinity Health, Wendy's, Mid-Town Chiropractic Massage, Gideon's Trumpet and ... Other sponsors include: Charlie's Main Street Café, Rick's Jewelry, Burger Time, Burger King, Marco's Dairy Queen KFC/A&W, Gary's Hairstylist, Gourmet Chef, Inc., Taco John's, Café Kiosk, Simonsons, Tires Plus, and International Inn.

Tickets are available at NDCPD for the Raging Rivers Water Park in Mandan. Tickets can be purchased for \$12.00 each from the North Broadway Cenex in Minot or by contacting Rich Berg, NDCPD, at 858-4349 or 1-800-233-1737.

For additional copies of the Collaborator contact Kari Arrayan at 1-800-233-1737.

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#### North Dakota Hearing Detection & Intervention (ND EHDI)

By Kimberly Witt, NDCPD

From the moment children are born, they are taking in information to make sense of their world. The things a baby sees, hears, smells, tastes, and touches are used for important learning. A baby's brain is born ready to learn.

Today, more than 30 babies are born every day in the United States with permanent hearing loss, making hearing loss the most frequently occurring birth defect. The incidence of hearing loss outnumbers cleft lip/palate, Down Syndrome, Spina Bifida, and PKU combined (NCHAM 2005). Parents can have their baby's hearing tested before they are discharged from the hospital. No baby is too young to be tested. At a minimum, all babies should be screened for hearing loss before the baby is 1 month old. Every baby with a hearing loss should be identified before 3 months of age and provided with timely and appropriate intervention by 6 months of age.

In 1988, the average age children were identified with congenital hearing loss was 2-1/2 to 3 years of age, with many children not being identified until 5 or 6 years of age. Consider this for a moment. What were most of our children absorbing during the first 2-1/2 to 3 years of their life? What kind of communication was occurring? What were they learning? Moreover, what could they have been missing?

Now in its sixth year, the *ND First Sounds* Project emphasis has been to ensure that babies receive an initial newborn hearing screening and the results of this screening are tracked on a statewide data system called OZ Systems eSP. Originally focusing on Universal Newborn Hearing Screening, First Sounds made a shift along with national organizations for focus on Early Hearing Detection and Intervention (EHDI). Beginning July 1, 2005, *Project Kaylyn* joined the ND EHDI initiative. This project focuses more on the follow-up phase of the screening process; ensuring that babies receive a second follow-up hearing screening or audiological assessment if needed, and be provided appropriate early intervention services as necessary.

Together, our mission is to ensure that children with hearing loss achieve communication and social skills appropriate to their cognitive abilities. To do this, it is essential that infants with hearing loss be identified early, and appropriate intervention services are initiated. Without early identification and intervention, children with hearing loss may experience delays in developing language, cognitive, and social skills leading to poor academic and occupational outcomes. According to the National Center for Hearing Assessment and Management (NCHAM), "Left undetected, hearing impairments in infants can negatively impact speech and language acquisition, academic achievement, and social and emotional development. If detected, however, these negative impacts can be diminished and even eliminated through early intervention" (NCHAM Fact Sheet, 2005). Further, early identification and intervention has helped children with hearing impairments make dramatic progress in communication, in school, and in their overall quaility of life.

Since 2000, ND newborn hearing screenings prior to hospital discharge have risen from 39% to over 95% and each birthing hospital in ND is equipped and has trained staff to screen every newborn for hearing loss. ND EHDI is continuing to work with our partners to address weaknesses in ND's capacity to follow-up, track, and refer infants who have not passed initial hearing screenings. There is a need to inform parents, prenatal health care providers, child health care providers, and others who work with children birth to 3 years of age about the ease, cost effectiveness, and availability of infant hearing screening.

#### Remember:

Screen by 1 month, Evaluate by 3 months, and Early Intervention by 6 months. If you are interested in more information about ND EHDI, please visit www.ndcpd.org/ehdi or call 1-800-233-1737.

