North Dakota (ND) is at a crossroad and needs to decide what direction to take in its effort to provide a continuum of long term care services to the elderly and people with disabilities. The home and community based services (HCBS) situation is not currently a “burning” issue in the state. A recent report prepared by Dave Zentner former director of the Medical Services Division of the ND Department of Human Services, At a Crossroad, North Dakota Home and Community Based Services – An Overview and Recommendations¹, however provides an opportunity for this issue to be more widely understood, more commonly embraced, and an issue of urgency in addressing the needs of ND’s growing population of elderly citizens and people with disabilities.

In March of 2007, the North Dakota Medicaid Infrastructure Grant (NDMIG) through the ND Center for Persons with Disabilities began coordinating efforts necessary to produce this report. This grant is funded through the U.S. Department of Health and Human Services Center for Medicare and Medicaid with the goal of helping states remove barriers to employment for people with disabilities. There is a major impact on the lives of people with disabilities when they are able to receive personal assistance service (PAS) in the home and workplace. In ND individuals with disabilities receive these services through HCBS. Currently, PAS is particularly underutilized in the workplace and HCBS often have limited availability.

By the year 2020, the number of citizens in ND over age 65 will be approximately 150,000 and the number of individuals over age 85 will increase to about 24,300, a 59 percent increase in just 15 years (Rathge, 2002). While institutional nursing home care will continue to remain a vital part of the long term care continuum, the use of HCBS are overall less costly than institutional care and meet the wishes of most citizens who would rather remain in their own homes or in a community setting (Armstrong, 2006). At a Crossroad, North Dakota Home and Community Based Services – An Overview and Recommendations outlines actions that should be taken to meet the long term care needs of the elderly and (continued on page 2)

people with disabilities in ND. Today services are provided through a variety of programs that are supported by federal, state and county funds for individuals who do not have the resources to meet their long term care needs. Consumers with adequate resources can also access the continuum of long term care services by paying directly for them. ND HCBS are delivered primarily by independent contractors or agencies called Qualified Service Providers (QSPs). Other local agencies provide home delivered and congregate meals and respite care for family caregivers as well as other services to help maximize consumer independence. Approximately 3,400 individuals in ND received HCBS through state and county programs during 2007 and over 6,000 individuals received home delivered meals during the last federal fiscal year (ND DHS-ASD, 2008). Expenditures of state and federal funds for these programs totaled about $29.4 million during 2007. It is estimated that institutional nursing facility expenditures will total $371.5 million over the two years of the current 2007-2009 biennium (ND DHS-FA, 2008). The contrast is clear. The difference in spending for HCBS versus institutional nursing facility care is a clear indication of the gap and need for additional resources and funding for HCBS in ND.

This report contains seven specific areas that need attention in order to ensure that adequate and appropriate services are available to elderly citizens and people with disabilities in the near future. These areas include: 1) access to adequate information for decision-making about services through assessments/screenings provided by a coordinated care system; 2) flexibility of programs/services to deliver community services to consumers; 3) additional funding to attract and retain adequate numbers of QSPs; 4) improvement of recruitment, retention, training and recognition of QSPs; 5) incentives to develop and subsidize affordable, accessible housing with services for elderly citizens and people with disabilities who have low and moderate income, and 6) increases to the medically needy income levels or allowing more access to the Service Payments for the Elderly and Disabled (SPED) program to obtain personal care services for individuals with a large Medicaid recipient liability. Each of these areas of concern is further explored in the main body of this report.

The issues surrounding the delivery of continuum of long term care services has been studied and discussed in ND for more than 20 years (Armstrong & Kraft, 2007). The demographics clearly show that the need for additional services will increase dramatically as the number of individuals over age 85 grows in the next decade. Now is the time to take action to strengthen the availability of HCBS in order to avoid a drastic increase in expenditures for institutional long term care services in the very near future and to provide the community and workplace with HCBS that North Dakotans need and prefer.

To access the complete report, At a Crossroad, North Dakota Home and Community Based Services – An Overview and Recommendations, please visit www.ndmnicg.org under publications and click on An Overview and Recommendations: Home and Community Based Services or go directly to http://ndcpd.misu.nodak.edu/projects/medicaid/publications/pdf/HCBS.pdf.

Benefits Planning Training Events

**Eight Facts a Service Provider Can Use to Inform a SSA Beneficiary About Work Incentives**

**Presenter:** Health & Disability Advocates

**Dates, Sites, & Times**

- June 24-25 Doublewood Inn, Bismarck 9:30am-4:30pm
- July 14 Doublewood Inn, Fargo 9:30am-4:30pm

**Work Incentives Policy Institute**

**Presenter:** Health & Disability Advocates

**Dates, Sites, & Times**

- June 24-25 Doublewood Inn, Bismarck 1:00pm
- June 26-27 NDSU Research Center, Minot 1:00pm
- July 15-16 Doublewood Inn, Fargo 1:00pm
- July 17-18 CMen Inn, Grand Forks 1:00pm

Register at: www.ndcpd.org/benefits. Refer to section on Free Training Opportunities
A follow-up to the NDCPD Symposium on Autism
by Cathy Haarstad, Consumer Affairs Coordinator

The North Dakota Symposium on Autism was held on March 17, 2008 at MSU. Attendance certainly exceeded expectations. A total of 300 people registered and 284 attended. The majority of participants attending came from rural communities in the central areas in the state. The conference hosted a panel discussion, town hall meeting and two national presentations.

Panel participants discussed the need for early diagnosis and treatment and concerns about limited services especially in many rural communities. The panel also discussed the importance of access to an array of services and the need to understand that behavioral intervention is not limited to discrete trial training. Finally the panel discussed the importance of having a systematic training program in place at both the pre-service and in-service level so that families need not rely on the lack of the draw in finding a teacher with expertise in autism.

The Town Hall Meeting was one of the more exciting features of the conference. This survey was not intended to be a scientific study. It was used to give both the presenters and participants a general awareness of some of the issues and challenges facing ND. Participants indicated their responses to a series of questions using individual remote devices.

Data showed that the majority (about 30%) believed children in ND are not diagnosed until after their second birthday. They also indicated that services available in local communities are typically financed by the public school system.

Forty two percent indicated that they did not know if services for families of children and youth with autism (CYWA) were available or did not have services in their community.

Early intervention was identified as the most important service needed by children with autism. Professionals showed the highest interest in learning more about social stories, screening and diagnosis and positive behavioral supports. Training for families on social stories and screening and diagnosis were also rated as high. However, a potentially troubling trend was shown when the option of “don’t know” about training for families was selected as the third highest option.

Intensive in-home behavioral support was selected (42%) as the most important support for families. This was followed by financial support and trained respite providers (at 25 and 22 % respectively.) The two highest changes that should be addressed in the next year were: 1) Develop models for early intervention and treatment and 2) Establish clinics to diagnose and treat CYWA.

Overall, about 83% of the participants rated their level of satisfaction with the symposium as satisfied or highly satisfied. Participants were complimentary about many aspects of the conference. A detailed list of participants’ comments can be viewed at www.ndcpd.org/autism. You may also view our website to learn more about upcoming trainings and events.

CD Casts on Autism

Back to School Basics for Families with Children with High Functioning Autism
Presenter: Jennifer Heftner
Date: August 7
Time: TBA
Fee: $30.00 per site

Back to School Basics for Families with Children with Moderate to Severe Autism Spectrum Disorder
Presenter: Jennifer Heftner
Date: August 14
Time: TBA
Fee: $30.00 per site

For more information contact JoLynn Webster at 1-800-233-1737.

Game On for Health!
by Kari Arrayan, Program Director, ND Disability Health Project

The North Dakota (ND) Disability Health Project, through the North Dakota Center for Persons with Disabilities at Minot State University, has incorporated a game room that features a Wii and other active games for youth and adults with disabilities. The game room is in line with the project mission to promote the health and wellness of people with disabilities, and to prevent or lessen the effects of secondary conditions associated with disabilities.

The Youth Risk Behavior Survey (YRBS), which is conducted every 2 years, monitors health risk behaviors of students that contribute to the leading causes of death, disability, and social problems among youth. According to the 2007 YRBS survey, 52% of ND students (grades 9-12) did not meet recommended levels of physical activity, 25% watched TV three or more hours per day, and 10% were considered obese according to a body mass index based on age and gender. Within the adult population, the ND Behavior Risk Factor Surveillance Survey (BRFSS) indicates that adults with disabilities have a higher prevalence of health conditions such as obesity, diabetes, cardio vascular disease, high blood pressure, asthma, and high cholesterol.

Studies show that many kids and young adults are more likely to engage in fitness activities that are connected to a video game. The Nintendo Wii is a video game console that allows the user to actively engage in a variety of games/activities. This ‘active gaming’ gets the user moving and engaging in a more physical way than typical video games. In addition to physical movement, some games can also increase range of motion, balance, or hand-eye coordination. Studies also suggest that active gaming can contribute to the development of skills in other areas such as communication and problem solving. All of these benefits can positively affect self esteem and social well-being.

Games currently available in the game room include Wii tennis, golf, boxing, baseball and bowling. There is also a hand control version of Dancing with the Stars. The game room is open Monday through Friday, 8:30 am - 4:00 pm; alternative times may be requested. Parents are expected to remain with their children in the game room. To schedule a game room experience, contact Kyleene Kraft at kyleene.kraft@minotsstateu.edu or 701-858-4365.

For more information about this and other activities supported by the ND Disability Health Project visit the website at www.ndcpd.org/health.
MIDP: 30 Years of Service to Children & Families

June 2008 marks 30 years of service for the Minot Infant Development Program (MIDP). This program housed at the North Dakota Center for Persons with Disabilities at Minot State University and funded by the North Dakota Department of Human Services supports activities which identify infants (birth to three years) who are developmentally delayed, high risk, or at risk. MIDP staff assist parents and caregivers in identifying natural learning opportunities that occur throughout their child's day during daily routines and guide parents in using these opportunities to enhance their child's development. In addition, staff assist parents in finding supports available through local, state and national programs to help with needs related to their child's developmental issues.

To commemorate this accomplishment, the MIDP would like to invite children and families who have participated in the program throughout the years to join them on Thursday, September 18th at the Holiday Inn Riverside for a 30th Anniversary Celebration. In connection with this celebration, MIDP will host a variety of carnival games and activities for the children and is looking for any community members wishing to volunteer their time to help man booths. There will be free refreshments.

For more information or to volunteer, please contact Kathy Lee, MIDP Program Director: 1-800-233-1737, e-mail kathy.lee@minotstateu.edu

Walking for a Cure

Congratulations to the NDCPD's Relay for Life team which raised $1,632 for this year’s event. Fundraising activities took place throughout the year and included “Soupers Tuesdays”, a Baby Picture contest, and a Garage Sale that was combined with a bake sale. This year’s team participated in the annual event held on the campus of Minot State University May 30, 2008.

We Care Winners

Congratulations, André Miller, Richard & Linda Vise, and Kathy Lee! Winners for April, May, & June

Thanks to all who contribute to NDCPD fundraising efforts by bringing in MarketPlace receipts. For every receipt turned in with the “WE CARE” stamp, MarketPlace Foods will give 1% of the total back to NDCPD for the NDCPD Endowment/Access Scholarship fund. Continue to bring your receipts to NDCPD and be sure to include your name and phone number on the back of the receipt to be eligible for the drawing.

May Celebrated Better Speech and Hearing Month!

In celebration of Better Speech and Hearing Month, ND EHDI staff and grant partners offered free hearing screenings to families in the Minot area May 8th on the MSU Campus. The screenings were held in the lower level of Memorial Hall under the direct supervision of audiologist Tom Froelich. Eight families participated that morning and received a free hearing screening. They were also able to ask questions about their child's hearing. ND EHDI staff want to thank Holly Pedersen (MSU Special Education Faculty) and Tom Froelich (MSU Communication Disorders Faculty) for taking time to volunteer their services!

NDCPD Bids Farewell to Fifield

For more than ten years Dr. M. Bryce Fifield has served as Executive Director for the North Dakota Center for Persons with Disabilities (NDCPD) on the campus of Minot State University (MSU). Dr. Fifield will leave NDCPD this July to assume a new position as the Executive Director at the Center for Persons with Disabilities in Logan, Utah. This will be an exciting opportunity for Dr. Fifield to return to the university and center where he began his career in the disability field.

In his time at NDCPD, Dr. Fifield was a part of dynamic growth in the center, providing leadership and expertise, specifically in reaching rural communities through distance technology and services. NDCPD faculty and staff will miss Dr. Fifield’s leadership but look forward to continuing collaborative efforts with him through the Association of University Centers on Disability (AUCD) network and the Utah Leadership Education Neurodevelopmental Disabilities (ULEND) training program.

Brent Askvig Appointed New Director

Askvig’s role as Executive Director of the Center for Persons with Disabilities in Logan, Utah, will be an exciting opportunity for Dr. Fifield to return to the university and center where he began his career in the disability field.

In addition to four years of service as Associate Director of NDCPD, Dr. Askvig brings 18 years experience as a MSU Special Education faculty. He previously served as MSU’s Department Chair in Special Education and as Assistant to the Dean of the MSU Graduate School. A graduate of MSU, Askvig has a bachelor degree in education and special education and a master’s degree in severe disabilities. He received his doctorate degree in Education and Special Education with a specialty in educational research from the University of Idaho.

“I am excited about my new role in NDCPD and the people in the center. Dr. Fifield has done a tremendous job over the past 10 ½ years, and has in place a solid foundation for NDCPD’s future growth,” says Askvig. “I am also excited about NDCPD’s role in supporting persons with disabilities throughout the state, and in working with MSU on its Vision 2013.” Dr. Askvig will assume the responsibilities of Executive Director on July 1, 2008.

New Faces at NDCPD

With goodbyes to colleagues and friends, we also welcome a few new staff to our administrative team at NDCPD. Nicole Flink, a former MSU graduate, will serve as administrative assistant for the new Executive Director. She will provide support to the Disability Health and the Rural Youth Recreation Communities projects as well as managing the center’s webcasts. Jana Kremer also joins the team as administrative support to the ND Comprehensive Employment Systems, Rural Health Network for Family Support, and Benefits Planning grants and the Consumer Advisory Committee. She will serve guests and visitors to NDCPD at the front desk. Welcome!

2007-2008 Graduates

Congratulations to the following NDCPD staff who completed degree programs during the 2007-2008 academic year:

- Kristin Jackson, Transition Project, Master Degree
- Tina Mack, Administrative Assistant, Master Degree
- Rich Berg, We’re Ready Project, Bachelor Degree
- Colleen Johnson, ND SMP Project, Bachelor Degree
- Jerusha Olthoff, ND EHDI Project, Bachelor Degree

For additional copies of The Collaborator contact Cynthia Salazar at 1-800-233-1737. Please feel free to copy and distribute articles or excerpts from The Collaborator, provided the following acknowledgement is used: Used with permission from the North Dakota Center for Persons with Disabilities, a center of excellence at Minot State University, Minot, North Dakota, USA.