



NORTH DAKOTA CENTER FOR PERSONS WITH DISABILITIES

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April 2009

ND Integrated Services Project Focuses on Quality Services in the State

By Cynthia M. Salazar, Project Coordinator, North Dakota Integrated Services Project

The North Dakota Integrated Services (NDIS) project is a three year grant funded by the US Department of Health and Human Service – Maternal and Child Health Bureau to the North Dakota Center for Persons with Disabilities (NDCPD) at Minot State University. The NDIS project is assisting state agencies, local medical providers, and families of children and youth with special health care needs (CYSHCN) ages birth to 21 years of age to develop the knowledge and infrastructure to assure that all children and youth receive the coordinated care they need.

This project focuses on the six components of quality service:

- Families of CYSHCN are partners in decision making at all levels and are satisfied with the services they receive.
- CYSHCN receive coordinated, ongoing, comprehensive care within a medical home.
- Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.
- CYSHCN are screened early and continuously for special health care needs.
- Services are organized in ways that families can use them easily.
- Youth with special health care needs receive the services necessary to make appropriate transitions to adult health care, work, and independence.

To achieve quality services, the NDIS project has partnered with the North Dakota Department of Health – Children’s Special Health Services Division, Family Voices of North Dakota – Health Information and Education Center, the North Dakota American Academy of Pediatrics, the North Dakota Office for the Elimination of Health Disparities, and the North Dakota Department of Public Instruction to create a network of learning collaboratives, pilot programs, and a comprehensive plan for integrated services. [\(continued on page 2\)](#)

NDCPD Receives Exclusive National Contract

By Neil Scharpe, Project Director, Tele-Audiology Project

The North Dakota Center for Persons with Disabilities (NDCPD) at Minot State University (MSU) was awarded an exclusive contract with the Center for Disease Control and Prevention (CDC) to promote the utilization of the telemedicine network as it relates to early hearing detection with newborns. This contract will put NDCPD and MSU in a unique position to establish standards that will be utilized by the profession on a national basis. While NDCPD has been awarded many grants over the years this is the first contractual arrangement that has been secured.

NDCPD will develop a diagnostic and management protocol that will be utilized as a basis to replicate audiologic testing of infants employing a telemedicine network around the country. [\(continued on page 3\)](#)



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Project Focuses on Quality Services in the State (Continued from page 1)

The network of learning collaboratives provide significant education, training, and opportunities to collaborate for primary care providers, families and other important partners in coordinated care. Each collaborative integrates the six components of quality services as they focus on three core areas: medical home, healthy transition to adult life, and family involvement and cultural competence.



In February 2009, NDIS held its first *Medical Home Learning Collaborative* meeting. This two day meeting brought together mentors from the Minnesota Medical Home Learning Collaborative and three medical home teams in North Dakota (ND). Each team, consisting of a pediatric physician, care coordinator, and two family representatives, received information on the initial steps for creating a medical home in their practice. Teams learned how to use medical home tools, identify and create a registry of CYSHCN in their practice, provide comprehensive care coordination and use care plans, assess the extent of their medical home, and identify areas of improvement.

Teams will convene until April when they will meet again to review their progress and receive additional training to move medical home forward in their practice. In the interim, teams are participating as pilot sites providing data on the process and barriers to medical home implementation in ND. In between collaborative meetings, additional teams are being recruited and NDIS staff are providing current medical home teams with technical assistance.

The first *Transition Learning Collaborative* meeting was held in March 2009. At this half day meeting, a national speaker from the Healthy Ready to Work National Center and families, youth, and stakeholders working with youth in transition to adult life discussed health as an essential component in successful transition. This learning collaborative identified gaps in services and discussed steps to improve transition services in ND. A second meeting will be held in May. Training to integrate family involvement and cultural competence into ND services is planned for May and June 2009.

The NDIS project is working with partners to create a comprehensive plan for systemic implementation of an integrated services system for CYSHCN in ND. The NDIS will coordinate an annual stakeholder symposium to create top level buy-in to an integrated system. NDIS held the first annual stakeholder meeting in December 2008 in Bismarck. During this symposium the current service system for CYSHCN in ND was discussed and workgroups were formed to work on identified goals. These workgroups will develop leadership to direct statewide partners in sustaining future efforts. As the work of the NDIS project continues best practice features of the models to influence system changes will be evaluated and disseminated.

For more information on this project, contact Kora Dockter, NDIS Project Director, at 701-858-3423 or by email at kora.dockter@minotstateu.edu.

Ram Good Job Award



Ram Good Job Statue

NDCPD has re-instituted a staff appreciation award, the Ram Good Job Award. Each month a staff member receives a bronze-styled statue of two ram sheep. This award is given by the preceding month's award recipient, and honors the staff member's work to enhance the lives of people with disabilities and further the center's mission.

The award goes to the staff member who has done such a "ram good job" that they must be publicly recognized. This award was first started in the early 1990s by NDCPD's first Executive Director, Dr. Stephen Ragan. It lay dormant for nearly 15 years, and was started again at NDCPD's 2008 Fall Staff Retreat. Winners over the past months include:

- November 2008** Nicole Flink, Administrative Assistant
Lisa Johnson, Strategic Planning Coordinator
Linda Madsen, Project Director
Cheryl Rystedt, Administrative Secretary
- December 2008** Amy Armstrong, Project Coordinator
- January 2009** Mary Mercer, Community Training Core Coordinator
- February 2009** Donna Weishaar, Administrative Secretary

National Contract (continued from page 1)

The development of technology allows professionals to use video networks to view real time performance in remote locations. Pediatric audiologists can direct the placement of electrodes by trained paraprofessionals and then manipulate evaluation equipment using computer technology from a distant location.



As a participant in the Early Hearing Detection and Intervention project for the past eight years, NDCPD understands the need to provide audiological testing for infants prior to three months. In a rural setting such as North Dakota it is difficult to get newborns who fail the initial hearing screenings to return for a complete evaluation. The combination of travel and access to professionals many times has led to a lack of testing.

We will make use of MSU as a hub facility for existing networks and place equipment in several remote locations to complete the beta testing. It is our intent to develop a training manual for paraprofessionals that would be used to train people in remote sites to connect infants to equipment while they are monitored and directed by a pediatric audiologist at a hub site.

We will develop a technical protocol that can be used to replicate this procedure across the country. This document will address minimum requirements of the network, equipment, procedures etc. A management protocol will also be developed that will explain a variety of approaches and methods that could be used to address problems that are encountered by this project.

After completion the CDC project staff will be asked to provide technical expertise in the establishment of other TeleAudiology networks in the United States.

Project personnel consist of Neil Scharpe, Service Contract Specialist, who will be the Project Director; Tom Froelich, MSU Audiologist, who will design the technical protocol and perform long distance testing of infants; Steve Peterson, NDCPD Online Disabilities Service Coordinator, who will assist with system design and maintenance; Darren Seifert, NDCPD Computer Programmer, who will develop and maintain compatible software; and Nicole Adams, NDCPD Administrative Secretary, who will provide administrative support to the project.

The project has specific timelines for completion of each element of the contract with the entire project to be completed in two years.

We Care Winners

December, Jana Kremer (Minot)

January, Brenda Munson (Minot)

February, Mary Mercer (Minot)

Prizes included certificates to the Pita Pit, KFC, and Pizza Hut. 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.

Also, special thanks to our sponsors who donate gifts that are used for the WE CARE and other fundraising events. Our sponsors include:

Brown & Saenger, Burger King, Dairy Queen (North), Hardees, Headquarters, Herberger's, KFC/A&W, MarketPlace Foods, Minot State University, Minot Visitor's Bureau, Papa Murphy's Pizza, Pita Pit, Pizza Hut, Point of View Winery, Royal Fork, Scheels All Sports, Sevens Bar & Restaurant, Simonson's, SRT, and Taco Johns .

NDCPD wants to hear from you!

In order to meet the needs of our customers, NDCPD gathers satisfaction information from time to time from the individuals who receive and use our products. We want to hear what you think. Please complete the enclosed customer satisfaction card and rate this newsletter. Then visit our website at www.ndcpd.org and take a few minutes to tell us what you think of the site by completing the "Visitor Survey".

We welcome you feedback!



Director's Message: Leadership in the Field

By Brent A. Askvig, Ph.D. NDCPD Executive Director



Dr. Christy Carroll
TBI State Initiative
Committee

Recent state and national legislative and policy changes have been staggering. There will be an influx of federal money into states. New areas of focus (science, health care, education) are more prominently emphasized in public policy. Economic depression (or success in North Dakota) causes us to reflect on new ways to plan and act. Old strategic plans must now be reviewed and revised.

Sorting out this sometimes confusing, and sometimes contradictory information and policy is daunting. But local, state and national leaders need not face this alone. UCEDD faculty and staff have the ability, and I might suggest the responsibility, to provide leadership in these future policy and practice decision processes. Here are some ideas on how we might provide leadership in the field for the future:

Get involved. The simplest way to effect change and provide leadership is to make a call or visit, or send an email to a state or community leader. Make an offer to provide information on questions about topics for which you are an expert or are familiar.

Share evidence. Good leaders need good evidence and data to make appropriate decisions. Our work at UCEDDs, community services and public and private agencies and programs generates considerable data. Compile and organize these data, and then share it with public leaders.

Establish networks. This time of change is a great opportunity to re-invigorate existing partnerships or to establish new networks. Discussions with partners can result in common initiatives. When these common issues are presented to leaders, they may carry more weight and may result in a more effective message.

Personalize the message. Public policy makers want to know how funding, regulation and practice changes will influence people. We can provide leaders with personal stories about what happens when changes do, or don't, occur. Putting a face and a story with a policy or program helps public policy staff make sense of what they are trying to do.

There are several other methods for helping policy makers effect important changes including state or national task force or committee membership, advocacy organization involvement, newsletters, mass mail (or email) campaigns, and others. What is important is that we take our responsibility of leadership seriously. We have the evidence, we have the partnerships and networks, and we have the stories that need to be shared. When this happens we are clearly being leaders in the field.



Janet Green
NLTSS2 Trainee

NDCPD Staff Recognized

Dr. Christy Carroll, NDCPD Associate Director, has been appointed to serve as a member of the Traumatic Brain Injury (TBI) State Initiative Committee. The purpose of this committee is to promote the rights of people with traumatic brain injury (TBI), develop a state registry, and provide awareness throughout the state. This committee is lead by the North Dakota Department of Human Services. The committee is composed of representatives from agencies and organizations working with people with TBI like the Center for Rural Health, North Dakota Brain Injury Association, United States Air Force, and North Dakota National Guard, as well as individuals with TBI and their family members. Dr. Carroll's research on TBI with the federal government and the military will provide needed insights to this committee.

Janet Green, Project Director for the Transition Partnership Project, attended a National Longitudinal Transition Study-2 (NLTSS2) Training Seminar hosted by the Institute on Education Sciences and the National Center on Special Education Research. From the 93 applicants, Green was one of the 30 invited to attend the seminar. The NLTSS2 is a study "funded by the US Department of Education and is documenting the experiences of a national sample of students ... as they move from secondary school into adult roles" (www.nltss2.org/). The study is described as "an inch deep and a mile wide" by presenters at the seminar, indicating that it includes a wide range of important topics that may be of interest to many audiences. Due to the enormous amount of data collected by this study, the hosting agencies and the US Department of Education sought qualified participants who might further the analysis of the data and disseminate the findings to impact policy and spark future research on the transition of youth with disabilities into adult roles.

Cathy Haarstad, Principle Investigator for the ND FamNet project, has been elected to serve as the secretary of the North American Coalition for Parents with Intellectual and Cognitive Disabilities (NACPID). This recently formed multi-national organization highlights research and promising practices for supporting at-risk parents that have intellectual challenges. We know that 50 to 80% of the children born into these families are removed by Child Protective Services. With appropriate support, research shows that many of these families can learn to demonstrate adequate parenting behavior. When children are removed, parents typically give birth to more children and the cycle continues. For more information about NACPID view the website at <http://cdd.unm.edu/swconf/summit/index.html> or contact Cathy Haarstad at cathy.haarstad@minotstateu.edu.



Cathy Haarstad
secretary of
NACPID

April 2009

Sun	Mon	Tue	Wed	Thu	Fri	Sat
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5	6	7	8	9	10	11
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May 2009

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June 2009

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28	29	30				

Upcoming Conferences & Training Events

North Dakota Association of Community Facilities (NDA CF) Annual Conference

Dates: April 29 – May 1, 2009

Site: Minot – Grand International/ International Inn

Registration Fee: \$150

At this three-day conference, participants will have the opportunity to attend plenary sessions, concurrent sessions, poster sessions, and displays on a variety of topics. Preliminary agenda includes the following presenters:

Creating a Culture of Excellence: Actions for Everyday Leaders by Eli Pagonis, Director of Training, Baptist Health Care Leadership Institute.

Life in a Blender: Generational Diversity by Rick Gessler, Employment/Employee Relations Manager, and Jeff Frank, Compensation and Benefits Manager, Altru Health Systems.

Working with Autism: An Inside View by Bev Harp, MA, Self-Advocate, Lexington, KY.

Warm Up the Workplace by Frank Pastizzo, Saranac Lake, NY.

For more information contact: Cheryl Rystedt @ 1-800-233-1737 or email @ Cheryl.rystedt@minotstateu.edu



LEND Trainee

LEND Training Program

NDCPD participates in the Utah Regional Leadership Education in Neurodevelopmental Disabilities (LEND or URLEND) training program. The Utah Regional LEND is an interdisciplinary program that trains professionals to move beyond narrow disciplinary boundaries to provide optimal services to child and adolescents with special health care needs. Because families are essential to well-being, this program emphasizes the role of family-centered care. In the fall of each year, LEND Trainees are brought together with faculty and families of children with special health care needs, to form an interdisciplinary learning cohort. Each long-term trainee participates in three forms of learning: didactic (classroom), leadership, and clinical.

NDCPD supports professionals in the following fields to participate as long-term LEND trainees:

- Audiology, Dentistry/Pediatric Dentistry, Education, General Medicine, Genetics, Health Administration, Nursing, Nutrition, Occupational Therapy, Pediatrics, Physical Therapy, Psychology, Social Work, and Speech-Language Pathology.

NDCPD also supports people with disabilities and their family members to participate in the LEND training program.

Currently NDCPD is recruiting people with disabilities or their family members to participate as LEND trainees. This is an excellent opportunity to work with professionals in the field to increase your skills as leaders and advocates for children and youth with special health care needs. For more information about this program visit www.urlend.org. To learn more about becoming a LEND trainee, contact JoLynn Webster at 1-701-858-3206 or email jolynn.webster@minotstateu.edu.

For additional copies of the Collaborator contact Cynthia Salazar at 1-800-233-1737.

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COLLABORATOR
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 1-99

Economic Stimulus Scam



Typically, this scam is sent through regular mail or e-mail with a letter congratulating the victim that they have been chosen to receive an economic stimulus payment in the amount of \$2,500. In order to receive the payment, a stimulus form must be completed and mailed back within seven days along with a processing payment of \$119.05. The offer also states that as a thank you for your participation in the new stimulus program, you are the recipient of a dream vacation giveaway.

How to Avoid Falling Victim to Fraud Unauthorized Charges Scams:

- Be suspicious of requests for upfront fees and never click on links sent in unsolicited e-mails.
- Do not give out bank account or credit card numbers over the phone or by e-mail if you didn't initiate the call/e-mail to a reputable, known company.
- When tempted by a great deal proffered out of the blue by a business entity you have no direct knowledge of, remind yourself that offers which sound too good to be true generally are. Keep in mind that that is presented as a fabulous value for an amazing low price (e.g. coupons for \$200 worth of gasoline in return for \$1.95 mailing fee) might be no more than a set-up for the real purpose of persuading you to give up your financial information.
- Be wary of any "free trial offer" that requires bank account or credit card numbers to cover shipping and handling charges.
- Examine your credit card and bank account statements every month, keeping an eye peeled for unauthorized charges. Immediately challenge items you did not okay.
- Stop believing in the chimera of "something for nothing."

If you believe you're a victim of fraud, call the Consumer Protection Division in Bismarck at (800) 472-2600, or go to your local police.

For more information on how to protect yourself against Medicare and other fraud, contact Linda Madsen, Senior Medicare Patrol Project Director, at 1-701-858-3424 or linda.madsen@minorstateu.edu.



Eftalia Esser



Korie Huettl



Connie Irely



New Staff

Eftalia Esser comes to NDCPD as a research associate. Her projects includes research for the State of the State on Abuse and Neglect of Individuals with Developmental Disabilities and work on proposals for Autism research and Utilizing Health Information Technology (IT) to improve Health Care Quality. Before coming to NDCPD she was the Vice President of Academics at Cankdeska Akana Community College. Eftalia or Thalia, as she is more commonly known, is from Greece and has been in Minot since the late eighties. She came to Minot State University where she received her master's degree in special education.

Korie Huettl joins us as the Administrative Assistant to the Executive Director of NDCPD. She serves as the Share Point Administrator as well as the Project Secretary for the ND Disability Health project. She also provides secretarial support for the IVN teleconference studio and assists with the SPDG evaluation project for the state. Prior to joining NDCPD, Korie worked ten years in the Developmental Disabilities unit at the North Central Human Service Center in Minot.

Connie Irely works as the Administrative Secretary for the Great Plains Autism Spectrum Disorder Treatment Program (GPAST) and the I Can Do It project. She also provides secretarial support to the North Dakota Developmental Disability Network through a series of monthly summits and to the State Autism Initiative. Connie worked previously at Dakota Family Services. She is a North Dakota native and a proud grandmother of one very special grandson.

Each year NDCPD also employs many Minot State University students to assist in research and training projects while providing them with the opportunity to gain skills they can use when they leave the university. This year several MSU undergraduate/graduate students are participating in autism and special education research projects, mentoring high school students in nutrition and exercise, and providing support for NDCPD community training and awareness programs.

Part 2- At-A-Glance: The Final Ticket to Work Regulations

By Tom Alexander, Project Director, Medicaid Infrastructure Grant

As stated in the previous article, the Ticket to Work Program final regulations were published on the Federal Register on May 20, 2008. Within this article I will highlight changes to Eligibility of Beneficiaries and Employment Networks (ENs); changes to Payment System; changes to state Vocational Rehabilitation (VR) Agency Relationship with the Ticket to Work Program; and changes to the Timely Progress Requirements.

Changes to Eligibility of Beneficiaries and Employment Networks

All Social Security Disability Insurance (SSDI) and Social Security Income (SSI) beneficiaries in cash status between the ages of 18 and 64 will not be eligible for the ticket.

Changes to Payment System

Social Security Administration (SSA) has changed both the amounts of the payments and the benchmarks that must be achieved in order to receive payments. Under the Outcome Only EN Payment System, the payments have been increased. Under the Outcome-Milestone EN Payment System, the payments have been converted into three phases:

During Phase 1, payments are made based on gross income (ignoring deductions for work incentives) and working at the Trial Work Period amount. Phase 1 payments on the SSI and SSDI tickets are the same.

Phase 2 payments are also based on gross income (ignoring deductions for work incentives) and working at the Substantial Gainful Activity.

Phase 3 payments are based upon countable income and leaving the SSA roles.

Changes to the State VR Agency Relationship with the Ticket to Work Program

State VR agencies are no longer required to assign Tickets in order to assure cost reimbursement from SSA. State VR agencies have the option to participate in the Ticket to Work Program and assign tickets for reimbursement through the two EN payment systems if they choose to do so.

When beneficiaries works with the state VR agency under the cost reimbursement method, their ticket is not technically assigned to the state VR agency. But, the beneficiary cannot assign the Ticket to another EN while the VR case is open. While the VR case is open, the beneficiary will have the protection from a Continuing Disability Review just as he or she does with an assigned ticket.

Changes to the Timely Progress Requirements

SSA conducts timely progress reviews to assure that beneficiaries are making progress toward great self sufficiency. If it is determined that a beneficiary is not making timely progress, the Continuing Disability Review protection is removed. No loss of benefits or other negative consequence is imposed.

I would strongly encourage interested readers to go to the Amendment to the Ticket to Work and Self-Sufficiency Program: Final Rule located at <http://edocket.access.gpo.gov/2008/pdf/E8-10879.pdf>.

Reference:

National Consortium for Health Systems Development (2008) Ticket to Work Toolkit. A project of Health & Disabilities Advocates.



**NORTH DAKOTA
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The Collaborator

The Collaborator is the quarterly newsletter for the North Dakota Center for Persons with Disabilities (NDCPD). NDCPD is a University of Excellence on Developmental Disabilities in Education, Research, and Services at Minot State University. It is part of a network of similar programs at universities throughout the United States.

Our mission...

To provide leadership and innovation that advances the state-of-the-art and empower people with disabilities to challenge expectations, achieve personal goals and be included in all aspects of community life.

Vision Statement...

We believe that people with disabilities have the same rights as all citizens. We believe that people with disabilities who receive publicly funded services have the right to expect that those services appropriately promote their independence, productivity, integration and inclusion. Furthermore, we believe that the public expects that these services will be provided in an effective manner.

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