

NDCPD TRAINING EVENTS**The Impact of Movement Differences and Sensory Processing Challenges on the Abilities of Individuals with Autism Spectrum Disorders***Presenter: Kim Davis, M.S., Indiana Resource Center for Autism***Dates & Sites:**

February 27: Comfort Inn, Bismarck
 February 28: Research 1, NDSU, Fargo
 February 29: Development Homes, Inc., Grand Forks

Train the Trainer to Train the Staff in Therapeutic Intervention*Presenter: Ron Odden***Dates, Sites & Times:**

April 9, 2008: Comfort Inn, Bismarck-9:00 am-4:00 pm
 July 10, 2008 (follow-up): Comfort Inn, Bismarck
 9:00 am - Noon

North Dakota Association of Community Facilities Annual Conference (NDACF)

Dates: April 23-25, 2008
 Site: Fargo - Doublewood Inn

Contact Person: Cheryl Rystedt @ 1-800-233-1737

The COLLABORATOR

North Dakota Center for Persons with Disabilities
 at Minot State University

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Rural Health Network for Family Support

by Cathy Haarstad, NDCPD Project Director

The Rural Health Network for Family Support (RHNFS) is a recently formed collaborative effort to enhance support for rural North Dakota (ND) families whose children have special health care needs. The ND Center for Persons with Disabilities (NDCPD) received a one-year planning grant in 2007 from the Health Resources and Services Administration (HRSA) to work with potential partners and stakeholders and consider development of such a network. Two key partners, the ND Center for Rural Health at the University of ND and Family Voices of ND (a statewide grassroots organization that provides informational emotional and policy support to the target population) assisted NDCPD in implementing the grant. These three agencies have formed the RHNFS under this funding initiative. Family and support stakeholders from across ND participated in a series of stakeholder meetings in the spring and summer of 2007 to consider further development of a rural health network.

Typical rural health networks are formed by rural clinics and hospitals that collaborate to explore options such as workforce training, joint purchasing, and electronic records. The RHNFS is unique in that it brings together non-profit groups providing an array of family support services to families whose children have special health care needs. *Children with special care needs* (CHSCN) are

those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Conditions may include various types of disabilities such as Autism, Downs Syndrome or Cerebral Palsy as well as chronic health challenges such as asthma or diabetes. *Family support* is defined as an array of emotional, informational and navigational supports designed to enhance a family's ability to find or develop services to improve their children's well being, provide access to health care and strengthen/preserve their family.

Participants in the stakeholder meetings showed a strong interest in collaborating. The efficiencies and focus that might be achieved through such a network appeal to diverse families and groups. The mission of many such organizations in ND could be strengthened through collaboration that was well-planned and executed. Finally the ability of a network to tackle projects and fund new service models also holds appeal for some participants. As a result of the stakeholder meetings four activities were identified as those having the strongest interest among constituents. These include: 1) resource mapping to identify existing training programs held jointly among network members with development

(Cont. from Page 1 – Cathy Haarstad)

of joint training programs; 2) implementation of rural leadership development models that provide state partners and rural communities with knowledge and information about how to duplicate evidence-based family support models that have proven effective in rural communities; and 3) creation of a joint educational policy platform for system change that focuses on the needs of families and children in the target population. A fourth activity that has moderate interest among stakeholders involves bringing in external consultants to inform the network about the process of funding and operating a universal application for services.

Many ND families have expressed frustration in trying to navigate and access multiple-systems in raising, educating and caring for children with special health care needs. A universal application provides families with one application process to access the multiple programs that they need to support their children. Many partners are interested in the process yet cautious. Some past efforts to align forms and pursue joint applications have not been wholly successful. The network is aware of numerous groups in ND who are pursuing similar ideas with different populations. The idea behind this activity is to bring those diverse groups together to collaborate in considering similarities and differences among the initiatives and to examine how a universal application has been successfully developed in other states.

Several additional agencies have stepped forward to participate in ongoing activities to form and sustain the RHNFS. They include: The Federation of Families for Children's Mental Health, the ND Child Care Resource & Referral Network, UND Center for Rural

Health – Family to Family, Path Inc. of Grand Forks, the Pathfinder Family Center and the Arc Upper Valley. These partners are working closely with Children's Special Health Services and the ND Department of Health on various formative activities. As a result, NDCPD has submitted an additional grant proposal on behalf of the network to HRSA for development funding.

Many additional activities will need to be completed before the network is a sustainable and productive entity. Challenges include: creating a mission and vision statement and board structure to direct the network; identifying priorities that strengthen the mission of participating agencies; and providing the network with sustainable long term funding. Development of sustainable funding will involve identifying dues, fee-for-service and contracts to access work that would be completed by the network. Through the proposed development grant the network will achieve outcomes in collaboration, training, system navigation, leadership and sustainability to strengthen its capacity to improve the health and well being of children with special health care needs through enhanced family support services.

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.

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



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Several States Take the Lead on Inclusive Practices

by Don Brunette, Chief Operating Officer - Friendship, Inc.



In some states, disability service funding is beginning to shift towards community-based employment and away from sheltered employment. Recently, Vermont had a state conference focusing on their experiences in sheltered workshop conversion and closure. Vermont's State Plan now dictates that the Division of Developmental Services funds cannot be used to increase the availability of enclaves (segregated work environments within an employer's worksite) and cannot be used at all to fund sheltered workshops. Other states with progressive initiatives include:

- **Washington State:** Employment for people with developmental disabilities is shifting from segregated, sheltered workshops to integrated, meaningful jobs. Washington has been one of the most successful states in the nation in the numbers and percentage of individuals gainfully employed in jobs in communities.
- **New Hampshire:** Since 1984, New Hampshire had not provided any funding to open new sheltered employment programs and in 1985 a systems change grant with state Vocational Rehabilitation system helped to spur the closure of sheltered workshops.
- **Colorado:** In 2004, Colorado developed an "Ad Hoc Committee on Employment and Community Participation". The group had three goals: 1) Raising the priority for integrated employment; 2) Ensuring equality of opportunity for all individuals to participate in paid community employment; and 3) Promoting the use of natural supports in the workplace.
- **Tennessee:** In 2002, Tennessee developed an Employment First Initiative. The goal of Employment First was to make employment the first day service option and the preferred service option for adults with MR/DD. "Employment" was defined as an integrated job in a community setting that provided the opportunity to earn competitive wages.

Possible reasons for this shift in state funding priorities may be attributed to mandates such as the Americans with Disabilities Act, passed in 1990, which requires that government funds support people in the "most integrated setting appropriate". Recently, Vocational Rehabilitation decided that sheltered employment can no longer be considered as a successful closure. Other mandates such as the landmark 1999 Olmstead Decision also refers to the need for people being served in least restrictive settings. Many disability advocates believe that this is a civil rights issue as well as a human rights issue. The Supreme Court wrote that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life".

One argument used by opponents of sheltered employment directly relates to the language used by the Supreme Court. The mere existence of sheltered workshops "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life". Are we inadvertently sending society a double message? Would state funding that prioritizes outcomes and provides incentives to service providers for improved outcomes benefit people receiving services? One outcome we know for sure is that adults with developmental disabilities continue to be unemployed or underemployed at alarming levels throughout the United States.

Workers with Disabilities Fill Employment Gap

by Rich Berg and Susie Mack, E³ Project

In September 2006, NDCPD was awarded funding for the Employment Expansion Effort (E³) project from Creative Training Accelerating Talent (CTAT). The project's purpose was to develop an employment experience program for people with disabilities at Minot State University (MSU). The project accomplished three goals: 1) five individuals with disabilities became gainfully employed; 2) MSU expanded their hiring base and heightened their awareness of hiring people with disabilities; 3) the project established a model for employment replication by other campuses, agencies or places of business.

E³ staff collaborated with three local disability provider agencies and various MSU departments to accomplish these project goals. Workers with disabilities were recruited through Vocational Rehabilitation (VR) and REM Inc. of Minot and Community Options of Stanley, both developmental disability service providers. In addition, MSU administrative officials, directors, deans, and chairs were contacted to establish work placements.

E³ staff worked on eight activities simultaneously to achieve project goals. The activities were: 1) Identify five adults with disabilities as MSU employees; 2) Identify five MSU employment options/funding; 3) Match employees to work sites; 4) Conduct job interview experience and selection; 5) Create E³ documentation; 6) Begin employment and 7) Monitor continued employment; 8) Evaluate and disseminate information. Each of these steps was critical to the success of the project and allowed the project staff to track each employee throughout the project.

Ratings about the employment experience were collected. Within the year's project duration, the five individuals worked approximately 8 months. During that time frame, employers were asked to rate their employee's job performance based on a scale of 1 – 5, "1" being needs improvement and "5" being excellent work. The overall average rating was 4.4. Anecdotal comments from the feedback forms included:

Comments from Employers and Employees:

- is a hard worker and does a great job at work
- is working faster and is taking initiative
- fairly positive attitude, completes tasks and asks for more
- very friendly and a great asset to our office
- I enjoy coming to work at MSU
- I like all the different jobs and the people I work for
- I enjoyed my week off for vacation
- I get my job done quickly

The E³ project supported four successful placements to the project's end (October 2007). Each employee received a pay raise in July 2007 and final performance evaluations were done by each employer, all were positive. Continued employment for the workers will be based on employer budgets and other determinations. To date, two of the four employees continue their employment.

Typically, the unemployment rate of people with disabilities is high. Employers often feel individuals with disabilities are unable to do tasks in a timely, efficient, accurate or acceptable manner. In reality, employees with disabilities have a positive affect on office environments and coworkers, are punctual and consistent in their attendance, have a better-than-average job performance and take an enormous amount of pride in the quality of their work, thus, often producing a better product. Statements and data presented to project staff as part of monthly performance updates show the ability of workers with disabilities to fulfill job requirements and meet the needs of employers. For more information please contact Rich Berg, Principal Investigator at 1-800-233-1737 or rich.berg@minotstateu.edu.

NDCPD Consumer Advisory Committee:

An Opportunity for New Leaders

By Shannon Simonson and Cathy Haarstad

There's nothing like seeing for yourself when you want to learn what an activity is all about. That's how I got involved in the Consumer Advisory Committee (CAC) for the North Dakota Center for Persons with Disabilities (NDCPD). A friend of mine was serving on the CAC. She came home from meetings and talked about what they learned and I got curious. So when she suggested that I send in my application I did. That was about five years ago. This year I became the new chairperson for the advisory group.

The NDCPD is a University Center of Excellence in Teaching, Research and Service for persons with disabilities and their families at Minot State University (MSU). NDCPD's mission is to:

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

University Centers of Excellence in Developmental Disabilities (UCEDD) are funded under the Developmental Disability (DD) Act. Centers are required to get input and advice from the disability community on a regular basis. NDCPD does that by hiring people with disabilities and by working with partners such as the State DD Council and the ND Protection & Advocacy Project (called sister agencies). NDCPD also gets lots of suggestions from the CAC.

The committee meets four times a year and members come from all across ND. Last year we started using video conferencing for two of those meetings. The other two meetings are held in Minot, face-to-face. NDCPD pays travel costs, meals, and lodging and provides a stipend for our time. They even help with the cost of attendant care services.

NDCPD gets a core grant from the Administration on Developmental Disabilities. They use that money to leverage other grant dollars to benefit people with disabilities and those who

support them. It is the CAC's responsibility to advise NDCPD as they develop a five year plan for how the funds will be used.

During our meetings, we review NDCPD's annual plan and their progress toward that plan. We make suggestions and talk about what we have been observing and doing as leaders in our community. We get to hear about projects that NDCPD staff members are doing throughout the year and they often ask us for our advice. Sometimes, we serve on committees or work on a specific project if we are interested. Some of our members have even helped with fundraising or presentations.

Why get involved? Well, we need new members and ideas. Current members can only serve two, three-year terms. Most people are recruited by word of mouth. I keep going because I like it. Serving on the CAC is interesting. You get to meet all kinds of different people and hear about innovative ways of solving problems and learn what is being done. The biggest thing for me is that, hopefully, the people involved get a better understanding of what NDCPD does. Before I joined, I was hearing about it from a friend but it didn't really make a whole lot of sense back then. Now that I have been a member, I really understand how the University is a good partner for the disability community.

NDCPD has helped ND get Workers with Disabilities coverage so people with disabilities can work and keep their health care benefits. They work to make sure all new babies can have their hearing tested in the hospital. They provide speech therapy through the Internet and captioning for classrooms. NDCPD and their partners look at needs across the lifespan. They write grants to fund projects that help people with disabilities, families, schools, communities and health care providers. NDCPD needs new leaders to step forward and get involved with the CAC. Maybe you never thought of yourself as a leader. But, you will be surprised what you can learn and do with NDCPD.

Continued from Page 3 - Shannon Simonson

Being on the CAC has given me all kinds of new opportunities and helped me grow as a leader. The biggest experience for me was a recent trip to Washington D. C. As a chairperson for CAC I got to meet with people from different Universities all over the country and to hear what they are doing. I have also chaired a scholarship committee and helped to make decisions about which students with disabilities deserve funding. It was interesting to learn how that process works and to suggest ways to make it better.

I guess the biggest lesson that I have learned by serving on the CAC is a new understanding about how other people are impacted by disabilities. It changes the way you think about your life. We all tend to think our disability is the worst but other people have a few more challenges that I never thought about. For example, many people in ND need attendant care services to help with everyday activities. The pay for these jobs is low with no benefits and the turnover is high. It is hard to be dependent on a service that is not always available. As we all get older we need to think about how we want to live out our lives and what choices we want if family and friends are not able to care for us someday.

Getting involved in the CAC is easy. You just call the toll free number 1-800-233-1737 and ask for an application. You can fill it out or have someone complete it for you and send it back by mail or electronically to cathy.haarstad@minotstateu.edu. A CAC subcommittee reviews each application and makes recommendations to Dr. Bryce Fifield, Executive Director. The application is available in alternate formats. Good luck and maybe we'll be seeing each other in the near future.

COLLABORATOR
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Winter

**PROTECT Yourself
From The FLU.....**

The **flu** is one of the most serious illnesses of the winter season. For some people with existing health conditions, it can be even more serious.

The best prevention is the flu shot. It is the safest and easiest method of protection.

To find out where to get a flu shot, or whether or not a flu shot is recommended for you, check with your doctor or the public health unit. For more information about the flu, visit www.ndflu.com.

This message brought to you by the ND Disability Health Project at the ND Center for Persons with Disabilities. For more information about the ND Disability Health Project, call our main office at **1-800-233-1737**.

NDCPD CD Casts

Age Appropriate and Meaningful Social, Recreational, and Leisure Activities for Adults with DD

By: Cathy Haarstad
Date: Tuesday, January 29, 2008
Time: 2:00-4:00 PM



National Instructional Materials Accessibility Standard (NIMAS)

By: Teresa Monicken
Date: Monday, February 11, 2008
Time: 2:00 - 3:30 PM

Anger Management

By: Karen Edens
Date: Tuesday, March 11, 2008
Time: 1:30 - 3:30 pm

Contact Person

Teri Aufforth @ 1-800-233-1737



STOP Prescription Drug Scams: Protect Your Personal Information and Report Complaints

Con artists and fake companies are taking advantage of the new Medicare prescription drug benefit to steal your information and money **or worse...**

How Do They Do It?

- Call and offer to sign you up for a \$299 prescription drug plan (or similar amount)
- Use emails and the internet to offer to help you find free or low-cost prescription drug programs for a fee — often asking **\$195** or as little as **\$5** for each prescription
- Pretend they are from Medicare, Social Security or the American Medical Association
- Ask you to sell your prescription drugs or use your Medicare benefit to buy someone else's drugs
- Offer bribes to pharmacies, doctors, or other health care people to get them to change your prescription or prescribe drugs you don't need
- Prescription "shorting"— the pharmacy gives you 1 or 2 fewer pills

Know the Facts:

- The Social Security Administration and Medicare do **not call or visit**.
- No one can come into your home uninvited.
- Medicare Prescription Drug Plans are not allowed to ask for your bank account, Medicare number, credit card, or other personal information over the phone.
- Information on free and low-cost prescription drug programs is available **at no charge**. Ask your pharmacist, physician, or local senior agency for information or check out websites like www.pparx.org or www.benefitscheckup.org.

To Avoid These Scams, Take the Following Steps:

- Hang up the phone immediately. It's shrewd to be rude!
- Call 911, if you feel threatened.
- Never give any personal information, such as Medicare, Social Security, bank account, or credit card numbers to anyone who calls on the phone or comes to the door.

- Sign up for the National Do Not Call Registry at 1-888-382-1222 or www.donotcall.gov.
- Count your pills before you leave the pharmacy or when you receive them in the mail.
- Call ND Senior Medicare Patrol (SMP) at 1-800-233-1737 to report or discuss possible fraud or scams.
- Call Medicare at 1-800-MEDICARE (1-800-633-4227) with Medicare questions or concerns.

Report Anyone Attempting to Steal Your Money or Personal Information or Selling Fake Prescription Plans, Call:

- Your local police department
- **ND SMP 1-800-233-1737**
- 1-877-7SAFERX (1-877-772-3379) **OR** 1-800-HHS-TIPS (1-800-447-8477)

New Faces at NDCPD

NDCPD would like to welcome two new faces to the Center. The ND Senior Medicare Patrol (SMP) project has hired Loretta Monson (Region 4) and Colleen Johnson (Region 2) as Regional Volunteer Coordinators. They will be responsible for recruiting and training volunteers, as well as working on educational presentations describing the SMP project and Medicare fraud to community members in their region.

Loretta started in October and has already participated in local outreach events. She has been interviewed by local radio stations and brought some publicity to SMP through some of the state's major newspapers. She says she's always looking for volunteers.

Colleen began in November and is eager to get up to speed. She is originally from Devils Lake, ND and has 6 children and 22 grandchildren. She brings with her 30 years of civil service experience with the Air Force.