

# Leadership

*An online newsletter for ND Families raising children with Special Needs*

## Family Support Project: Conference Plans

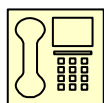
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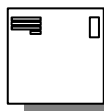
**Registration:** Registration for the ND Family Connections Conference is now available:



Register online at:  
<http://www.conted.und.edu/connections>



Register by phone at:  
1-800-233-1737



Brochures will be mailed on or about May 1, 2004 or are available online



Apply for a **family scholarship** from NDCPD or ask your special education unit or another family support agency for a stipend.

You CAN afford this one!

NDCPD will make hotel registrations for all families who receive a scholarship. Other families and professionals must make their own hotel reservations. Contact:

**Best Western Doublewood Inn**  
3333 13th Avenue S. Fargo, ND  
58103 Call Toll Free at:  
800-433-3235 or at 701-235-3333

Pre-conference Fee:	\$15
Conference Fee	\$50
Conference Fee for additional family members	\$10
Graduate credit (optional)	\$50
CEUs	\$10

Blocks of rooms have been reserved for **ND Family Connections Conference** participants. To receive the special rates of \$45 plus tax for single occupancy or \$55 plus tax for double/triple/quad occupancy. Please make your lodging reservations before **Thursday, June 1**, and refer to the **ND Family Connections Conference**.

### See you at the conference:

## Leadership Opportunities:

### Why Attend a Statewide Conference?

Let's face it—families are busy and families who have children with special needs may be busier than most. So why scramble around and interrupt the routine to come to Fargo on June 10-12 for the first annual ND family support conference? Here are the top ten reasons submitted by members of the steering committee.

1. **You are not alone:** Getting together

with other families is critical to getting the information and support needed to raise a child with special needs.

2. **You are not here forever:** Your spouse/partner will find information that helps them sustain their role as a (mom, dad, grand parent, step parent, foster parent) should something happen to you.

*(Continued on page 3)*

### Special points of interest:

- Would you recognize a toddler with mental health concerns?
- Why do some families attend conferences?
- How do you balance the needs of a child with disabilities and the rest of the family on vacation?
- What are self-directed supports anyway?

## Leadership Topics : Early Identification

Families and educators in ND sometimes get caught in a rhetoric rut. That happens when we say we want what is best for children and families but do not make the changes needed to help those things happen. Early identification is a good example of how easy it is to say one thing and do another.

Ask anyone; teacher, administer or early intervention specialist, and they will tell you the same thing. It is important to identify children with special needs as quickly as possible. Then ask knowledgeable professionals when children are usually identified as being someone who would benefit from special education? The answer is that only about 10% of children who eventually receive special education are identified before age 3. The majority of children with disabilities are not identified until they reach school age, often not until the second grade. Children with mental health challenges are often not identified until much later than that. These circumstances are not unique to ND but are happening throughout the United States.

ND has in place what are called "child find" activities that are designed to identify children with special needs at an early age. These activities involve telling families about agencies that can conduct comprehensive evaluations and providing families with information about the growth and development of young children.

Both the Department of Human Services and the Department of Public Instruction are responsible under Federal and State Law for conducting activities to find and identify as quickly as possible children with special needs. Both agencies work hard to improve early identification efforts. For that reason, in the past few years they have begun to focus on barriers to early identification of children with emotional/behavioral challenges. Early identification is critical for this population of children and very difficult. Many conditions such as obsessive compulsive disorders, Attention Deficit Disorder or bi-polar disorders can look similar in young children and be hard to identify.

While neither families or teachers are qualified to identify these conditions they are in a position to make critical observations about behavior and to share that information with informed physicians and professionals who can help identify conditions and refer children for appropriate early intervention. **What are the early indicators of potential emotional problems in**

**young children?** These **Early Indicators of Mental Illness** were provided by the ND Department of Public Instruction in collaboration with the Federation of Families for Children's Mental Health.



Early Symptoms

- Symptoms: Infants & Toddlers**
- Display very little emotion
  - Shows little interest in sights, sounds, or touch
  - Rejects or avoids being touched or held
  - Unusually difficult to soothe or console
  - Extremely fearful or on-guard
  - Does not turn to familiar adults for comfort and help
  - Exhibits sudden behavior changes
  - Appears driven to repeat routines when other more rewarding play activities are available.

- Symptoms: Preschool Children**
- Cannot play with others or objects
  - Very sad
  - Unusually fearful
  - Sudden behavior changes
  - Loss of earlier skills
  - Very accident prone
  - Inappropriate responses to situations (laughs instead of cries)
  - Frequent fights with others
  - Absence of language or communication

- Things to Consider:**
- How severe or unusual is the behavior?
  - How many weeks or months has the behavior been occurring?
  - How long does the behavior last?
  - How does the behavior compare with the behavior of the other children the same age?

There are many reasons why it is difficult to identify children at an early age. There is still a great deal of fear and stigma attached to both disabilities and to mental health challenges. If you not agree with this concept consider the following: How often do we complement a parent on their child's behavior when we approve of that behavior? Does not that imply that if a child is not behaving well, something is wrong with the parenting? Under those circumstances how ready will families be to step forward and say that something is bothering them about their child's behavior? Every person needs someone in whom they can confide? What are we doing to be that person for families? What do we say as a trusted friend when we see behavior in young children that concerns us? How do we avoid the rhetoric rut?



What behaviors concern us in young children?

“How often do we complement a parent on their child's behavior when we approve of that behavior? “

## Family Support Policies: Self Directed Supports

**What is this support option? Self-Directed Supports** assists families to **self-direct services** needed to carry out an individual family support plan. Supports include: **health care services, in-home or community-based care** as well as **disability related supports** (e.g. child care, therapy, equipment).

**What is this program designed to do?**

- Keep families together
- Prevent unwanted placement in an institution
- Increase family choice and control

**Who is eligible?** Families of children with DD who:

- are ages 3 through adulthood for SDS
- are ages 3-22 for disability related supports
- are ages 21+ for employment supports
- receive case management services
- need a specially trained care-giver
- would be eligible for services in a special group home (ICF/MR) if not living with family.

**How is need determined?** The family develops a **person-centered plan** for the individual with a disability. The team reviews his/her current hopes, dreams, and needs and identifies goals to achieve the lifestyle described in the plan. The plan lists informal and formal supports needed to meet goals. The DD case manager (DDCM) develops a **budget** to fund the minimum amount of services needed to maintain the child in the family. The budget supports only those **formal supports that are needed** but not available through informal or generic community supports.

**How does the program work?** If not already covered, the family applies for Medicaid for the child either directly at the county social

service office or from home with help from the DDCM. A short easy to complete application is used. Families must reapply for Medicaid annually. **Family assets and income are disregarded ONLY** when applying for benefits for the child with a disability.

A budget is developed for the family by the DDCM based on the person-centered plan. The budget provides for the minimal number of formal services (i.e. disability related services, personal care assistance) needed to keep the child in the home. The plan must specify training qualifications for support workers and include emergency back-up systems that describe what would happen if a support worker or family were not available.

The family hires and trains its own in-home support workers. A fiscal agent is assigned to the family to provide support in accessing the budget. The family draws on the budget as needed and the fiscal agent bills vendors for allowable expenses, writes payroll checks and keeps related financial records. The family has the flexibility to change the plan or use funds differently as a child's needs change without getting advance approval.

**What services are included? Case management services** The DDCM assists families with planning, teaches families to use self-directed supports and develops the budget.

**Health care services** (e.g. medical, dental, medication, ) covered under ND's state Medicaid plan

**Support brokerage** – assistance from a case manager to self-direct services (all families)

**Primary Caregiver Assistance** – in

home /community support given while family is away or present. (if needed & eligible by age)

**Disability Related Supports** – payment for equipment, therapy, and other excess costs related to a child's Supports listed under Family Subsidy (if needed & eligible by age)

**Fiscal agent** – Someone to pay bills, cut paychecks, assist with record keeping, taxes, obtain a background check of support workers

**Employment supports** – on the job training for individuals with DD who need long-term support to maintain a job placement (if needed & eligible by age)

**How is this option different than the other options (i.e. family subsidy or support)?** Families do not pay for costs up front. Families draw on a budget and so have fewer out of pocket costs. The fiscal agent assists families with financial responsibilities by issuing checks, paying employer taxes and insurance and keeping financial records. The fiscal agent also arranges for employee background checks at no cost to the family. The family recruits and hires support workers. Families have more responsibility for planning and more risk in assuring that their child's health and safety needs are met. Families can ask for help in learning to self-direct services. Families receive both in-home support AND help with excess costs. **Self Directed Supports may be available in ND in the Near future. Contact your DDCM if interested.**

### Experienced Parents (continued from page 1)

3. **You have a voice:** This opportunity gives families a chance to speak face-to-face with ND family-support policymakers.
4. **You contribute to the economy:** At the conference show how family support is critical to the economic development of our communities.
5. **You can bring the family:** Most training events require parents to leave kids behind. This event provides support for child care and is family- friendly enough for most ND families to attend with children.
6. **You will benefit from technology:** Seeing and touching new technology can show you what is possible.
7. **You need best-practice information:** This conference like no other focuses on what families need to know to educate children.
8. **You have something to contribute:** This conference will highlight ways to build on family strengths and tackle community challenges.
9. **You are a provider:** This conference helps you tend to the home base so that you are free to bring home the bacon.
10. **You know rural communities:** Solutions for rural communities have to fit in order to work. No one knows rural communities better than you do.

Leadership is not being important or recognized but the ability to say, What if .... Why not . . . and What Else? Bring your leadership to the Family Connections Conference.

## Family Partners: Protection and Advocacy

What is the ND Protection and Advocacy Project? The Protection & Advocacy Project (P&A) is an independent state agency that protects and advocates for the rights of people with disabilities (PWD) within established priorities. **P&A serves eligible individuals, of all ages with all types of disabilities, at no cost.** P&A also advocates for individuals to receive disability-related assistive technology devices & services. **The mission of the Protection and Advocacy Project is:** *Uniting to champion the equality and inclusion of people with disabilities where we live, learn, work and play.*

### How does P&A carry out its mission?

To carry out its mission, the P&A project has designed seven advocacy programs to focus its efforts on behalf of PWD. These include:


1. DD Advocacy Program
2. Mental Health Advocacy Program
3. P&A Project for Individual Rights
4. P&A for Beneficiaries of Social Security
5. Assistive Tech Advocacy Program
6. Help America Vote Act
7. Traumatic Brain Injury

P&A provides **information & referral**, as well as **education**, to individuals and organizations. Training topics include disability-related rights & self advocacy. P&A also provides advocacy, legal representation, and protective services. Finally, P&A provides assis-

tance to develop **support groups for individuals with traumatic brain injury** and their families, **systems advocacy** to address broad concerns with adequate services and rights and support to **advocacy groups** during the Legislative Sessions. **How does the P&A Project make decisions to use its resources in the most effective manner?** The P&A project reviews information and referral data as well as litigation and conducts an annual survey of its constituents as well as regional focus groups to develop priorities for the coming year. Priorities change over time as the needs of PWD change. Current priorities include:

- Freedom from abuse and neglect
- Opportunities to participate (accessibility)
- Least restrictive environment (integration)
- Criminal justice
- A free and appropriate public education
- Access to meaningful employment
- Health care
- Outreach to un/under-served communities

P&A acts for the exclusive benefit of the PWD and advances the interests of that person, and not those of the parent, guardian, or other third-party representative. For more information contact P&A at 400 East Broadway, #409 Bismarck, N.D. 58501  
Phone: (701) 328-2950 Toll free: 1-800-472-2670  
Relay ND 711 TTY Fax: (701) 328-3934 E-mail: panda@state.nd.us  
Weekend/after hours emergencies 1-800-642-6694 to get help or find the Regional Advocate nearest you.



"P&A acts for the exclusive benefit of the Person with a Disability."

## Summer Vacation Stories (continued from page 5)

*Wore the rest of us out. It was a perfect day. Encouraged by this experience we decided to explore a cave the next day as part of a guided tour. We chose the Lantern Tour of Jewel Cave. This was not a wise decision for a child with extreme sensitivities. Everything was great until we actually entered the cave. Sasha showed great excitement until she realized it was cold and dark. We coaxed her up and down the narrow stairs but no reassurances reached her. The last straw came when I accidentally stepped on her fingers as we climbed down a particularly narrow*

*staircase. Sigh! The only redeeming part of the whole exploration was that Sasha got to tell everyone that I had abused her by stepping on her fingers. That is her primary memory of the cave experience. Yikes!*

*Well we made up for that by leaving for home the next day and stopping at McDonald's, the highlight of Sasha's trip. It felt good to be back on familiar ground and I realized once again how much better Sasha does on her home turf where*

*everything is familiar and predictable. Her ability to cope with change is limited and yet in some strange way I think she benefited from having her boundaries stretched. At least when her class studied caves at school she was able to shudder and speak with authority about bats and darkness and cold and narrow stairs, even if she does still humph about it.*

If you have a vacation story about a child with special needs please send it to LEADERSHIP at haarstad@minotstateu.edu

## Family Stories: Summer Vacation Stories

The trip to South Dakota had been planned for several months. The Dawson family was looking forward to getting away. Mary was worried about how Sasha, their 10 year old daughter with Pervasive Developmental Disorder would handle the trip.

*“Sasha is highly sensitive to any changes in her environment. She startles and cries when she hears someone hum a tune, the vacuum is on, the phone rings, a train whistles or the organ plays at church. Sasha is also highly sensitive to touch, often flinching at accidental contact and refusing or protesting loudly when tactile sensations such as hand lotion, tooth paste, shampoo, insect repellent, and sun screen are applied. Finally Sasha pays inordinate attention to unimportant visual details and misses much of what goes on around her. Thank God she is not wandering away as much as she used to during the past few years.*

*Leaving Sasha behind was not an option. Our philosophy has always been that Sasha is part of our family and she goes where we go. Also, we just don't get enough family support hours to leave her home and even if we did, a week is a long time for Sasha to be without her family. She doesn't understand enough about what is going on. I know that many people rely on family but although our family is supportive, frankly a week with Sasha is more than they can handle.*

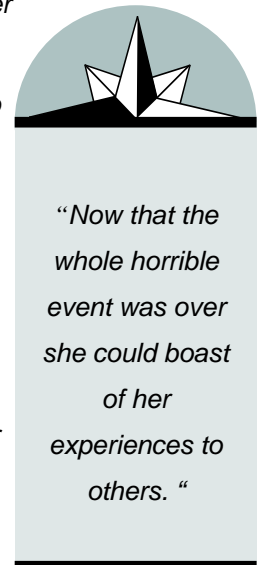
*Well we went and it was quite a trip. I came close to pulling my hair out on a couple of occasions. At first we were all irritated with Sasha whenever*

*her behavior seemed to spoil our fun. The things we like to do as a family like having a picnic by Rock Creek are torture for poor Sasha. We broke all the rules. The table was different, the tablecloth felt different, picnic food is different (none of the five favorite foods she has learned to tolerate). Imagine insisting that someone eat sandwiches and fresh veggies. Her legs dangled and that bothered her, she had to sit too close to her sister (now that would be a normal complaint) and the fresh open air, bugs and sunshine were just too much. Then, the final straw when we all pulled off our shoes and went wading in the creek she lost it. Trying to explain to other picnickers why a ten year old girl is screaming on the bank of a creek in SD is not a fun experience. We didn't insist that she join us but that made little difference. Her stress level became so high that she wet her pants and we had to do a clothing change (something else that she doesn't tolerate well) in a port-a-potty no less. Guilt and frustration were running pretty high. Finally after her clothes were changed we both sat down on a bench in the shade to cool off. I tried to explain how much she was spoiling what was supposed to be a fun adventure for everyone. That of course got me no-where. Finally I said: Sasha, we love you so much but we don't know how to reach you. Your world is so narrow and we are just trying to open it a little bit so that you can come into our world without so much stress. That simple statement seemed to get through to Sasha, probably because it told her that she was loved rather than blamed her for being different. After that the vacation seemed to go a lot smoother. After all this was the first day and first days are always the hardest. It turned out that Sasha thought a vacation meant eating out at restaurants and we remembered that we had done that on a trip the*

*year before to visit family in New York. All that planning we had done had gone right over Sasha's head and she didn't pick up on the details of what “stopping by Rock Creek like we always do” meant. So we learned a valuable lesson. After that we made sure we rehearsed every event in advance and decided what Sasha could do if she did not like that activity. That worked some. Mt Rushmore was fine, she could sit down a lot and trace the freckles in the cement and use her portable camera to take pictures of whatever she liked.*

*Rock climbing in the Needles Eye was not so great. She protested all the way up and all the way down—probably a mistake to bring her I thought, but we just didn't want to leave her alone in the car in the heat and we didn't want to make one of us miss the adventure. After we got back to ND however when people asked her about the trip and her favorite part, she surprised everyone by bragging about the rock climbing and showing off the tiny cut on her knee that she acquired. She was actually proud of her wounds and now that the whole horrible event was over she could boast of her experiences to others.*

*A side trip to Evan's Plunge, a waterslide park in the Black Hills proved to be great fun for all. Sasha loved the water and finally decided after we dragged her up the easiest slide six times that it was kind of fun and began to go all by herself. In fact she couldn't get enough of the experience and (continued on page 4)*



*“Now that the whole horrible event was over she could boast of her experiences to others.”*

North Dakota Center for Persons  
with Disabilities

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**We're on the Web!**  
[www.ndcpd.org/n2k](http://www.ndcpd.org/n2k)

The North Dakota Center for Persons with Disabilities (NDCPD) is a Center for Excellence in teaching, service and research for persons with disabilities. NDCPD is located at Minot State University. The mission of NDCPD is to provide leadership and innovation that advances the state-of-the-art and to empower people with disabilities to challenge expectations, achieve personal goals and be included in all aspects of community life.

The ND Family Support Project is a collaborative project designed to enhance family support in ND. Partners include: The Family to Family Network, the Arc, Upper Valley, the ND Department of Public Instruction, the ND Department of Human Services, the Pathfinder Family Center, the ND Protection & Advocacy Project, the Federation of Families for Children's Mental Health, Family Voices, and many more persons committed to supporting ND families who are raising children with special needs.

## Announcements

**IDEA Reauthorization** This important legislation will go to the floor of the US Senate on or about May 10th. If you support or have concerns about the proposed legislation, why not write to your Senator as soon as possible.



**ND Family To Family Network** If you want to meet other parents of children with special needs can contact the Family to Family Network by calling toll free at +1 (888) 434-7436.

**North Dakota Family Connections Conference: When Kids Have Special Needs** Best Western Doublewood Inn in Fargo on June 10th-12th. This is a family-friendly event and will provide opportunities to meet face to face with policymakers to discuss family support. A second conference will be held at the Doublewood in Bismarck on September 30 and October 1 & 2.

### 20/20 Special on Siblings

On May 14th at 9:00 p.m. EST ABC will be airing

a special segment on siblings as part of its 20/20 show. The overall segment will include broad coverage of siblings but six minutes of the segment will be dedicated to siblings of children with special

**Foster Care:** Many children with special needs receive foster care. The "Babies Can't Wait" project highlights the particular health and developmental needs of young children in foster care, and how to connect infants and parents to evaluation, intervention, and support services. The faculty of the Children's Evaluation and Rehabilitation Center at the RFK UCEDD developed the "Babies Can't Wait" curriculum and furnish the instruction. For more information, please contact Susan Chinitz, Psy. D. (Director at the RFK UCEDD's Early Childhood Center) at [Schinitz@aol.com](mailto:Schinitz@aol.com).