



# Leadership

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

## Family Support Project: Where Are We Going?

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### Special points of interest:

- Opportunities to strengthen leadership skills
- What families need to know about standardized assessments
- Challenges in finding child care for older children with special needs
- New opportunities created by the ND State Improvement Grant.

The ND Center for Persons with Disabilities at Minot State University received a new grant on September 30, 2003 from the Administration on Developmental Disabilities. The project will **involve families as active partners in shaping policies and make it easier for families to find and manage supports.**

New families will be recruited to serve on a Family Support Advisory Committee. The committee will **review outcomes that are important to ND families.** These outcomes make it possible for families of children with special needs to stay together and continue to live and work in ND.

Project staff will **conduct a state-wide survey of over 1000 ND families** who have children with disabilities. Families from diverse cultures will be



Thinking it over!

included. The survey will measure family satisfaction with services. **Project staff will also confirm information gathered by case managers about family satisfaction.** Families and policymakers will get accurate information about the experiences of ND families who are raising children with special needs. Policymakers will be able to use the information to decide how well outcomes are being met.

Project staff will also develop **new tools to help families learn about Independence Plus**, a new waiver option that gives families increased choice and control in accessing Medicaid dollars. This newsletter will **describe project activities, accomplishments and resources** during the next 17 months and beyond. Hold on, it will be one exciting

## Leadership Opportunities for ND Families

**Family Support Advisory Committee:** The ND Family Support Advisory Committee (FSAC) is a **15 member committee of partners and family members** who have children with disabilities or special health conditions. They come together twice a year to review project activities. Members advise partners on how to design pro-

grams and services that really work for ND families. This relatively new committee **provides an excellent opportunity for families to strengthen leadership skills.** Participation is family-friendly because interim meetings take place over the phone or using other technology so that families can (continued on page 3)

## Leadership Topics : No Child Left Behind

At a recent IDEA committee meeting, concerns were expressed about the No Child Left Behind (NCLB) law and its impact on ND schools. Several educators shared concerns that schools might discriminate against students with disabilities if their scores on standardized tests fell below the levels needed for adequate yearly progress.

One parent asked this question. What action now by educators could be worse than failure to ensure that students with special needs make adequate yearly progress in reading and math? What could be worse than seeing your child's scores remain the same year after year because they did not qualify for special education or because it did not make a difference? In the discussion that followed, several important issues were raised.

First, both educators *and* families must believe that *all* children with disabilities *can* learn, achieve high standards and benefit from meaningful activities that prepare them to be employed and live as independently as possible. Together we must become familiar with state standards and what they mean for a child who is 2-3 grade levels below his or her peers. What do those standards mean for a child in grade 12 whose ability to problem solve is the ability to reach out and select an object?

IEP teams make important decisions about modifications and accommodations to state standardized tests. Parents and guardians need to learn the difference between a modification (e.g. giving a student more time to complete a timed test) and an accommodation (e.g. allowing a student to type answers using a communication device). Both modifications and accommodations must be spelled out in the student's IEP or 504 plan. When accommodations are not



Is your child held to high standards?

spelled out in the plan, teachers can only follow the rules set by the test maker.

IEP teams also decide whether students should take an alternate assessment. The original alternate assessment process required teachers to develop an extensive portfolio of student performance indicators, a process that was unfamiliar to many special educators in ND.

Families may have heard that this procedure was time-consuming and created an extra burden for their child's special education teacher. The process has since been streamlined. But the message about the process may not have changed. Educators disagree as to how much time it takes.

Parents need to enter the team planning process with the same information as teachers if they are to make effective decisions for their child. Without information, families can only rely on what their child's teacher or principal tells them about an assessment option. Given the pressure for schools to succeed, both families and educators need to understand the ethics of making decisions about standardized testing (typical or alternate) when deciding which assessment processes are in a child's best interest.

Assessment issues that measure adequate yearly progress are awakening such an intense national debate that the U.S. Senate may be persuaded to remove IDEA requirement that the scores of students with disabilities be included with those of typically developing children. This would certainly make things easier for everyone. Unfortunately it might also return families to a point where the education of children with special needs may be separate but not equal to that received by typically developing students. We measure what is important. Assuring that NO child is left behind requires everyone's commitment and cooperation.



Maria and Sophie enjoy looking at a classroom activity together.



"Both educators and families must believe that all children with disabilities *can* learn."

## Family Support Policies: What is the Plan?

What do families of children with disabilities really need to continue living and working in ND?

**Two years ago, a group of ND families and family support partners developed a preliminary plan to enhance family support in ND.** The plan targets specific outcomes that are important to ND families raising children with special needs. **ND family support policies are effective when they result in these outcomes:**

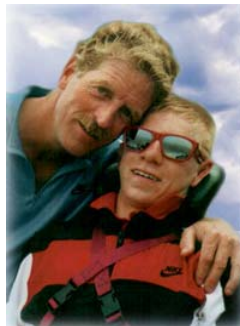
- Families stay together
- Families are healthy
- Families have income
- Families have support
- Families are informed
- Families are satisfied
- Choices are honored
- Children succeed

How well are we doing at achieving these outcomes in ND? Sadly, no one knows for sure. Different agencies have some pieces of information about each outcome but no way to share data with one another. Without an undupli-

cated count of families across agencies the picture of what is happening is incomplete.

**Some outcomes can only be measured by directly asking families how satisfied they are with services and to what extent important outcomes are present in their life.**

This plan is a good beginning but more needs to be done to make it a viable tool for enhancing support. Project staff and partners will gather new data on specific outcomes. The goal is to move this plan from a paper document to a real effort among families, partners and policy-makers to strengthen family support in ND.



During the next several months, the LEADRSHIP newsletter will try to tell the story behind the data so that you can decide for yourself where ND is in regards to family support policies and outcomes.

Policies guide providers in serving individuals and families within the resources available. **When resources are insufficient, decision-makers must review priorities.**

This summer, families across ND saw a reduction in family support as a result of the budget changes mandated by the ND state legislature. The people of ND require legislators to balance the budget. There is no such mandate for the legislature to provide family support services. Family support is considered optional!

“How well are we doing at achieving these outcomes in ND?”

### Family Support Advisory Committee (continued)

participate from home during much of the year.

**Families are reimbursed for travel, per-diem and child care.** The next meeting of this group will be held in Bismarck, ND at the Heritage Center on October 28, 2003 from 1:00 to 4:30 PM.



Leadership skills for parents equal new options for kids.

**If you are interested in participating, please contact Cathy Haarstad,** toll free at 1-800-233-1737 or email her at haarstad@minotstateu.edu

## Family Partners: ND State Improvement Grant

State Improvement Grants (SIG) help states look at systems for improvement especially, personnel development. The ND SIG is a 5-year project awarded to the DPI to enhance educational services in ND. The grant is housed at the University of ND. Staff include Cindy Wilcox, project director, Carolyn DeLorme, project coordinator, Jane Nelson and Cathy Haarstad, parent liaisons.

Most SIG activities are done with partners including parent organizations, schools, colleges, education-related organizations, and other agencies.

During the last 3 years this project has started several important activities. These include:

- **A one-stop recruitment website**
- A “grow your own” special educator program called **Resident Teacher Program** to provide a larger pool of

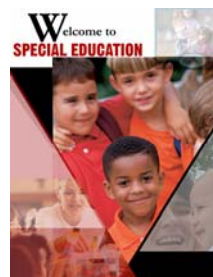
teacher applicants for North Dakota.

- A **video** that can be used with high school/college students to promote careers in education or related services.
- A **speakers’ bureau** of educators/related services personnel who speak with students and the general public about a future career in education or related services.
- **Collaborative training** for parents/educator teams on the IEP planning process.
- An **Orientation Kit** with materials to welcome families to the system of Special Education.
- **Activities** that schools can use to **enhance family involvement**.
- Training for pilot schools on **using data on student performance to make decisions**
- Supporting **higher education** to unify and align efforts to prepare future teachers to work with students who have special needs.
- **Subgrants** to Pathfinder, P&A for Common Ground Training,

LEAD Center for Data Driven School Improvement, and NDEA for training for general educators.

- Stipends for Federation of Families Conference, GRAAIN Conference, and an upcoming Collaborative Conference

For more information contact: **Cindy Wilcox**  
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**Box 7189**  
**Grand Forks ND**  
**58202-7189**



Welcome to Special Education



“We understand that you may have some real fears and concerns about your child’s future happiness. We are here to face those fears with you, to help if we can and most of all just to listen. “

## Child care for Older Children—continued.

*and one home that looked very unsafe. All told it took about 6 hours of time to conduct a search and about 35 hours of false starts and worrying to figure out what I should do.*

*One thing I learned from this experience is how dependent I am on support agencies. When I had to do this without help it seemed a lot harder than it turned out to be. Of course, my daughter*

*walks, talks, and is independent in self care. What would happen if she used a wheelchair, needed help with personal care or were aggressive?*

Families of children with special needs often cope with extra demands and concerns that prevent them from reaching out to others. It is especially difficult to find care in rural areas and that makes working outside the home a challenge. Families

are easily discouraged and may believe an agency could not help, when in fact they just might.

**Next issue: Coping with sleep depression.** If you have a story or thoughts to share on that topic please contact project staff at LEADERSHIP 1-800-233-1737 or sending a brief email with your thoughts or story to Cathy Haarstad at haarstad@minotstateu.edu

## Family Stories: Finding Child Care for Older Children with Disabilities

**Finding child care for older children with disabilities can be challenging.** This story from one ND parent highlights some of the barriers and solutions.

*I started the school year feeling rather smug. By asking around, I discovered an older than average university student willing to pick up my daughter after school and provide care until 6:00 PM. She had a car, didn't have other small children in her home (I am tired of asking my 13 year old to hang out with 2 year olds after school) and the maturity and warmth I was looking for.*

*Alas my luck did not last! Our new provider quickly became stressed-out and fell behind when her prime homework time was taken up with child care. Now I was starting over with only two weeks notice. It had taken a month to find this provider. How was I going to find someone else in such a short time?.*

*Most children 12 or older stay home alone after school. Our daughter has mental retardation, a seizure disorder and autism spectrum behavior disorder. Staying home alone for 3 hours is just not an option yet.*

*I have always been able to find child care as long as I was willing to settle for someone who works with very young children. Luckily I live in a larger community where providers are available. They are usually willing to include an older child even though ND only licenses providers to serve children ages 12 and under. All I had to do was to secure a letter from our pediatrician that confirmed the*

*fact that our daughter needed the care and the provider could access the Federal food program to cover the cost of her meals on school holidays.*

*But my daughter recently entered middle school and this time I wanted something different. It took three anxious weeks before I found a new provider; another student, younger this time, who could pick my daughter up after school, hang out with her, take her to the mall or ball games.*

*During those weeks my family put up with an unusually high anxiety level as I wondered whether I would continue to be able to work. Our daughter's medical care is covered through my health insurance and Medicaid. Not working is not an option for me. I went through a long list of strategies before placing an add in the local paper (\$38.00 for a week) and finding a provider. I can only hope that she works out.*

*The stress I felt is highlighted in this rather pessimistic list that describes the options I considered and my thoughts about each idea.*

- **Resource & Referral** — Sent a list of 5 providers—no luck— No one can pick up at her school & they only take young kids
- **Respite Care**—My hours were cut in August— I doubt I will get more
- **Family Subsidy**—that would pay for a provider but not find one. I would have to give up Family Support and we need Medicaid to cover extra

*expenses. If only I could buy-into Medicaid as a family.*

- **Church**—I could talk to our pastor. I hope he doesn't advise me to send our daughter away to a special school — again

- **Ask DD Case Manager** for more hours —They were just cut, is that likely?

- **Tell everyone I know** that I am looking — that worked last time but not this time.

- **Ask her school** if they know someone — was told all the teachers/aids are already providing care to children — isn't that a conflict of interest anyway? What would families do if teachers did not?

- **Put up flyers and posters** at the college—this feels a little like hosting a raffle but if it helps my daughter I will do it.

*My anxiety spilled over in a dramatic outburst when I called the **newspaper** to place an add. As I hesitantly read the draft out loud, the staff person asked me to slow down and wait saying: "My computer is acting so retarded today." "Excuse me!" The comment hit a nerve and I burst into tears and hung up.*

*Eventually I calmed down, called back, apologized for my outburst and placed the add. I also placed an add in our church bulletin, realizing that I only had to talk to the secretary and not the pastor. We received 10 calls. I interviewed responders, screened out students who had cars but no insurance, families with small children, (continued on page 4)*



*"I am tired of asking my 13 year old to hang out with 2 year olds after school."*

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 of 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



Look at me Dad. I did it!

**Fall 2003 Autism Workshop: Asperger's Syndrome and Adolescence—October 20-21**  
Sioux Falls SD  
<http://www.usd.edu/cd/commed/cford.htm>

The Office for Special Education Programs has a new resource: **Identifying and Treating Attention Deficit Hyperactivity Disorder: A Resource for School and Home**

- \* How the condition is identified.
- \* Treatment alternatives
- \* Legal requirements

Ways to improve the quality of life  
The document is available at <http://www.ed.gov/about/reports/annual/osep/> & in hardcopy/alternate formats. Call U.S. Department of Education, P. O. Box 1398, Jessup, MD 20794-1398; 877.433.7827 or 800.872.5327 (voice), 800.437.0833 (TTY/TDD), 301.470.1244

**North Dakota Youth Leadership Conference** April 14-16, 2004 is being hosted for young people with disabilities ages 14-21 at Minot State University. Call Dawn Olson toll free at 1-800-233-1737 to learn more about it.

- Learn about the history of disability as a culture
- Meet successful professionals who are people with disabilities
- Learn about community resources to reach goals
- Develop a "Personal Leadership Plan"
- Learn ways to make positive contributions to the community
- Enjoy fun, motivating activities that build self confidence
- Meet other young people with disabilities who are future leaders