



Leadership

An online newsletter for ND Families raising children with Special Needs

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Special points of interest:

- Accommodations at Assessment Time.
- Upcoming conferences that bring families and professionals together.
- Challenges and rewards in making summer plans for children with special needs.
- New leadership opportunities as Experienced Parents.

Family Support Project: Conference Plans

The ND Family Connections Conference is shaping up to be an exciting program for ND families and professionals. At the heart of the conference will be a two hour meeting (lunch provided) with ND policymakers in which families and professionals get to discuss hot topics in family support and make suggestions for system change.

In addition an agenda of exciting speakers is planned. Sue Swenson, Camille Catlett, Patsy Pierce, Steve Street, Marj Bock, Cathy Breedon, Teri-Lewis Palmer, Tom Pomeranz and many other speakers will dazzle families and professionals with new ideas for collaboration and support. In addition to these speakers, the following topics will be offered.

- Unlock Literacy for Kids Who Are Deaf or Hard of Hearing
- Get the Facts About Special Ed
- Assistive Technology
- Adapting Your Child's Work and Play

- Environment
- Self-Directing Supports
- Early Literacy
- Resources for Culturally Diverse Families
- Orientation to Special Ed.
- Sign Me More than No
- Veteran Family Training
- Dads of Kids with Special Needs (includes a dad's panel)
- Transition Panel
- Autism Strategies (w/panel)
- Nutrition for Kids with Special needs
- Serving High Risk Rural Youth
- Babies Need Books
- Universal Enhancement
- Kids with Special Health Care Needs
- What is a Medical Home
- Teaching Adult Learners

Go to: www.conted.und.edu/connections to learn more. Registration information will be available soon.

Leadership Opportunities: Experienced Parents

What is an Experienced Parent? This relatively new position created by the ND Department of Human Services hires parents of children with special needs to work with new families. These "experienced parents" work full or part time and engage in a variety of activities that help families learn more about the early intervention system. *Experienced Parents* have been hired in Regions 1, 2, 4, 5, & 7 to offer information

and support to other parents with a child enrolled in Developmental Disabilities services.

One exciting feature of the *Experience Parent* position is that each region can outline differently how the parent will interact with families. Some *Experienced Parents* have opted to participate in the intake (continued on page 3)

Leadership Topics : Alternate Assessment

Next year, IEP teams for students in the 3rd— 8th grade, or 11th grade, who have will made decisions about whether to have that student take the state standardized test as written, with accommodations, or take an alternate assessment.

It is important to be informed about options and to understand how to make an appropriate decision. Families need information about assessment options, accommodations and decision making in order to participate as an equal partner in planning.

The state of ND has developed standards in reading/language arts, math and other key subjects. All ND students are tested against those reading and math standards using an instrument that has been modified to include ND standards. All students take this test or receive an alternate assessment.

Including students with disabilities in the test process is a relatively new requirement. Schools measure what is important. Prior to the passage of No Child Left Behind Legislation NCLB, the progress of students with special needs was often not measured by schools. Schools were not held accountable for that progress by the Federal government or the community, only by individual families. Today, schools across ND are discussing how to be more effective in helping special populations make progress, including students with disabilities. This unique group of students has the unfocused attention of the whole administration and teaching staff in a way that was not happening before. Whatever else it has done, good or bad, the No Child Left Behind legislation certainly has obtained our collective attention.

Teams try to look at what is in a student's best interest. Because specific guidelines for teams in making the decision about which option to select are not yet available in many schools, teams must sift through an array of issues to get to the heart of the matter. Families want to do what is best for their child and they are also conscious of the enormous pressure that schools and teachers feel about this high-stakes testing business. In this situation it is all too easy for teams to focus on issues that are not related to the child's best interests. Whether a not a given teacher likes the alternate assessment process, or whether the school believes including one more student might leave them under the total needed to achieve adequate yearly progress is not really not the point. If

teams are held hostage to worrying about these issues, they will not be free to focus on the best interests of the student.



High Stakes Testing in ND

Side issues can divert teams from the real issue which is holding all students to high standards and deciding how should we measure this student's performance against those standards? What combination of testing options and support is needed by this student to give the

school a measure of his or her performance against North Dakota standards?

Remember that simply measuring the student's performance on IEP objectives does not tell a school how well the student performs against state standards compared to other students also tested. Remember too that a standardized assessment is not a comprehensive assessment used to make decisions about disability or individual educational planning. Instead it is a snapshot of performance on one day that is used as a check for school accountability.

Many accommodations can be used during testing. These accommodations can involve strategies related to the environment, such as lighting, room size, or location or time of day. Accommodations can also involve changing test conditions by giving students more time to finish or letting a student stop when they are ready. Finally accommodations can involve actions that impact the test content including reading material to the student. The important thing to know is that any accommodation is allowable as long as that accommodation is spelled out in the student's IEP. If an accommodation is not in the IEP or the test protocol it won't be allowed. Some teams have not included accommodations they think of as common sense for example letting a student stop when they have answered all the questions they can. This can result in students

being forced to sit while their peers continue to answer while they are directed to guess. When this does not make sense to a student it can lead to frustration behavior and a negative experience for all. Be sure your team has a list of accommodations to choose from in advance. The criterion for receiving an alternate assessment are stringent and if a student does not meet those criterion then accommodations can help everyone succeed.



Writing in the test booklet is an accommodation.

“ Whatever else it has done, good or bad, the No Child Left Behind legislation certainly has obtained our attention. “

Family Support Policies: Family Support Services

What is this support option? Family Support Services provides families of children having DD with **in-home and/or community-based support** to assist the family in meeting the needs of a child and prevent unwanted out-of-home placement.

What is this program designed to do?

- Keep families together
- Prevent unwanted placement in an institution

Who is eligible? Families of children with DD who:

- are any age (birth –adulthood)
- are ages 0-21 for a family-care option,
- receive case management services,
- need a specially trained care-giver
- would be eligible for services in a special group home (ICF/MR) if a family could no longer provide support

How is need determined? The DD case manager discusses needs with the family and authorizes support hours based on the minimum amount of support required for the child not to be placed outside of the family. In-home care from a trained care-giver must be 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 DD case manager. 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.

Once found eligible, the case manager au-

thorizes the provider to deliver services for a specific number of hours. That authorization is renewed quarterly.

The provider contacts the family to discuss needs and develop a support plan. The provider links the family with care-givers and the family provides the support workers with an orientation to their child/home.

Services may be provided in the family home, in the care-giver's home or in the community.

What services are included? Case management services The case manager helps families assess needs, connect with informal and formal supports, explore options, weigh decisions, help with referrals, access funding, assure satisfaction with services and resolve new issues.

Health care services (e.g. medical, dental, medication,) covered under ND's state Medicaid plan **In-home support** (in-home and/or community based support). Examples:

A direct support worker comes into the home to care for a child with a disability while the family takes a break or attends to other minor children.

A direct support worker cares for the child in their home while the family gets a break.

A direct support worker takes a child into the community to experience recreational activities with same-aged peers and provides support

How is this option different than the other options (i.e. family

subsidy or self directed supports?

Families do not pay costs up front. Instead, health care providers bill Medicaid directly.

In-home support workers may be hired only through a licensed provider who bills the DHS directly.

The provider helps coordinate services, hires and trains staff, and handles all financial requirements related to being the employer. The support worker works for the agency and not the family.

Families may choose to receive **both Family Subsidy** to pay for excess costs related to therapy or equipment (but not excess child care) **and Family Support Services.**

What are the potential benefits of this option?

- Families get relief from stress
- Families have new ways to involve their kids in the community
- Families have more time to spend with other children
- The work of directing services is turned over to a trained provider
- Families have the benefit of health care and services available through Medicaid

What support is available to help families use this option?

Licensed providers help families assess needs, recruit and hire support workers, conduct employee evaluations and manage payroll responsibilities.

For more information, check with the Human Service Center near you.

Experienced Parents (continued from page 1)

process when new families are welcomed into Infant Development programs. Others have concentrated on providing new families with newsletters, bringing in speakers or using informal meetings to address families needs for information. A number of experienced parents have begun to concentrate on the transition process because when children reach the age of 3 public schools become responsible for services. This can often be an anxious period for families and being able to talk with an experience

parent can be helpful.

New families are often bewildered by the array of support options available and unsure of how to access the system. Visiting with an experienced parent about what is available, what helps, and why it helps can go along way to inspire confidence in a young parent that they will be able to handle whatever come along.

Of course although *Experienced Parents* have children with special needs they cannot be fa-

miliar with all disabilities. For that reason *Experienced Parents* often work with the ND Family-to-Family network to refer families to other veteran parents who have been trained to act as mentors. To learn if you region has an *Experience Parent* contact the Department of Human Services—Disability Services Division or ask your child's case manger. Unfortunately, *Experienced Parents* are not funded for families of children older than age 3 although some regions have continued to include families in ongoing activities.

Family Partners: Pathfinder Family Center Inc.

What is the Pathfinder Family Center? The Pathfinder Family Center, is ND's Parent Training and Information Center funded under the Office of Special Education Programs, or the USDOE. Services are provided statewide in response to individual contact from parents/families, professionals and programs that serve families of children with disabilities.

The center offers current information resources, a book/video lending library, and family support services that train parents to participate effectively as members of Individual Education Plans and Individual Family Support Plans. Families looking for information on a topic related to their child's disability, or seeking support in planning for a meeting with their child's teachers or early intervention specialist often contact Pathfinders.

The Center's work scope is based on the Individuals with Disabilities Education Act, (IDEA) Section 504 of the Civil Rights Act, the Americans with Disabilities Act (ADA), and No Child Left Behind (NCLB). Through its services the Center helps parents to better understand and communicate needs related to the nature of their child's disabilities. Parents are encouraged to begin in home support of their children's programs and the practice of life skills for successful transition to independent living when they transition

from high school. Parents are also encouraged to communicate effectively to resolve conflicts and find common ground with educators in meeting the unique needs of their children.

Pathfinder is also North Dakota's federally funded Parental Information Resource Center, "ND Parents and Supportive Schools" also called NDPASS which targets family involvement under Title I, ESEA which is not the No Child Left Behind. This balance across families enables the Center to respond to all parents/families at one central location.

Pathfinder's board of directors is comprised of parents and professionals involved in providing free and appropriate public education for all children. The board and staff express appreciation to other entities that serve children and cooperate in an exchange of referrals with parental permission so that families can access services appropriate to their needs. The Pathfinder director, Kathy Erickson, often says that "The rural nature of ND demands extended effort and collaboration with others to respond to families children and youth with disabilities. Pathfinder Center is in its 16th year. Together we can respond to one child or many." The center is located in Arrowhead Mall, 1600 2nd Ave. SW, Minot, North Dakota 58701. **Contact Information:** Phone: 701-837-7500, or toll free 1-888-245-5840. Fax: 701-837-7548, email: ndpath01@ndak.net. Web site: <http://pathfinder.minot.com>



"Together we can respond to one child or many."

Planning for the Summer (continued from page 5)

25 miles from a small rural community in northwestern ND. *"We don't have a summer recreation program on the farm. Summer is prime work time. It takes both of us to take care of the crops and the animals and I can't spend much time in the house with Jason. He is too little (4) to be trusted around the machinery and I have to have someone to watch him. His older sister just has to help out. But she resents that. My mother used to look after him but she went into an Alzheimer's unit last fall. That was hard on all of us. Sara is 15 and she might not like having Jason tag after her but*

we have no choice."

Jim mentioned this problem to his pastor who also does the mail route for his community. The pastor contacted a confirmation group at the local church. The group agreed to do "Sara Support" two days a week. Two kids from the group join Sara for two hours, twice a week. Sara and one of the other kids hang out or go to town while the other kid looks after Jason. Sara showed everyone how to put in his hearing aids and give

his medication. The kids enjoyed learning sign language so they could communicate with Jason. He in turn likes all his new big brothers and sisters and Sara gets a badly needed break to spend time with her friends. *"At age 15 that's really important. She knows she is helping out but she gets some special attention and support too."* ND families often develop unique solutions to summer challenges. For more information visit www.ndcpd.org/n2k to learn about family resources in ND.

Family Stories: Planning for the Summer

Families across ND look forward to the summer. Everyone can spend more time outdoors, the schedule is less hectic and we all get a healthy dose of sunshine.

Families of children with special needs face unique challenges in the summer. These family stories highlight some of the different challenges and solutions that families have found to be helpful.

Tom (not his real name) is being raised by his grandmother in one of ND's larger cities.

"Our grandson mopes around the house all summer. He has no friends. I work at the nursing home and can't be home during the day. I could get the swing shift but then I am too tired at night. Tom just doesn't seem to know what to do with himself. I told Tom's special education teacher about his summer and she helped us make some plans. She and Tom made a list of the houses in the neighborhood and the other kids who lived there. I got her the phone numbers and they found out who had plans and who was gonna be around. She and Tom made a schedule of what he could do every day, like when he could go to the park or playground. She got Tom signed up for some talking books and now he gets those every week. They made a list of TV shows like Animal Planet and stuff that would be good for Tom to watch. Tom still gets bored some but he has lots more to do now. Some of the other families in our neighborhood have started to include him. I guess I just always had friends as a kid. I didn't know

how to help a boy like Tom who is shy about getting with other kids."

Families like Tom and his grandmother often struggle with how to plan time during the summer. Many families are afraid to let their child with a disability join the neighborhood kids especially if their child has a history of difficulty in getting along or they worry that the other kids might tease their child. Getting to know the neighbors and making plans with other families is not a skill that everyone has developed.

Bill and Shirley Parker (not their real name) wanted to find some activities that would help their 9-year-old daughter Marsha gain confidence over the summer. They described Marsha as a shy, dreamy girl who was behind her peers in both reading and math and who preferred to spend most of her time in front of the television set. *"We don't have a lot of money to spend on adventures and we knew we couldn't afford anything too much."* Shirley mentioned this problem to her daughter's case manager. To her surprise Shirley found out that she was able to get her daughter a scholarship to spend a week at a summer camp. Although the camp was not specifically for children with special needs, they had supported several young people with delays and disabilities. *"Marsha was welcomed, and stayed in a cabin with three counselors and eight girls. She rode a horse for the first time and loved canoeing. We found out too late for this year that we could help Marsha raise money for next year by selling candy. We will help with that and the scholarship can go to another family this time. It wasn't the whole summer but it made a big difference for Marsha. She is asking if she can learn to ride a bike and if she can have a sleep over with some of the girls from camp."* Marsha's family is like many ND families, not sure what is out there and unwilling

to take on extra costs that would strain the budget.

Janet's family has a slightly different challenge. *"I am home most of the time so finding child care is not a problem. But I guess I just am not cut out to be with our son 7 days a week. He is very active and cannot be left unsupervised for even a few minutes. He likes to take things apart and at the age of 14 he is too big to physically control once he has his hands on something he shouldn't. I am ready to have him go back to school after the first two days and he is here for the whole summer."*

Janet talked to an experienced parent from her community who helped her locate other families whose children had special needs. The group made a list of recreational activities available during the summer and paired up to drive to activities and supervise the kids. They pooled their funds and hired two high-school kids to join them for an extra pair of hands. *"The kids enjoyed the experience and the activities were easier to coordinate with more help. We really relied on the summer parks and recreation program. Although they don't have much for kids with special needs we were able to keep Jim and the other kids very busy so that when we got home he was ready to crash for a while."*

The shift in intensity that comes with a summer schedule can overwhelm a family even when one parent is at home.

Irene and Jim live on a family farm about *(continued on page 4)*



"Our grandson mopes around the house all summer. He has no friends. "

North Dakota Center for Persons
with Disabilities

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We're on the Web!
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

Pathfinder Family Center Relationships, Responsibilities, & Reciprocity - Building Educational Partnerships Through Teamwork. At the Holiday Inn in Minot on April 16 and 17, 2004. For more information call 837-7500.



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 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 register. Scholarships are available.

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.

Summer Camp Experience Camp Grassick is a summer camp sponsored by the Elks of ND for children ages 7-15 with special needs. Services include: speech/language, craft activities, swimming instruction, supervised recreation, occupation therapy activities, reading instruction and some physical therapy. A Youth Transition camp is also held. **Contact Director, Elks Camp Grassick, Box F, Dawson, North Dakota, 58428, (701) 327-4251.**

Camp Inspiration in NY is for children who are ventilator dependent. The camp will be held from June 10th-13th. The deadline for registration is April 15th. Call (518)696-5676 or go to the web site, www.DoubleHRanch.org to learn more about this opportunity.