



Leadership

An Online Newsletter for ND Families Raising Children with Special Needs

Family Support Project: Outcomes That are Important to North Dakota Families

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The ND Family Support Advisory Committee (FSAC) met in Bismarck on October 28th, 2003.

The purpose of the meeting was to review the statewide strategic plan for enhancing family support. Project **Partners include:**

- Protection & Advocacy
- Pathfinders
- Federation of Families for Children's Mental Health
- Path Project
- Cultural Diversity Resources
- Family to Family Network
- State Improvement Grant
- Family Voices
- Partners in Policymaking
- Department of Public Instruction - Special Education
- Department of Human Services (DD Services, Children's Special Health



Services, Children & Family Services)

The FSAC reviewed outcomes that are important to ND families, measures that will be used to decide if those

outcomes are being met and data that is currently available on each outcome. Members looked at related outcomes from the National Core Indicator Survey. This survey will be mailed in February to over **1000 ND families** who have children with disabilities. The survey will give families an opportunity to participate in policymaking by indicating their satisfaction with services. Families from diverse cultures will be included. ND will be able to compare services with other states.

Data on the outcomes can be obtained by contacting project staff at 1-800-233-1737 or reading the article on page three.

Special points of interest:

- Learn how to Self-Direct Services
- An early look at outcomes that are important to ND families.
- Meet other ND families with challenges like yours
- Read about family opportunities for leadership

What if you could sit down, face to face with people in ND who make decisions about services for families raising children with special needs? What would you tell them about the excess costs your family encounters? What would you like them to know about insurance, transportation, community acceptance,

child care, health care, isolation, mental health or the quality of education that your child receives? Where do we need to go from here? Families will have this opportunity during round table discussions at the first Annual North Dakota Collaborative Conference to be held in Fargo at the Doublewood on June 10-12th in 2004. *(continued on page 3)*

Leadership: At the Table with Policymakers

Leadership Topics : Independence Plus

Did you know that the ND Department of Human Services has submitted an application to the Federal government for a new type of family support? **What does that mean for ND families?**

If the application is approved, beginning January 1, 2004, eligible families of children between the ages of 3 to 21 will have an opportunity to sign up for the ND Self Directed Supports (NDSDS) program.

The NDSDS program offers eligible individuals/families the opportunity to self-direct a fixed amount of public resources in a flexible manner than is meaningful and helpful in achieving personally defined goals. The program is based on a belief that persons with disabilities and their families can participate fully in their community only when they define the life they seek and are supported as they direct a mixture of generic and formal supports that will help them achieve personally defined outcomes.

The process of defining personal strengths, needs, wishes and hopes is called Person-Centered Planning (PCP) and lies at the heart of self-directed supports. Using PCP, the family develops their own support/case plan. The plan lists outcomes and the supports needed to achieve those goals. The family/individual self-directs or coordinates those supports. Not everyone will choose to self-direct supports. For families that do, NDSDS offers five supports:

- Support Broker
- Fiscal Agent
- Primary Caregiver Assistance
- Disability Related Supports
- Employment Supports *

*for persons 21 years of age and over.

What are each of these supports and how do they work?

Support Broker: A support broker is a Developmental Disabilities (DD) case manager. The support broker provides a family with training or assistance in learning how to self-direct supports. Support brokerage may be a new role for a case manager. Families can ask for support in learning to use PCP, identify outcomes and support options, and access



Are Self-directed Supports Right for You?

identified supports and services. The support broker helps the family to set-up an individual budget that the family will draw on to implement the plan. A support broker offers practical training to help families and individuals remain independent. Examples include providing information on recruiting, hiring, and managing personal care

workers and effective communication and problem solving. Support Brokerage provides families with enough information to assure that they understand the responsibilities of self-direction and have effective back-up and emergency plans. The family sets up and directs the plan. The support broker assists the family in getting the information and training they need to support this new role.

Fiscal Agent: A fiscal agent assists the family or individual to manage and distribute budgeted funds in the plan. Services may include payroll, tax payments, unemployment compensation, fiscal record keeping, requesting criminal background checks, and submitting appropriate bills to the DHS as allowed for in the individual budget. This service frees families from the most difficult responsibilities required of an employer. Currently families



who receive family subsidy must pay for services up-front and be reimbursed later. This creates a cash-flow problem for many rural families. Families receiving Family Support Services can select a care worker only from a licensed provider. NDSDS allows families to recruit and hire their own worker. This will be helpful to many families living in rural communities where a service provider may not be available. The family direct the fiscal agent to write payroll checks and pay bills from the allotted budget. **Other NDSDS will be described in the next addition of the LEADERSHIP newsletter.** For more information about NDSDS contact your DD case manager.



“ The process of defining personal strengths, needs, wishes and hopes is called Person-Centered Planning (PCP) “

Family Support Policies: What Are the Results?

Members of the ND Family Support Advisory Committee (FSAC) reviewed several outcomes and related data at its meeting in Bismarck. Let's look at two of the outcomes, the data that was available for these outcomes and their specific FSAC recommendations.

Families stay together

What % of ND children with disabilities are placed outside of the home ?

From July 1, 2001 to June 30 2002 as many as 679 children were placed outside of their regional special education unit. Of these placements, 374 were in other public schools outside of their regional special education unit. Many of these children probably continued to live at home. This leaves about 305 students who are living apart from their families in order to receive a free and appropriate public education.

FSAC Members wanted to know:

- How many placements in that category involve kids who live apart from their families versus kids who attend school out of the district but live at home with par-

ents? Also clarify what other residential placements in or outside of ND may be involved besides those listed by DPI.

- How many kids under age 3 are placed out of the home? This data will be obtained from the Department of Human Services.
- Look at trends or changes in the # of students placed outside of the home. Find out how many of the placements are new or repeated.

What % of children returned to a family home in the past year?

The ND Department of Public Instruction does not keep data on this indicator.

Families are healthy

What % of ND families have health insurance for children or adults?

What % of ND families are satisfied with their health care services?

What % of ND families have needed health care services available in their community?

No data was available for the

group to review.

FSAC members said this:

These measures give a limited rather than a holistic picture of health.

- Check with staff from the Children's Health Insurance Program (CHIPS) to identify the number of ND families who have health insurance for kids. Using data on percentages of children from the 2000 census, estimate how many ND families who have kids with special needs have insurance for those children.
- In the upcoming survey, ask families about satisfaction with general, dental and mental health services to get a more holistic picture. Ask if services are available within 25 miles.
- Also, see if other ND agencies have holistic health measures. Options include: CSHS, Children & Family Services, and the ND Mental Health Assoc.

Look for a review of additional outcomes and data available to ND families in next month's newsletter.



"How many kids under the age of 3 are placed out of the home? "

Leadership: At the Table with Policymakers (continued from page 1)

This will be the first of two annual conferences, one held in the east and one in the west each year. Many family support agencies have collaborated to bring families of children with delays, disabilities or chronic health conditions and professionals together to discuss best practices and quality of life issues in ND. Round table discussions will take place in a

small-town café atmosphere. Over coffee, rolls, and conversation, policymakers, families and professionals will take a look at what is important to families, how we are doing, and what needs to change. Families will have face-to-face access to persons making the big decisions about what to fund, which families get access to services, what programs to

keep and how to build communities that accept and welcome families and children with disabilities. Families and professionals will also hear national speakers on a wide range of topics.

Sound good? Registration packets will be available beginning January 15, 2004. Watch for more information in upcoming newsletters.

Family Partners: ND Family-to-Family Network

Does ND Need a Family to Family Network? Sue Offutt and staff at the ND Family-to-Family office believe that we do. This belief is based on feedback from hundreds of families across ND who have asked for help in meeting other parents, grandparents or siblings.

The ND Family to Family Network (F2F) provided through the Center for Rural Health at UND links families of children with special needs with other families. Special needs may include children with delays, disabilities or chronic health problems (e.g. asthma or diabetes).

Why is this service so important to ND families?

Raising a child with special needs is often an atypical experience. Although children with disabilities are more alike other children than different, their development and challenges are often unique. No matter how good a family's social net-

work may be, this experience often leaves families feeling isolated and overwhelmed. **Meeting another family whose child has similar needs helps what is an extraordinary experience to become more every-day.** This relieves stress and gives families a sense of confidence that they too can succeed.

We all know that men and women are different. Sometimes meeting another family is more important to one partner than other. **Access to another family can help meet needs that a partner is not prepared to support.** This may relieve the pressure that partners sometimes place on one another in expecting the other person to respond to challenge in the same way. Stress and increased expectations for a partner may lead to increased rates of divorce or separation following the birth of a child with special needs.

What does NDF2F offer?

In addition to matching ND families with veteran families, the F2F project offers:

- **Leadership training** for families in how to access systems

- **Support for American Indian families** especially those living on reservations.
- **Collaborative training** for schools on involving and supporting ND families.
- **Peer mentoring** for high school students with disabilities on leadership.
- **Transition support** for families and youth

To be matched with a veteran family, individuals can call the toll free number at 1-888 434-7436. Or sign up online. The F2F website has other valuable information. F2F can be found online at: <http://medicine.nodak.edu/crh>

Other facts to know about NDF2F:

- Responds in 24 hours
- Matches are confidential
- Veteran family training
- Ask for as many matches as you wish
- Agencies can refer families as well



“ This service is especially critical for families who live in rural communities where the opportunities to meet and visit with similar families simply does not exist. “

Sleep Deprivation—continued from page 5

the rest behind the couch. We didn't find it until two days later. He has also eaten whole birthday cakes and boxes of popcicles If some items are in the house he will wake up to get them. Once he stood on the glass top stove to reach candy and broke it. He wasn't hurt but it cost over \$400 to fix.

Our son has learned that certain things will really upset his family. At first he got a charge out of situations in which we showed frustration. We were nervous. "If we can't handle him at 6 how

will we handle him at 18?" But as time went by he really came to understand the benefits of pleasing people and became more concerned about fitting in. Now we can say "it makes us so sad when you do something we've told you not to." It took a long time but he wants to stay out of trouble. We can trust him a little more.

Our pediatrician did a lot of research on sleep medication and we got information from the National Foundation on CDLS on what had worked for other parents. Lots of letters from other families offered advice. Our pe-

diatrician came up with a suggestion and we found out that other parents were using it. So we knew it was a good resource.

Families sharing with other families is so important to building an effective circle of support. See the article above this one for tips on what works in ND. **Next issue: Building a Circle of Support for Your Family or Child.** If you have a story to share on that topic please contact project staff at LEADERSHIP 1-800-233-1737 or send a brief email with your story or thoughts to Cathy Haarstad at:

haarstad@minotstateu.edu

Family Stories: Surviving Sleep Deprivation - What Do You Do When A Child Doesn't Sleep Through the Night?

When a child is born, parents know that they will be up with their new baby in the middle of the night. But most parents believe that the child's nighttime wakefulness will end, hopefully within a few weeks but certainly within the first few years of life.

But what happens when your child does not go to sleep or sleep through the night due to a disability-related condition? What do you do when nighttime wakefulness continues into adolescence or even adulthood? How do you cope?

One family from Fargo, ND has encountered this problem and survived (so far) to share these insights and recommendations with other families.

Our 14-year-old son has a condition called Cornelia de Lange Syndrome. A common challenge of this condition is compulsive behavior and sleep difficulties. Children with CDLS sleep lightly and may require medication to get to sleep and continue sleeping through the night. Medication helps but is not always effective in keeping our son asleep. Consequently he may wake up during the middle of the night and stay awake for several hours. If he gets overly tired he has more difficulty getting to sleep.

Staying awake with a child soon results in sleep deprivation for the parents. This becomes an issue for the whole family, especially if the child tends to be a little bit disruptive when awake at night.

When our son was younger safety was a big issue. Often he woke up and we didn't know it. We had to think of ways to keep him safe. Gates at his door and having nothing in the room he could hurt himself with were

critical.

We had younger babies in the house who would wake up. They often woke up our son but unlike the baby he did not go back to sleep. Toilet training at night is still difficult, because if awakened to use the toilet, he can't get back to sleep.

During the early years before an effective medication was found, with both parents working, we decided to use tag-team parenting with one parent going to bed early and then being the one to get up. Soon everyone is tired and you start over the next night. It's a little more frustrating knowing it is not going to go away soon. Eventually we reached the point where we asked ourselves: "OK! If it's not going to go away, how can we make it better?"

Medication has certainly saved our lives in terms of helping him and us sleep. How awful for kids and families when meds are not an option. Tag-team parenting creates dysfunction in homes and marriages. When going through that difficult time if one person can take time off from a job or be home that certainly helps but it is still difficult.

It's stressful for the other kids too because parents are always tired. It took a lot of communication, "I'm sorry, I'll try not to be crabby, this is what is going on," but kids are forgiving if there is a reason. Also they understood that at his very worst it was so awful for him. He had huge mood swings; giddy one minute, crying the next. It's hard to watch him go through that. I never understood child abuse until

that period in my son's life. Although we never were pushed to that point, it became easier to understand how abuse can happen. Parents (many of whom have lots of other stressful things going on in their lives) who are overly tired and trying to deal with out-of-control behaviors at all hours of the night, are only human.

In the beginning, I was an anti-medication person. I thought anyone could change any behavior with behavior modification. I wanted to try other things. However I soon learned I wasn't doing anybody any favors by insisting we all lose sleep.

Our son prefers to listen to music with head phones, talk and sing out loud and look at magazines. He often stays in his room but not always. If he thinks it's morning he will go to his favorite place in the family room. After many years he understands he is not to touch anything else. If it is 3:30 you can't talk him into coming back to bed. When he does stay upstairs at least we know he is in his room and safe.

When he was real little we had a baby gate. When he got old enough to climb over that we had to add a second gate. One night he shredded all the wall paper in his room while waiting for us to wake up and open the gate. He was sure proud of his efforts.

When he first started coming out of his room he would go to the kitchen and make a snack. Thank goodness he never turned on the stove or oven but he did try to make hot chocolate in the microwave. He has also taken out ice-cream, eaten as much as he could and hidden



"OK! If it's not going to go away, how can we make it better?"

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 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

IDEA Committee Meeting—The next meeting of this committee will be held on December 5th, 2003.

The meeting will be held at IVN sites in Bismarck, Grand Forks, Minot, Fargo, Williston, Devil's Lake, and Dickinson. This state-wide committee acts in an advisory capacity to the Office of Special Education.

If you are interested in serving on the IDEA committee contact:

Bob Rutten
Office of Special Ed
600 E. Boulevard Ave Dept 201
Bismarck ND 58505-0440
701-328-3277

This is truly a leadership opportunity.

The North Dakota Center for Persons with Disabilities (NDCPD), issued five Community Services Pilot Project Awards at a total of \$6,890.96

- **Minot Vocational Adjustment Workshop**—teach people with disabilities to use a PDA to assist in self-medication and increase their independence.

- **Manchester House of Pride Incorporated in Bismarck**—teach youth to relieve stress/anxiety, and integrate brain/body system functions to reinforce new learning and support positive behavior change.
- **Friendship Incorporated in Fargo** provide people with disabilities resources to allow them an opportunity for self-employment.
- **Bismarck Public School – Life Education After Hours Activities** will provide students with disabilities a greater chance to participate in community leisure activities.
- **ABLE Incorporated in Dickinson**—assist a person with significant disabilities to remain in his rural community by using natural supports and linking him to existing services

To learn about the next award cycle contact: Dr. Brent Askvig at 1-800-233-1737 or askvig@minotstateu.edu

