



Leadership

An Online Newsletter for ND Families Raising Children with Special Needs

Family Support Project: What's New?

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The ND Family Support Project continues to collect data on outcomes identified by the ND families as *important*.

Most families know if they are satisfied with the availability and quality of health care services in their community. What happens in one town may not take place in other communities. Most families need to concentrate on their own situation. Information about the big picture can help families work together for system change.

Several partners have forwarded data about health outcomes in ND. Family Voices of ND shared the results of an informal phone survey conducted with about 30 families. Only 10 or 33% knew what Health Tracks was and only 5 used ND Health Tracks for their child.

ND Health Tracks (formerly EPSDT) is a preventive health program free for children age 0 to 21 who are eligible for Medicaid. This includes children with



disabilities who receive family support services. Health Tracks pays for screenings, diagnosis, and treatments to prevent health problems from occurring or becoming worse. **HT** also pays for teeth braces, glasses, hearing aids, vaccinations, counseling and other important health services. Health

tracks helps families make appointments and find transportation.

Tammy Gallup Millner, director of ND Children's Special Health Services, pointed out that in ND we have Healthy Steps, Health Tracks and Right Track, three separate programs with different purposes and similar names. No wonder families get confused!

The second survey (State and Local Area Integrated Telephone Survey for Children with Special Health Care Needs) was conducted by phone in ND by the Federal Bureau of Child and Maternal Health. The results show that most *Continued page 3.*

Independent Living Centers

North Dakota families have so many options for support in raising a child with a disability. One option available to a growing number of ND families are services from a Center for Independent living. **What is a Center for Independent Living?**

Centers for Independent Living (CIL) are non-residential, private, non-profit,

community-based organizations providing services and advocacy by and for persons with all types of disabilities and their families and communities. ND has four primary sites:

- **Freedom Resource Center** for Independent Living in Fargo/Moorhead.
- **Option Center for Independent Living** in East Grand Forks.

Leadership Topics : Partners in Policymaking

We learn much of what we know by watching other people. Do you know someone who seems to use just the right words, handles conflict calmly, has a plan and carries it out?

If you have met parents in ND who have these skills, chances are they are a graduate of the Partners in Policymaking training program offered through the Dakota Center for Independent Living.

What is Partners in Policymaking?

Partners in Policymaking is an internationally-known program that has successfully trained thousands of advocates in the field of disabilities. Every September, the North Dakota Governors Council sponsors Partners in Policymaking in ND. This exciting and innovative leadership program:

- **Trains participants in the most effective strategies for successful advocacy.** Members who have graduated from the class gain a great deal of personal confidence when learning advocacy skills. They build on abilities and strengthen personal communication skills.
- **Provides state-of-the-art knowledge from national leaders, about today's disability issues.** This information base creates a spring-board to action for parents who have children with disabilities. Not only do they come away with more knowledge about disabilities in their community, they also develop life long friendships.
- **Creates partnerships between participants and policymakers at all levels of government.** Families have opportunities to form new, positive relationships with decision makers in local schools, educating mayors and city councils, working with the legislators, and even influencing federal laws.
- **Gives participants important tools required to play a leadership role in policy development and advocacy within their communities.** According to Joyce Smith who facilitates the course, people come to the class wanting to attain information for their own personal life situation. As the class progresses, they begin to venture out of their



Partners in Policymaking

own circle and start to advocate for change at the local and federal level.

- **Brings adults with disabilities together with parents who have a child with disabilities.** Bringing these two groups together has been a powerful experience for both groups. It is important for families to see the kinds of achieve-

ments and experiences that adults with disabilities experience. Lifetime friendships are formed and a community of advocates for disabled persons continues to grow in North Dakota.

Partners in Policymaking is a FREE, two-day training course that meets once every month, from September through April. Participant's hotel stay, meals, travel expenses, and child care are paid. Partners in Policymaking starts in September, but applications are accepted throughout the year. Training sessions are usually held in communities from which the majority of students enroll.

PIP Content includes:

- History of disability
- Disability rights movement
- People first language
- Building inclusive settings
- Inclusive education
- Team meetings
- Supported/Independent living
- Supported/competitive employment
- Personal futures planning
- Assistive technology
- Advocacy
- Supporting behavioral growth
- State/Federal Legislation
- Vision Building
- Community Organizing
- Alliance Building



“Bringing adults with disabilities together with parents who have a child with disabilities has been a powerful experience for both groups.”

For more information contact Joyce Smith toll free at 1-800-489-5013.

Centers for Independent Living

- **Independence Inc.** A resource center for independent living in Minot.
- **Dakota Center for Independent Living** in Bismarck with branches in Mandan and Dickinson.

Centers for Independent Living were first started by people with disabilities who were dissatisfied with living in hospitals or nursing homes merely because of their disability. They decided to start a unique business that would be run by people with disabilities who knew what it took to really help someone establish the life they wanted outside of an institutional setting. This movement soon swept the country and today Independent Living Centers can be found in all 50 states.

Although families have traditionally looked to schools, human service agencies or adult service providers for support CILS offer some unique perspective and services that families may want to pay attention to when building a life for/with a young person with a disability.

Each CIL in North Dakota provides four core services most of which are FREE:

1. Information & referral for all persons with disabilities.
2. Peer support from staff members most of whom have a disability
3. Individual and system advocacy by

helping to educate legislators.

4. Assessments to build on personal skills and obtain support for needed services.

Areas of support that CILS might offer a family include:

- Instruction in daily living skills
- Maintaining living skills
- Assistance to find housing
- Help to find employment
- Help with transportation
- Access to recreational facilities
- Money management

CILS in ND offer or sometimes develop many innovative services that are community based to support persons with disabilities. For example:

Computers - The Dickinson CIL recently had businesses donate their older computers and refurbished them for use by persons with disabilities.

Transportation - The Dickinson CIL also established a voucher ride-program by collaborating with the ND Center for Persons with Disabilities.

Senior Companions- CILs often link people to this program that, in collaboration with Lutheran Services, connects seniors to other seniors with disabilities, providing added

support and companionship.

Representative Payee Services

- Provides an advocate to help manage the complex Social Security system and teach consumer money skills. There is a fee for this service.

Rights Education: - Independence Inc. in Minot offered a summer transition program for students that included an online course on how people with disabilities may exercise their rights. The course was developed by the ND Center for Persons with Disabilities and can be available to young people statewide.

Partners in Policy-making Program - Consumers and families learn how to advocate for system change. To find out more about *Partners in Policy-making*, read the article on page 2. For more information on how your family could benefit from CILS call the consumer toll free number at 1-800-489-5013.



CILS offer a unique perspective and services when building a life for/with a young person with a disability.

NDFSP What's New ? *continued*

ND families are satisfied with health care services. About 8.6% of the 7526 respondents reported that their children have significantly greater health care than peers. That's 644 ND families.

The reason stated most often (5.8%) for why health care was delayed or foregone was the family did not have the money to pay the provider. About 21.7% of responding families indicated that their child's special health care needs created a

financial problem for the family. About 4.7% of families were not receiving dental care. Again cost was cited as the biggest factor.

CSHS is working hard to address these factors among eligible families. CSHS has additional questions about health care services for families of children with special health care needs and is planning a new five-year survey of ND families. CSHS will look at the SLAIT data and take input from ND families about what questions to ask in

their upcoming survey.

Other Action: Project staff also attended the IDEA committee meeting via IVN network. Along with Jane Nelson from the State Improvement Grant, an orientation kit on welcoming families was presented. The kit is available to families in all ND special ed. units.

Bids are being accepted for a conference planner for the upcoming collaborative conference. Contracts with the DHS and DPI to fund the conference are being developed.

One Stop Centers

What if, no matter where you lived in ND, you could access a one-stop center that was prepared to offer your family all of the information and support you might need to raise a child with a delay, disability or chronic health condition?

One-stop service models have been growing nationally. Are one-stop services available for ND families? Should they be?

If a family wanted to meet another family who has a child with a disability would they be matched with a veteran family locally or referred to the Family to Family office at UND? If a family needed information about their child's educational rights under IDEA, would they be offered several resources or be told to contact the Pathfinder Center in Minot? If the family was looking for respite care would the center provide the service, or refer the family to a provider in the next town? What if you could go to one

place to access all the services you needed instead of being referred to multiple agencies?

The concept of a one-stop center may have been part of the original idea behind the creation of Human Service Centers. ND is currently divided into 8 regions each of which has a Human Service Center. Ask ND professionals today if a one-stop center works and you will get a mixed response.

Some administrators believe in the concept and strive to align resources and meet diverse needs. Others claim that the needs of families are too diverse and the array of support options too numerous for this model to work. The rural/frontier nature of ND and the distances between towns as an insurmountable barrier to the one-stop model.

Last year the Department of Health and Human Services' Administration and Children and Families awarded 31 one-year planning grants of \$100,000 to help states create a seamless system of services for underserved families of people with developmental disabilities. The eventual goal of these projects is to plan for

the establishment of "one-stop shopping"---centers where coordinated, outcome-oriented and family-centered services would be delivered. These centers would offer families one point of entry to establish eligibility for many services and develop a comprehensive plan to preserve and strengthen the entire family.

Because ND is a continued recipient of a family support grant as a third tier project no application for a one-stop center was submitted. One stop centers have become the primary focus of funding from the Administration on Developmental Disabilities, replacing the previous "family support" projects. North Dakota will be in a position to decide if we think this kind of model will work here. This would require players to move from collaboration on projects of interest to coordination of services. It would require intense planning and discussion and challenge players to resolve turf issues.

Would the results be better or less confusing for families? Could we make such a concept work? Do we really want to?



" This would require players to move from collaboration on projects of interest to coordination of services. "

Family Stories — continued from page 5

Partners in Policymaking is an investment worth making. Negotiating for what your child needs takes skill and can be easier than you think.

Next issue: Building a Circle of Support for Your Family or Child.

Many families struggle to find and balance both generic and disability specific supports. We are looking for stories about every-day supports that families create to meet the needs of children

with special needs.

If you are a parent and have a story or suggestion that you would be willing to share please contact project staff toll free at LEADERSHIP 1-800-233-1737 or send a brief email with your story or thoughts to Cathy Haarstad at:

haarstad@minotstateu.edu

We also welcome your ideas for future stories or articles.



Family Stories: Family Experiences As Partners

Finding opportunities to learn more about your child's disabilities and how to best advocate for his or her needs is something every parent with a child with a disability hopes to do. This is a story of two ND parents who found Partners in Policymaking to be a solution to challenges they had encountered.

Ardeen graduated from the Partners in Policymaking Program in 1998. She has a teenage son with a disability and was working in the field of disabilities when approached about taking the class. *I agreed to go because it would be fun to spend a free weekend in a Bismarck hotel and have time to shop! After the first day, I knew I was hooked on the program and I forgot all about the shopping!* She now laughs about her motive for going to the program. *It changes your life and I wish everyone knew about this opportunity.*

For eight weekends, one weekend a month between September and April, Ardeen came to Bismarck to learn more about the field of disabilities and to become an advocate in disabilities. A different national speaker came each month and Ardeen says she learned so much from each speaker.

Friendships were quickly formed as participants began to share their stories. *You don't feel like you're the only one going through this experience. I met another person who had a child with a similar behavior disorder as my son. She helped me understand how this disorder manifested itself and how it can affect the family. For the first time I began to see the disability through my sons eyes. I went home and hugged*

my son and explained how I finally understood about his daily trials.

Since starting the Partners program, Ardeen feels more empowered about how to handle school situations. She has worked with Congressmen and if time allowed, she would be more active in the local legislature. *I wish everyone knew how really simple it is to work with legislators to get an amendment passed. Sure it takes time and a coordinated effort, but it's not as difficult as I once thought.*

Ardeen continues to be keep in touch with some of the graduates in the class of 1998. Partners in Policymaking offers graduates an opportunity to attend a two day summer course called "Advanced Organizers Training." This class is designed to help graduates update skills and keep in touch.

I've really enjoyed these summer classes. The graduates have some input about the topic we would like more training in. One year we chose to do a grant writing class that was very helpful.

In the past few years, summer classes included such topics as; understanding personality and communication types, building computer skills, and using person-centered planning tools.

Besides the wonderful training, Ardeen finds the summer courses to be an opportunity to catch up with good friends. *It's so fascinating to see the change in other people as they become empowered. This class will definitely change your life!*

Melissa is a parent who is

currently taking the Partners class. She has a 12-year-old daughter with a disability and was unhappy with her daughter's special needs program at school. Like Ardeen, she joined the class thinking it would be a nice chance to spend the night in Bismarck and get some shopping done. *After the first night, I was emotionally drained. This is not a vacation, but a life-altering experience.*

Melissa's felt her daughter wasn't being challenged in school and she wanted to be a better advocate, but didn't know where to begin. *Now I've learned that I have the power to influence my daughter's education. So we've re-written her IEP to have her fully included in class. She was being pulled out of class so often that she began to resent going to school. Now that I've learned how to work with the school system, my daughter is having a much better school experience and, best of all, is now referring to all her new friends at school. I think of all the time that was lost when she was younger and I would like more parents to know about this program so they have the opportunity to get on board when their children are young.*

Melissa finds it comforting to see the adults with disabilities go through the class. *When my daughter is 18, I'm going to encourage her to take the class. It will be so empowering for her and I'll have the comfort of knowing that she has the skills necessary to meet the challenges of adulthood.*

Participation in a course like Partners in Policymaking is a real commitment for families because of the time. When you look ahead at the rest of your child's life, attendance at a



"I wish more parents knew about this program so they had the opportunity to get on board while their children are young."

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

The **ND Department of Public Instruction** will be holding a **Transition Institute** in Bismarck on March 8-10th of 2004. Jonathan Mooney, a 26 year-old college graduate with LD and ADHD, will be one of the exciting key-note speakers. Mr. Mooney will discuss his experiences in education from middle school through college and talk about accommodations, barriers and lifelong learning.



The **North Dakota Department of Human Services' Children and Family Services Division** has been awarded an \$83,545 federal grant to provide educational and training vouchers to help older foster children and young adults become self-reliant. Families usually help young people get started in life after high school. As they exit the foster care system, many foster care children do not have the family support they need to help with housing, higher education, employment. A large percentage of foster care youth have disabilities. Eligibility: "Age out" of foster care at 18 or be adopted at age 16, and be younger than 21.

Medicaid Service Limits: Effective Jan. 1, 2004 these service limits will impact all ND families receiving Medicaid, including kids under the HCBW.

Chiropractic visits - 12 per year

Chiropractic x-rays - 2 per year

OT Evaluations- 1 per year

OT - Visits -20 visits per year; (for services delivered in a clinic or outpatient setting. This limit does not apply to school-based services for kids).

Psychological Evaluation - 1 per year

Psychological therapy visits - 40 per year

Psychological testing - four hours per year

Speech therapy visits - 30 per year; (applies to services delivered in a clinic or outpatient hospital setting. This limit does not apply to school-based services for kids).

Speech evaluation - 1 per year

PT evaluation - 1 per year

PT visits - 15 per year; (applies to services delivered in a clinic or outpatient hospital setting. This limit does not apply to school-based services for children.)

Eyeglasses and exams for Individuals 21 and older - once every 3 years. (Pre-authorization to exceed limits is available when medically necessary).