



Leadership

An online newsletter for ND Families raising children with Special Needs

Family Support: What ND Families Have to Say!

Inside this issue:

Support: NCI Survey	1
Opportunities: FEET Teams	1
Topics: Job Clubs	2
Policies: Positive Behavioral Supports in Schools	3
Family Stories: Adopting a Child with Special Needs	4
Partners: Federation of Families for Children's Mental Health	5
Announcements:	6

Special points of interest:

- How a Jobs Club might help your teenager with a disability.
- Upcoming conferences that bring families and professionals together.
- Challenges and rewards in adopting children with special needs.
- New initiatives to create positive learning environments in ND schools.

Watch Your Mailbox! Within two weeks, over 1700 ND families will receive a survey asking them to comment on the family support services they receive. The survey is being conducted by the ND Center for Persons with Disabilities at Minot State University on behalf of the ND Department of Human Services –Disability Services Division.

Family support involves not only in-home or community based respite care but assistance to find or develop services, coordinate care and respond to unique developmental, health, or behavioral challenges. This is an opportunity for ND families to share their insights into the quality and availability of support as they raise a child with developmental disabilities. The information obtained from the survey will be shared with families and policy-



makers during an upcoming conference **ND Family Connections: When Kids Have Special Needs**, talking place on June 10th-12th in Fargo.

Some families who respond to the survey and give permission for the DHS to release their name, will receive a follow-up phone call. This call will give a representative sample of families an opportunity to respond by voice to a core set of questions.

Prizes are available for early responders to the survey! Research planners are hopeful that this will increase the return rate.

There are many families in ND whose children are not eligible for DD case management services. Unfortunately this survey will not represent their input due to financial limits in the budget. It is hoped that data from these families can be obtained at a later date.

Leadership Opportunities: FEET Teams

What is a FEET Team? FEET stands for **Family Educator Enhancement Team**. A FEET team typically includes parents, teachers and administrators from an area school district or regional special education cooperative. FEET teams review the local informational and training needs of families and teachers and locate or develop resources that will address those needs. Teachers and parents may both be

isolated within their perspective roles. FEET teams bring families and educators together as a collaborative study group. FEET teams help ND schools meet mandatory parent training responsibilities outlined under IDEA as well as bringing parent input to comprehensive personnel development. Funds to support FEET teams (continued on page 3)

Leadership Topics : Job Clubs

What are Jobs Club? A Jobs Club is an informal club for people who face common employment challenges. Members join together to share information about work opportunities and successful employment strategies. Although meetings are social events a Jobs club is not primarily a social group. Rather it is a learning community designed to enhance skills and self-confidence. Jobs Clubs provide members with information about job opportunities; support to set goals or make behavioral changes needed to either enter the workforce or improvement employment options. Jobs Clubs are an excellent resource for students or adults with disabilities.

A Jobs Club adopts a person-centered and practical approach to assisting people with disabilities to find work. A Jobs Club focuses on providing quality services by empowering the individual to learn about employer expectations and search for the job of their choice at their own pace. Jobs Clubs draw on both students and families to assume responsibility for finding work (an eventual adult skill) rather than relying on a school-based work experience that seldom leads to employment. This approach keeps people responsible, motivated and encouraged to keep working.

Jobs Clubs meetings while informal are conducted in a professional manner. Participants are encouraged to network and share experiences and information with one another about job-seeking, finding, and holding experiences. Speakers are identified as individuals who have faced similar challenges and succeeded in obtaining employment or changing jobs.

Jobs Clubs can be individualized to meet the needs of a broad number of individuals with diverse employment challenges or disabilities. Like typical classrooms, activities must be planned and managed so that they are meaningful for students who may not read, require more time to obtain in-



A Jobs Club is For Everyone!

formation and need an experienced based approach to learning. Jobs Clubs can be set up so that students try out and practice behavior in a safe environment and are given feedback from potential employers and peers.

To be effective, Jobs Clubs offer members access to phone, computer and media equipment to support the information seeking process.

These resources can be used to help people explore careers and look at job opportunities online.

Families are an important component of Jobs Clubs in several ways. Families are often key sources of job information through their many informal contacts within the communities. Families benefit from meeting with other parents to learn about successful job finding techniques. Families have indicated that they prefer Just-in-Time information so informal association with the Jobs Club for a brief time is to be expected and supported. Families also appreciate access to related information about adult services, higher education or benefits that can be made available through a Jobs Club. Once families have the information they need, they move on. New students and families are recruited and invited to participate.

In rural ND the number of individual students or families in any one school may be too small to form or sustain a Jobs Clubs. Since all ND schools now share access to a broad-band network, it is possible for schools to link families and students with participants from other rural schools via computer and video technology.

Jobs Clubs benefit from the support of experts in job development available through ND Job Services and/or a local adult service provider. Expertise for employment of students with sensory disabilities (vision or hearing) or for accessible materials available on the web is available at ND Vision Services in Grand Forks or the ND School for the Deaf in Devil's Lake.



Amy found her job through a local Jobs Club



“ A Jobs Club adopts a person-centered and practical approach to assisting people with disabilities find work. “

Family Support Policies: Positive Behavioral Supports in Schools

Positive Behavioral Supports in schools or **PBS** is not a new concept. It is a relatively new initiative that will be offered and piloted within growing numbers of ND schools in the future.

PBS strengthen the capacity of schools to educate all students, especially students with challenging social behaviors. PBS accomplishes this by helping schools establish a) clearly defined outcomes that related to academic and social behavior, b) systems that support staff efforts, c) practices that support student success, and d) behavior data used to guide decision making.

Schools serve students within groups. A wide range of student behavior may interfere with learning or success and can be expected to occur in any school community. It is easy for schools to react to disruptive behavior rather than to create a positive environment where students and staff can succeed.

A typical example of reactive policy is the "no tolerance" rules adopted by some ND schools following the rash of

in-school shootings that occurred throughout the nation in the late 90's.

Research shows that the zero tolerance approach did not prevent shootings or other violence and did not enhance student learning or lead to school improvement.

PBS is not a curriculum or a discipline program. Instead it is a process for decision making, planning and problem solving related to challenging social behavior seen in typical schools. PBS focuses on teaching behavioral expectations directly to all students, teaching social behaviors like academic skills, maximizing academic engagement and success and providing educators with instructional support for behavior change.

Many options are available to help families and schools teach positive behavior and response to disruptive behaviors. Unfortunately these strategies to be effective require creation of an environment where students, parents and teachers can succeed. PBS teaches schools and

families how to apply these strategies and create a learning environment that supports success.

Family involvement in PBS could be critical to its success in three ways: 1) Family input leads to better data and a more thoughtful approach to school-wide practices, 2) Family support may help to educate the community about the importance and positive impact of PBS and 3) Family involvement is critical to helping students generalize new skills to the home environment.

Unfortunately right now there is little data on the impact of family involvement on the success of the PBS model. Most research describes the importance of family involvement without showing actual data on how that helps. Hopefully that will change soon since the general data on PBS show it to be a very beneficial and effective program for students and schools. Ask your local principal or superintendent if they are involved with PBS.



"PBS is a process for decision making, planning and problem solving related to challenging social behavior seen in typical schools."

FEET TEAMS (continued from page 1)

are available to ND schools under IDEA. It is not surprising that many families in ND have not heard about FEET Teams. Not all ND schools have an active team. Why?

The FEET model for was developed by the ND Department of Public Instruction several years ago. There has been considerable turn-over in special education administrators during that time. The job

of recruiting, organizing and supporting a FEET team or encouraging parents to attend usually falls to the Director of Special Education who often has other informal sources of parent input and many competing responsibilities. Finally, administrators must believe in the concept of parent involvement in order to share responsibility for planning with parents. Even when a strong

team is organized and active, the team encounters turn-over and the interests of parents and teachers serving on the team change.

Some ND schools are meeting this challenge by pooling funds from several agencies and hiring staff to coordinate this and other related parent training and information activities. This relieves administrators from the ongoing work of supporting a team and allows families and schools to create a forum for parent input. Schools who do not have an active FEET team often support family attendance at workshops and conferences.

Family Partners: ND Federation of Families for Children's Mental Health

The ND Federation of Families for Children's Mental Health or **NDFF** is a state/national parent-run organization focused on the needs of children and youth with emotional, behavioral or mental disorders and their families.

NDFF has regional offices in Bismarck and Fargo. Recent legislative cuts forced NDFF to cut back to just 2 regional offices. However they continue to offer support to families state-wide.

NDFF provides advocacy for individual families and for system change. NDFF has helped to train professionals and families about the wrap-around process, a unique way of providing services to children with mental health challenges and their families who are served by multiple systems.

Services may include listening to family concerns, providing on-site support at IEP meetings, giving testimony before legislative com-

mittees on behalf of families and exercising leadership through service on various ND committees and projects that support children's mental health.

NDFF is *family focused*. They believe that every family has a right to an appropriate, available and accessible support base to meet family-identified needs. NDFF staff work to build systems that draw on the strengths of families by:

- **Family Voice:** Ensuring that families are equal partners in the planning, implementation and evaluation of services;
- Viewing the child as a whole person and the family as a whole system rather than emphasizing the disability
- Empowering families and children to make decisions about their own lives
- Encouraging innovative programming which increases options and promotes the integration of services.

How is this accomplished? NDFF staff use a variety of

unique ways to support families by:

- Supporting new initiatives on Positive Behavioral Supports in Schools
- Contributing to the ND Family Support Project
- Creating community based recreation options for children with behavioral challenges
- Supporting parent-led efforts to help families meet economic needs through food cooperatives (Fargo)
- Supporting diverse families who are English Language Learners.

To learn more about NDFF contact:

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"Every family has a right to an appropriate, available and accessible support base to meet family-identified needs"

Adopting a Special Needs Child (continued from page 5)

Parents need to be on the same page about adoption and about telling their child that he or she is adopted.

When we adopted several years ago the support network for new parents of children with disabilities, wasn't always there. I am sure the classes have improved on that point now.

To spend 1-1 time with another family who had adopted or was raising a child with similar needs

would have been helpful. Families need to really see for themselves what a child's condition is like rather than reading about that condition in a book and then trying to make a life altering decide.

The special needs adoption program in ND is known as A.A.S.K. (**Adults Adopting Special Kids**). This program is a collaborative public/private special needs adoption program of Lutheran Social Services of North Dakota, [The Village Family Service](#)

[Center, Catholic Charities North Dakota](#), and the North Dakota Department of Human Services (Toll-free: 1-877-551-6054).

Next issue: Supporting Teens & Their Families If you have a story or thoughts to share on that topic please contact project staff at LEADERSHIP 1-800-233-1737 or send a brief email to Cathy Haarstad at:

haarstad@minotstateu.edu

Family Stories: Adopting a Child with Special Needs

Why would a family adopt a child with special needs?

Families adopt for many reasons; the best being a desire to nurture and parent children within a permanent family environment.

Children with special needs are first and foremost children and above all need to be loved, cared for and supported as they take their place in the circle of life. The job comes with special challenges.

Families who adopt children with special needs don't always know how their journey with the child will evolve. Even when families are aware that the child has special needs before the adoption takes place, families typically go through a period of adjustment and cycles of love and loss as the disability impacts their lives.

Adopting a special needs child requires more information about health or sensory challenges and their treatment history. Adoptive families often begin by taking information about the child's condition to their doctor and by meeting other adoptive parents to hear about their life experiences.

Adding a child with special needs to a family requires realistic and objective decision making. There is no parenting that is easy and without problems. The addition of a child with special needs can intensify the difficulties and problems faced in parenting, but with support it can also be a joyous experience. An informed decision can make the difficult times easier to manage and be the most rewarding and fulfilling decision in the lives of both par-

ents and child. One ND family who adopted a young child with Down syndrome visited with us about their experiences.

"My husband and I were foster parents before adopting. We felt that foster parenting would speed the process and it did because becoming foster parents made us better prospective adoptive parents and qualified us to receive a child right away.

Adoptive parents must complete formal training that helps them learn what to expect. These classes are wonderful. There is a wide range of disabilities that families may encounter in children and even veteran foster parents may not have seen a particular condition in their home.

There is nothing unique about adoptive parents, they are not necessarily stronger or better than any other parents. Some children have very challenging conditions and to think that you can handle anything would be naïve. So the classes helped. However they focused on older children because the chance to adopt a baby with special needs is rare. So when the opportunity to adopt a five-day-old came we felt a little overwhelmed and very lucky.

The Special Needs Adoption Program did give us some training on where to look for help and assistance. We were referred to Infant Development. They gave us books and we sat down with the doctor and asked about a million questions.

Because our child was an infant we got to enjoy the spe-

cial experiences that come with a new baby including getting up at night.

We have not yet told our child about the adoption because we are unsure whether it is time to cross that bridge; would the concept be understood? That is a challenge when your child is both adopted and has a cognitive disability.

We believe that prospective parents really have to go through the adult adoption program. Families need to be prepared for the kids and be open to any "baggage" that comes along with the child. Some children have been through a very difficult time within their birth family. A lot of learning, adjustment and openness to going through that process is needed.

The trend today is to give birth parents who are capable up to a year to get their act together. If that is not done, the child is placed up for adoption much more quickly than they were even 3 years ago. If the birth parents themselves have special needs they may be supported for a longer period of time depending on the age of their child or the level of support available.

Special moments for our family related to adoption involve celebrating not only our child's birthday but also the "gotcha-day," when our child came home from the hospital and the "keep-ya" day when the adoption was finalized. Our child may not fully understand what these words mean but clearly enjoys the special attention and love they convey.

(continued on page 4)

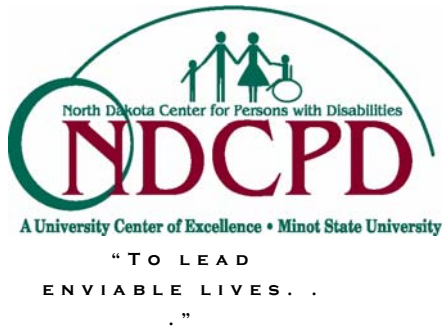


"We celebrate "gotcha-day," when our child came home from the hospital and "keep-ya" day when the adoption was finalized

North Dakota Center for Persons
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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

North Dakota Transition Institute March 8-10th in Bismarck is being hosted by the ND Department of Public Instruction and the ND Center for Persons with Disabilities. Call Val Fischer at 1- (701) 328-2277 to register today.

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 will be held at the Best Western Doublewood Inn in Fargo on June 10th-12th. This is a family-friendly event and will provide opportunities for families to meet face to face with policymakers to discuss family support.

Exceptional Family Members Connections This web site at: www.EFMconnections.org gives military families with special needs access to information on a variety of military, federal and local programs available to families. The site also allows families to exchange information.

Picture Exchange Communication System (PECS) Workshop Bismarck, North Dakota April 29 & 30, 2004: Presented by Anne Hoffman, M.Ed. & Donna Banzhof, M.Ed. Kelly Inn Bismarck 1.3 ASHA CEUS \$375 professional tuition \$235 parent tuition For registration information, visit us online at www.pecs.com or call 888-732-7462.

