



# Leadership

*An Online Newsletter for ND Families Raising Children with Special Needs*

## Family Support Project: Conference Update

What would it take for your family to *disabilities make friends.*

pack their bags and travel to a conference? An opportunity to do just that is coming up this spring. Planners of the **Building New Ties and Enhancing Family Support** Conference are

hoping that you will join other ND families at the Doublewood Best Western, in Fargo on June 10-12. This conference will bring families and professionals together in a way that is fun, informative and too good to miss.

Speakers for the conference are still being recruited but here is a peek at some of the topics and opportunities that are being planned.

- *An opportunity to hear national speakers in early intervention, family support, education, behavior intervention, health care, and transition.*

- *Best practices that child care centers, schools and communities in ND can use to help young people with*



- *Using technology (e.g. providing speech therapy using the Internet) to overcome educational barriers in rural communities.*

- *New opportunities for families to manage or self-direct services.*

- *Involving families in building school-wide programs for positive behavioral support.*

- *Best practice in helping young people with disabilities grow up and make healthy choices for fitness, diet and lifestyle.*

- *Providing early intervention in natural environments.*

- *Round table discussions with the folks responsible for developing family support policies in ND.*

*Best of all the conference will be FREE!*

*For more information contact: Cathy Haarstad at the ND Family Support Project 1-800-233-1737.*

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## Opportunities:NDCPD Consumer Advisory Council

Most families find themselves learning new *parenting* skills as they raise a child with special needs. It can be harder for parents to learn skills in *leadership*. Family members are often kept busy with home and work activities as they struggle to provide the extra support needed by their children.

The North Dakota Center for Persons with Disabilities (NDCPD) offers a unique opportunity for families to build

leadership skills with minimal disruption to family life by inviting families to serve on its Consumer Advisory Committee.

If you have never considered serving on a board or committee before, this opportunity offers special benefits. The committee meets face-to-face about 3-4 times a year. Meetings are held on Saturdays from 10 to 2 PM and families are reimbursed for travel, motel, and meal expenses. Each

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## Leadership Topics : Fitness, Obesity and Kids with Disabilities

Research shows that at an early age, children with Down Syndrome metabolize calories much less efficiently than other people of the same age (Medlin, 2001). For that reason we have always tried to provide our daughter who has Down Syndrome with a healthy diet and lifestyle.

Imagine our surprise when weight control became an issue not for our daughter with Down syndrome but for her older sister who has ADHD and Learning Disabilities. As her sister's previous high activity level and rapid metabolism slowed during adolescence she was left with impulsive eating habits that led to a 40 pound weight gain in one year.

Concerns with fitness and obesity are not limited to families who have children with disabilities. Research indicates that many American children are over-weight. In addition to the current lifestyle of many ND families (i.e. children play more video games, play outdoors less often during winter months and tend to eat more fast foods), families who raise children with special needs often face unique challenges that make it easier for young people with disabilities to put on excess weight, particularly when children face physical or intellectual challenges.

We know that when compared with the general population, people with disabilities:

- Have higher rates of chronic conditions
- Take part less often in wellness activities
- Make fewer healthy choices
- Have less health insurance
- Are less likely to access healthcare when on their own (Mercer 2003).

Research gathered by the Rural Institute in Montana suggests that **poor nutrition may be a risk factor for secondary conditions:**

- Weight problems
- Bladder dysfunction
- Fatigue
- Bowel dysfunction
- Depression
- Stamina problems
- Dental/oral hygiene problems
- Sleep problems/disturbances

In other words lifestyle and dietary challenges can lead to additional problems for children with disabilities over time.

As students with disabilities move into more



Lifestyle Choices

independent living situations, parents have little influence on nutrition, exercise, and health habits. It is critical for families and transition teams to prepare students to make lifestyle choices that will help them meet personal or work goals.

Whether a student plans to move into a supervised setting, college dorm or an apartment, after high school, the student will be responsible for his or her own health and wellness. Success in living on one's own, having the stamina to work or go to school, manage relationships and participation in community life may be jeopardized if a student is unable to get enough sleep, move around freely because of excess weight or suffers from low self esteem or depression linked to an inactive or unhealthy lifestyle.

**Information:** Because many ND families are concerned about diet and health, the n2k website <http://www.ndcpd.org/n2k> has extensive links to practical information that families can use to help research and build a healthy diet for children.

**Lifestyle Change:** Dr. Samuel Klien, MD, from Washington University School of Medicine says that the first thing parents should do is to decrease television viewing and sit-down activities at home. Watching TV, being on the



computer should be limited. Parents should also set up and model increased physical activity with their children. This means going out for walks on a regular basis after dinner, or doing

family activities that increase physical action.

Parents of children with special needs know these steps are important but may find them difficult to do particularly if they are working two jobs or using much of their energy to provide therapy for their child at home or just make ends meet. What solutions are available? What has your family tried? What works or is helpful. If you have ideas or suggestions as a parent or professional please contact: LEADERSHIP 1-800-233-1737 or [haastad@minotstateu.edu](mailto:haastad@minotstateu.edu) and share your thoughts for strategies that help young people stay fit.

“ As students with disabilities move into more independent living situations, parents have little influence on nutrition, exercise, and health habits

## Partners: The Arc, Upper Valley

**The Arc, Upper Valley (AUV)** offices located in Grand Forks, is a member-run organization whose mission is *to improve the quality of life for children and adults with cognitive, intellectual and related developmental disabilities through education and advocacy*. Like other Arc chapters in ND the AUV is affiliated with the Arc of the United States and has access to national resources and information.

**Why belong?** There are several reasons for joining the AUV. Look at the many advocacy and training opportunities the AUV provides to get a sense of who they are and what they offer. The AUV:

1. Is a volunteer organization run by families with opportunities to participate in leadership roles by serving on boards or committees or helping with local fund raising or service activities.
2. Is associated with the Arc of the United States with access to informational resources and a 50 year history of organized grass-roots advocacy that has successfully opened schools and communities to people with disabilities.
3. Offers opportunities to meet other families by working together on projects or through referral to other agencies.
4. Teaches families to speak up for individuals who may not be able to

articulate their needs to policymakers.

5. Presents the united voice of many families when advocating for system change rather than a single voice which is easily ignored.

6. Offers services designed to meet the unique needs of families

- An informational website [www.thearcuppervalley.com](http://www.thearcuppervalley.com)
- A family resource guide – that lists the benefits, supports, services for ND families.
- Public awareness events that promote a positive view of people with DD (local buddy walk).
- An annual state-wide conference on family support.
- A support group for mothers with intellectual disabilities.
- A Legislative Forum and Legislative Action Center that provides families with key information on legislative issues.
- Sib-shops – a program for the brothers and sister (ages 7-12) of children with disabilities.
- An awareness essay contest for 5th grade classrooms called Circle of Friends.
- Family education workshops. For example: GOOD Grief – Why do I feel so angry, sad, mad?
- Referrals for families who seek

help with the IEP process

7. Provides information and training resources that address the needs of individual across the lifespan in a one-stop model as your child ages.

8. Is committed to ongoing advocacy to support inclusion and continuation of home and community based services through ND. **System change** that the AUV has helped to bring about in ND includes.

- A class-action lawsuit that resulted in the development of home & community based services through ND and closed or reduced programs at institutions in San Haven or Grafton.
- Increased wages for direct service professionals during a period of extreme fiscal restraint.
- Legislation for a Supplemental Needs Trust to help ND families with financial planning.

The AUV is funded through membership donations as well as income from a local thrift shop and local donations. Annual membership dues are \$25.00 for a family. New AUV initiatives include:

- A task force working with the Aging Caregiver Project in the area of future planning.
- Physical and spiritual inclusion of persons with disabilities for faith based communities.

**For more information please call 1 (877) 250-2022.**

## NDCPD Leadership Opportunity — *continued from page 1*

participating member receives a stipend that they may use to cover costs related to time and child care. Members with disabilities who need personal care assistance also receive compensation for caregivers who travel with them. NDCPD provides materials in alternate formats and assists families to coordinate services.

What do members of a consumer advisory council do? Families bring their unique perspective to NDCPD grant activities. NDCPD is a University Center of Excellence at Minot State University in teaching, research and

service. Through the Consumer Advisory Committee families may:

- View or try out the latest technology or best practice materials developed at the center.
- Meet people with disabilities who are employed and successful in living outside of institutional settings.
- Recommend a line of research or service to benefit families in ND.
- Share stories about what kinds of solutions or strategies work best for your family.
- Identify areas of unmet need in ND.
- Help with grant writing, editing or

development if interested.

- Become familiar with support services and systems across ND.
- Receive leadership training in serving on a board or committee.
- Receive newsletters and updates on NDCPD projects.

Families who are interested in this leadership opportunity may contact NDCPD at 1-800-233-1737 toll free and ask to speak with the Consumer Liaison for an application. Selection is made by the executive director after peer review by the recruitment committee.

## Policies—House & Senate versions of IDEA

Groups across the US have bombarded families with information about possible changes to the special education law—IDEA. Most articles try to tell families *what to think* (e.g. the changes are bad) and *what to do* (i.e. it's a crisis, write your Congressman). Families benefit when articles outline what changes are proposed, how they may impact a child/family and encourage families to think for themselves.

According to a schedule published by Senate Majority Leader Bill Frist (R.TN), the Senate bill reauthorizing IDEA (S.1248) will be considered by the full Senate in March. Under a unanimous agreement, both parties have agreed to offer four amendments. The Republican amendments limits attorney fees for parents and reduces the "paperwork burden" on teachers. The Democrats' amendments focuses on full funding and homeless children. Each side also has reserved an "unspecified" amendment.

If the bill is passed by the Senate, it will go to a conference committee made up of members of the House and Senate to resolve the differences. Changes in the House and Senate versions that may have some impact on kids in ND include:

### 1. Focus on preparing students for further education:

Special education may be redefined as "services deigned to meet children's unique needs and prepare them for

employment, *further education*, independent living; further education is new language.

### 2. Requires special education teachers to be skilled:

The law would require special education teachers to be highly certified in teaching the elementary curriculum or pass a rigorous test or have an academic major in the content area they teach at a middle or high school level.

### 3. More minority teachers will be recruited:

Because 1/3 persons in the US are a member of a minority group or have limited English proficiency, greater attempts to recruit special ed. teachers from minority groups will begin.

### 4. Special education may reach more students:

May include children ages 3-9 who have developmental delays in only 1 area (physical, cognitive, communication, social or emotional or adaptive development); and who because of the delay need special education.

### 5. Families may receive new related services:

The senate bill adds interpreting services, school health services and travel training to related services.

### 6. Transition services may be strengthened:

Transition services are newly defined as a *results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities*, including post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

**See next months article for more details.**

" Families skim over the articles, trying to read around the hype and remembering very little "

## Family Stories — continued from page 5

*Well, we think it's important to:*

- *Rely on family and friends as much as you can.*
- *Have at least one friend who really knows your community—what is going on, where to tap into different resources. They don't need to have a child with a disability—just be well connected.*
- *Keep your ear to the ground yourself and look for new opportunities.*
- *Find a good pediatrician. Our doctor spends a lot of time communicating with specialists for us and that saves us long trips to other cities.*

- *Don't be afraid to try a disability clinic even if you already have doctors working with your child. You can go to all or some of the stations and see only the health care specialists that you need.*
- *Learn to get on the phone and ask questions.*
- *Take one day at a time. Give yourself the time to do that.*

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](mailto:haarstad@minotstateu.edu)



## Family Stories: Building a Circle of Support

You may have heard the phrase *it takes a village to raise a child*. If this is true, it means that grandparents, siblings, relatives, neighbors, friends, teachers, and community leaders all play some part in helping young people grow up and take their place in the circle of life.

When a young person has significant physical and intellectual challenges, their world and that of their parents can narrow to a never ending round of personal care, therapy, and health-care visits.

Every family takes a slightly different path in their attempts to widen their child's horizons and create a supportive routine (working, playing, learning and caring for one another) that lies at the center of family life. Families try to take what is an atypical experience and manage events so that the stress of coping with what is different or difficult is relieved by experiences that are fun-filled, relaxing and every-day.

One family, recently shared challenges they face in raising their son Harkin, an 8 year old boy who has cerebral palsy, seizures and intellectual disabilities. I asked Becky to comment on some of the issues and success they had experienced in building a support network for their family.

**Balance: How do you keep from being overwhelmed by the challenges of meeting Harkin's day-to-day needs?** *For us, balance means support not only with the physical challenge of lifting our son in and out of the tub or car but meeting the mental challenge that goes along with constant problem solving and an unclear future. We create balance by giving one another time, because we have often do the work of parenting together. It takes both of us to provide some of our son's physical care (he has gotten*

*so big); it is easy to get on one another's nerves. So we each take one night a week alone so that Todd can bowl with the guys and I can play basketball or golf with the gals. We also try to get out as a couple once a week. That is important, time together without parenting, just being a man and woman.*

**Support: What are some of the services available in your community that have helped you meet Harkin's needs?**

*Well the respite care we get every month that allows us to get out of town for an occasional weekend. It's not a lot of hours, there have been lots of cuts, but we feel we are getting as much as anyone. We get tired of asking friends to take Harkin or waiting for them to ask. If we lived closer to family we could maybe say, I need a break, you've got to take my kid. Respite is essential. Sometimes we think about moving closer to family but our jobs and all of our friends are here.*

*The Community Learning Center has been great. At first they seemed a little uncertain about taking Harkin after school but now he rides the bus and they have found the extra staff to help him. This is one of his only opportunities to be with kids who do not have disabilities and feel like one of the gang. That is really important for Harkin and for us. The kids have lots of questions "Why doesn't he, why can't he... why is he ... and we welcome that."*

**Family-to-family: Have you sought out other families? Would it be helpful to meet other families whose children face similar challenges?** *Well, sought out, no. I guess I would never turn anyone away, I would talk with another family if they wanted to visit but I guess I haven't gone looking for that. Maybe because I work with people who have disabilities and need to keep some balance or maybe because I am afraid it would open up issues that I am not ready to face right now.*

**Every Day Experiences: What are some of the every-day experiences that you have been able to give Harkin or enjoy as a family that are important to you?** *Oh wow, there are so many. Michelle Bliven organized an opportunity for kids with disabilities to play T-ball last summer. She had so many volunteers helping that we got to just sit in the stands and be parents and his grandparents could come and see him play. We go camping with friends and ice-fishing and Harkin loves that. We golf a lot, we even got him his own golf cart because otherwise we had to rent one every week and that got expensive. It's a lot of work to take him places but it's worth it. We go out to eat, it's important for Harkin to know how to act in a restaurant. And the people who provide respite care, it's more like they've adopted Harkin into their family, not just taking him for the evening. He goes with them to the mall or to their children's dances and that's the way we want it.*

**What are some of the strategies every family needs to have to learn to build a generic circle of support.**



*"We got to just sit in the stands and be parents, and his grandparents could come and see him play."*

(Continued page 4—Family Stories)

North Dakota Center for Persons  
with Disabilities

Cathy Haarstad  
LEADERSHIP  
Minot State University  
500 University Avenue W.  
Minot, ND 58707

Fax: 701-858-3483  
Email: haarstad@minotstateu.edu



“TO LEAD ENVIABLE  
LIVES. . .”

**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

IDEA is on the schedule to be reviewed by the Senate in March, 2004.

ND Children up to 21 years of age are limited from co-pays under Medicaid.



Both the Senate and the House of Representatives have passed bills to reauthorize the Workforce Investment Act (WIA). The WIA authorizes all federal job training programs including programs and services for individuals with disabilities. The bills will now go to a conference committee.

The ND Collaborative Conference — Building New Ties and Enhancing Family Support will be held June 10-12th at the Doublewood in Fargo. Call 1-800-233-1737 for more information.

Basic Emergency Lifesaving Skills in Schools provide training for teaching safety skills (CPR/First Aid) to adolescents in schools. Training will be offered in ND this winter as follows at upcoming BELSS workshops:

Fargo, N.D.                      January 26 - 27, 2004  
Holiday Inn

Rugby, N.D.                      April 5 - 6, 2004

COST: \$50.00 per person or

\$40.00 per person for a team of three or more participants representing the same school district (Registrations must be sent together).

Call Howard Walth at (701) 328-2953 for more information.