



Leadership

1-13-03 # 4



Leadership: Leadership is a weekly newsletter for ND families. Leadership is prepared by staff from the ND Center for Persons with Disabilities at Minot State University. If you are interested in receiving a copy, contact Cathy Haarstad at haarstad@minotstateu.edu with your email address.

Leadership Teams: Leadership teams in each region are responsible for sharing information on accessing systems and system change with other families. The Team in Fargo is meeting this week to begin planning. Has your team met? Several questions have come into the ND Family Support Projects about hosting a local presentation. Here are some typical questions and answers.

1. How much money is available for presenters and team members?

Each team may access up to \$800 for presenters. A presenter is a member of the leadership team and/or any local presenters who are invited to speak to the group. Generally this money is accessed in the form of \$100 stipends.

2. How much money is available for families who attend the local training?

Teams may provide up to 25 families with \$50.00 stipends to cover costs related to attending. Costs include travel, day care, time, meals etc. up to a \$50.00 total per family. Funds need not be provided to families who have little costs and may be combined for families that have excess costs as long as prior approved in writing from the project director. For example: Let's say a team recruits families and 20 families decided to attend. Families from rural communities have to drive over 50 miles to and from the presentation. A few have to stay overnight. Those families have more costs than the family that lives two blocks away from the center where the training is held. Teams may want to offer one family two stipends and another family may not need a stipend or may only need \$10.00 for child care.

3. Are funds available to cover other costs?

Yes, each team may occur (again after written approval is provided by the project director) up to \$250 for brochures, handouts, and mailing.

4. How will our team access the funds?

Complete a community assessment (only one), a written plan, and a request for funding and forward to:

Cathy Haarstad, Project Director
500 University Avenue W.
Minot, ND 58707

Once your plan is approved, the project director will discuss with your team leader which costs are acceptable, which items will be completed by P & A (i.e. P & A may print a requested number of handouts or brochures that you designed and send them back to you).

If you have other questions, send them via email to Cathy Haarstad at: haarstad@minotstateu.edu or call her at 1-800-233-1737. Cathy can let families know who the team leader for their region may be.

Legislative News: A copy of the most recent list of bills that will be discussed in the house and senate can be obtained through your legislative working group. Why not go to an upcoming meeting? Please contact:

Williston	Janelle Olson, P&A jfolson@state.nd.us
Minot	Laurie Davis, Independence life@minot.ndak.net
Grand Forks	Petra Clemens, Options petraclemens@yahoo.com
Fargo	Chuck Stebbins Freedom CIL guthrie@fargocity.com
Jamestown	Donene Feist, Family Voices & Freedom DCIL feist@daktel.com
Bismarck	Kathy Schmit ndpooh45@hotmail.com
Dickinson	Nancy Klatt, Dakota CIL klatt@ndsupernet.com dcil@ndsupernet.com

Human Services: In our last newsletter, we reported that: **The Governor's budget recommends that a *qualified individual provider* option in addition to DD licensed providers be added to provide Family Support Services and ISLA.** We indicated it would be important for families to become familiar with the standards for a qualified individual provider and to learn how those standards differ from standards that current service providers must meet. Currently the ND Department of Human Services – DD Division has not finalized what those standards will be. They hope to give as much flexibility to families and possible and still assure that people with disabilities receive quality services. If you are interested in this policy, we suggest that you contact your regional human service center and ask to be involved in any subcommittee's or groups that discuss this issue at the state or local level.

The Arc, of North Dakota Another excellent resource for information about legislation can be found at the **Arc Legislative Action Center**. How Do I Find the Legislative Action

Center? On the Internet, go to: www.thearcuppervalley.com Click on: Legislative Action Center. What does this center offer?

- **Find Your Legislators** – Enter your zip code, and you will receive information about the elected officials that represent your area. Provides biographical and contact information
- **Write Your Legislators** – Let's you communicate with elected officials via e-mail.
- **Guide to the Media** – Enter your zip code and find media organizations in your area.
- **Issues and Legislation** – Action Alerts from The Arc of North Dakota and The Arc of the United States will be posted here.
- **Guide to the Federal Legislature** – Offers access to the Arc of the United States Federal Legislative Action Center.
- **Action E-List** – Sign-up for the Action E-List and receive your Action Alerts from The Arc of North Dakota and The Arc of the United States immediately.

The Arc of North Dakota has long advocated for families and persons with intellectual disabilities. A list of legislative action that the Arc of North Dakota supports is listed below. If you would like more information about these topics we suggest that you check out the website at: www.thearcuppervalley.com

The Arc of North Dakota
Public Policy Platform
2003/2005 Biennium

Home and Community Based Services and Supports

We will continue to work to increase funding for Individualized Supported Living Arrangements (ISLA), personal assistance and other supported living options needed to decrease the excessive use of 7-15 or more person residential living arrangements.

We will continue to work to ensure that a high level of quality assurance is put into place for home and community-based services and supports.

We will support efforts in making the necessary changes to the DD funding system to eliminate barriers to providing quality services and supports.

We will work to ensure funding streams follow people and that sufficient funds are provided for ongoing services and supports.

We will work for better utilization of federal funds for Medicaid, Medicaid Waivers and Vocational Rehabilitation.

We will continue to support efforts to increase the average wage, fringe benefits and training for community residential and day service workers.

We will support efforts to increase funding to support jobs for people with developmental disabilities.

We will support the Medicaid Buy-In plan. The plan proposes the Medicaid income eligibility level for people with disabilities be raised to about \$22,000 a year (250% of the federal poverty level). People with disabilities could enroll in Medicaid Buy-In by paying a pro-rated premium that will not exceed 7.5% of their gross income.

Family Support Services

We will continue to work to increase funding for Family Support Services.

We will support the Supplemental Needs Trusts bill as approved and recommended to the Legislative Council by the Judiciary B Committee.

We will continue to support efforts to increase the income eligibility criteria under the Healthy Steps program.

Guardianship Services

We will support efforts to increase the current rate of reimbursement for each ward from \$3.20 per day to \$3.97 per day for guardianship services.

Olmstead Supreme Court decision

We will work with the State on implementing its report as a result of the Olmstead decision, North Dakota's Comprehensive Plan for Community Integration and Support of Persons with Disabilities.

We will support efforts to obtain funding to ensure that persons currently residing in State residential centers who can be more appropriately served in the community receive quality transition and community services and supports. Funding streams should follow people from state residential centers to community services and supports. Adopted by The Arc of North Dakota on 9/28/02

North Dakota Families: Families want programs and services that are practical, helpful and easy to use and understand. Families want their children to receive a free and appropriate public education. What is the impact in ND when

legislation to fund education or family support services is passed? How many families are really impacted? **How Many ND Families Have Children with Special Needs?** There is currently no single data source that would provide an accurate response to this question. Based on a statistical report from the Department of Public Instruction, 27,835 students with special needs received special education services in North Dakota from July 1, 2001 through June 30 2002.

Ages	Number of students receiving services
3-5	2,990
6-11	11,790
12-17	11,023
18-21	2,032

Because some families may have more than one student with special needs it is impossible to obtain an accurate count of the number of ND families with students who qualify for special education. These figures also do not include students who may have a disability not recognized under IDEA but who qualify for a 504 plan under the Rehabilitation Act. It does not include students who are living on Indian Reservations in North Dakota and receive their education from schools funded solely by the Bureau of Indian Affairs (Tribal Grant Schools). The Department of Human Services keeps a separate count of individuals (children and adults) who are eligible for DD services. Unfortunately it is impossible to compare the numbers because North Dakota has no common system of counting individuals served through these two programs. DPI has not wanted to use the social security number for individuals because of the growing risk related to identity theft and new laws passed which require government agencies to protect confidentiality. Currently both departments are working on a system that would protect information about families and allow stakeholders to have one unduplicated count for planning purposes.

IMPACT Just for a moment consider the number of students receiving special education services in North Dakota that was provided by the Department of Public Instruction. We can assume that most students with special needs have at least one parent or grandparent (although a few may not). Some students have two, not to mention brothers and sister, and relatives. Then consider those of us who will someday be the landlord, employers or neighbor of a person with a disability. When legislation is looked at in this manner we realize that any decisions made impact lots and lots of people in each community both immediately and in the future.

Before You Decide: Staff from the Family Support Project are collecting brief statements or stories about topics that families want legislators to be aware of before making decides on important legislation. The topics are:

1. Heroes
2. Families
3. Connections

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| 4. Education | 5. Health Care | 6. Budgets |
| 7. Family Support | 8. Taxpayers | 9. Vision |

Each week a short paragraph about the topic will appear in this newsletter. THIS WEEK'S TOPIC IS still EDUCATION because we did not receive enough input last week. Please take a few minutes to jot down your thoughts and forward them to reply to the newsletter or send an email to Cathy Haarstad at haarstad@minotstateu.edu

Education: Children with special needs are entitled to receive a free and appropriate public education in the least restrictive educational alternative under federal (P>L> 94-142 as amended, 20 USC 1401 et seq.) and state law. Most families want their children to be educated in neighborhood schools with their brothers and sisters and friends. They want the educators in that setting to set high standards, to provide learning experiences that are individualized and effective, to provide activities that are meaningful and lead their child to make adequate yearly progress. Furthermore the law requires that related services such as therapy, transportation and after school activities needed for the child to benefit from special education be in place. Families do not want this education to be something that they have to constantly secure (a sometimes full time job) but a service that is typically present through adequate funding and training and recruitment of qualified personnel.

Example: Our daughter is 12 years old. We are blessed by having educators spend time with her every day and teach her many skills that she may use in the future. When we look at her progress, we hope that it is based on more than maturation but on systematic and well planned activities and resources, delivered in a timely and effective manner to help her achieve her true potential. We believe that conflict is inevitable and not necessarily bad, arising out of circumstances that require her team to ask the tough questions. We worry about whether the teachers she needs in her life will continue in the field and be there for her in the future.

Leadership Links: If you are interested in new information on leadership, try one of the following web-sites.

One of the biggest issues for families of children with special needs living in remote rural communities is TRANSPORTATION. If you are interested in learning more about funding for rural transportation, check out this website. You will need an Adobe Acrobat Reader to open the file.

<http://www.ctaa.org/pdfs/informationstation.pdf>

As our children grow, we begin to understand and teach them about their rights. This process involves a letting go, a leading forward, and a walking with process that takes several years. Are you looking for simple information that explains

rights to young people with disabilities in a way that makes sense? Try this website at the National Center on Self Determination:

<http://cdrc.ohsu.edu/selfdetermination/>