



Leadership: is an online newsletter for ND families prepared by the ND Center for Persons with Disabilities (NDCPD) at Minot State University. If you want to get a copy, send your email address to Cathy Haarstad at haarstad@minotstateu.edu

Leadership Teams: To join a leadership team in your region, call Cathy at 1- 800-233-1737.

As leadership teams submit request for funding be sure to:

- Include the name and address for any business that you may need a service from (i.e. radio station, school, etc.
- An invoice showing that a service has been arranged

Remember to obtain approval for purchasing the service before the date of the training if you wish to be reimbursed.

Taking these simple steps will make it possible for us to spend the money wisely.

Legislative News: Before the senate adjourned on Thursday, they took several steps to reduce or change the governor’s budget. Here is a partial list.

Action Taken	What it may mean for families
Passed Medicaid buy-in	Adults with disabilities will be able to work and retain health care benefits.
Retained family support	Essential services will continue
Retained family subsidy	Essential services will continue and early intervention services will continue
Restored dental services	People accessing Medicaid will have dental coverage.
Passed SB 2025 to cover the short fall	Families should not see immediate and dramatic changes in services because the department will have money to finish the biennium.
Passed “money follows the person”	
Removed salary increases for Human Service Centers	Case managers and administrators will be asked to do more with less

Removed funds for Developmental Center (1 million)	Cuts in salaries, staff and services to individuals who are enrolled.
Approved budget increase for corporate guardianship	People with disabilities will have access to guardianship services when needed
Removed operating funds from Human Service Centers	Centers may lose case managers and those remaining will have larger case loads with less time for individual attention.
Restored funding for special needs adoptions	When families are unable to raise and support a child with special needs, funds to secure an appropriate adoption will be available.
Increase salaries for disability service providers (at a time when many others will have no increase at all)	Although not everything they wanted, it will help provider efforts to recruit staff for adult and family services.

The legislature is now experiencing a short recess before crossover begins. At crossover, all bills that passed in the Senate go to the House for consideration and all bills passed in the House go to the Senate. Bills that were defeated are basically dead unless they are resurrected as an amendment to another bill. It takes a lot of political power for this to happen.

Just because a bill passes in the Senate does not mean it will succeed in the House or visa-versa. In fact the need for continued efforts is critical as any group who dislikes a particular bill will be fighting to see it get a DO NOT PASS in the opposite legislative body. Note that the Dept. of Human Services will be giving its overview to the House Appropriations Committee on Wednesday of next week. We will keep you advised of opportunities to testify on specific parts of the budget and know that you can testify on any bill during any open hearing.

A longer description of these and other actions taken by the senate may be obtained through your Legislative Working Group.

The ND Disability Advocacy Consortium is emerging as a strong new player in legislative affairs because they

- Supported legislation that offered solutions in tough economic times
- Provided excellent data and research to back up claims
- Used effective arguments in presenting their case
- Implemented a grass roots effort to share the work of testimony
- Are maintaining energy and focus throughout the session
- Shared information quickly with constituents
- Gained credibility by representing over 31 advocacy and service organizations

About Families and Medicaid: Some North Dakota families feel a sense of stigma in applying for programs that are funded through Medicaid (in the case of Family Support). As leaders it is important to be informed about these programs, their source of funding and the rights of families to family support. Consider the following information about two typical beliefs held by families who are raising children with special needs when making decisions or sharing information about other families.

Belief: The state of North Dakota by law must have a balanced budget. Families will just have to accept this reality and do without some services.

Fact: Balancing the budget does not have to be done on the backs of families of children with disabilities. The biggest percentage of cost in human services does not come from supporting families. Many family support services allow families to work and continue to contribute to the tax base. The economic impact of limiting services would be severe.

Many families have enjoyed and appreciate an array of support services. Out-migration and an aging population are a growing threat to the tax base that has traditionally supported those services. As the population shrinks, there are fewer young families paying taxes. At some point essential services will be threatened unless appropriate measures in economic development, fiscal prudence, taxation and service design/delivery are taken.

However to suggest that a loss of critical services is inevitable is to believe that families have no choice and no voice. Families are represented in the legislature by several advocacy groups including: The Arc of ND, The Federation of Families for Children's Mental Health, The ND Disability Advocacy Consortium, The ND Protection and Advocacy Project, Family Voices, The ND Association of Mental Health and others. Families are also involved in the decision making process used by the Departments of Health, Public Instruction and of Human Services at several levels.

What ND families do not have but may need is:

- A written list of outcomes that have been identified by families across ND as critical to the job of raising children with special needs.
- A right to family supports and services equal to the rights of children with special needs to a free and appropriate education. (Right now, family support and family subsidy as well as early intervention are only options).
- Comprehensive data indicating the extent to which rights and outcomes are met or present (Data is random and does not always match specific outcomes for families or tell the story)
- A unified system of gathering input from families about their satisfaction with outcomes, supports and services with feedback as to the results.

- A policy analysis of the family support practices in North Dakota sufficient to position families to effectively proposed changes in current services.
- A routine, comprehensive and family-friendly system of soliciting input on local, state and Federal decisions that may impact families.
- A single unified legislative agenda on issues of importance to families of children with special needs. (Families needs are represented among several diverse agendas put forth by separate groups. Many families are unaware of their success and the issues these groups have supported).

Families have pieces of the picture but not all the pieces we need for vision, planning and leadership to impact the choices we may be offered. We have voice but the voices are sometimes fragmented and only advisory in nature. Most families are pre-occupied with the day to day reality of raising their children and earning a living and unaware of the forces and political decisions that have or will impact the services they need.

States and Medicaid While we in ND have been preoccupied with the legislative agendas at the state level, the Federal government has been doing some reorganizing at several levels and two important issues have surfaced:

1. New design options for Home and Community Based Waivers.
2. Changes in funding Medicaid that will merge numerous individual programs into single block grants.

During the next several issues of LEADERSHIP, we will cover what those options and changes may be and what their impact might be on families in ND.

Where Does the Money Go? This piece of testimony from Carol Olson Director of the ND Department of Human Services is an interesting look at how tax dollars are spent at the ND DHS.

- 26 cents on every dollar goes to pay medical services.
- 21 cents on every dollar goes to pay nursing homes.
- 21 cents on every dollar pays for services and benefits for clients of such programs as TANF, Food Stamps, and Fuel Assistance, and for services purchased on behalf of Vocational Rehabilitation clients, children in the child welfare system, and non-Medicaid services for people with developmental disabilities.
- 12 cents on every dollar pays providers of services for people with developmental disabilities that are funded through Medicaid.
- 7 cents on every dollar funds the entire operation of the eight regional human service centers.
- 6 cents on every dollar funds the two institutions – the State Hospital, the Developmental Center, and

- 3 cents on every dollar funds all long-term care outside of nursing homes, to include SPED, Expanded SPED, the Medicaid Waivered Services, and Basic Care.
- This leaves 4 cents, which is divided among: technology costs for all of the department's programs (2 cents), o program management (1 cent), and administration (1 cent).

Leadership Links: If you are interested in new information as leaders, try one of the following web sites.

Transportation is often a major concern for families of children with special needs. You may want to check out Project Action – Easter Seals which has vital information about accessible vehicles and other transportation issues.

<http://www.projectaction.org/>

The history and course of changes in disability policy is hard to follow. Cornell University has developed a wonderful new website that offers a guided tour of current disability policies in the US. It also has a quick reference guide that is very useful as well. These are two excellent resources to add to your tool box and ones that you may use over and over again.

http://www.ilr.cornell.edu/ped/il/Independence/pol_choice.htm