



Leadership



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 due date for teams to provide follow-up training for families on modules in the Leadership in Accessing Systems and System Change curriculum is April 18, 2003. So far at least four of our teams:

- ° Bismarck
- ° Linton
- ° Minot
- ° Grand Forks

Have active plans under way. I will be calling each of the teams within the next two weeks and hope to hear exciting news in future letters.

Legislative News: To keep up on information about legislative bills you may want to check out this ND website designed for the DD Council by the ND Center for Persons with Disabilities and updated by Tom Wallner. To access the site, go to this address: <http://www.ndcd.org/ndcpd/legislation/>

The Department of Human Services (DHS) submitted a budget to the Governor's Office at 95 % capacity as required. The Governor then announced his budget in mid-December. You may be wondering what was in the Governor's budget and how that would impact families of children with special needs. The table below shows the totals appropriated during the last legislative session and the amount in the governor's proposed budget for three critical programs.

	01-03 Appropriation	03-05 Governor's Recommended Budget
Family Subsidy	\$1,881,548 (Total) \$ 200,000 (Part C) \$1,681,548 (State)	\$1,792,256 (Total) \$ 200,000 (Part C) \$1,592,256 (State)
Family Support Services	\$5,481,694 (Total) \$3,298,913 (Fed) \$2,182,781 (State)	\$7,483,516 (Total) \$5,086,116 (Fed) \$2,397,400 (State)
Infant Development	\$3,555,872 (Total) \$1,236,208 (Fed) 2,319,664 (State)	\$ 3,926,612 (Total) \$ 520,513 (Part C) \$ 1,874,746 (Fed) 1,531,210 (State)

Totals	\$10,919,114	\$13,202,384
--------	--------------	--------------

This information was provided by the finance office through the DHS.

What does this mean for families?

1. The Governor's budget shows **an increase in spending on three critical programs** over the amount budgeted during the last biennium.
2. Keep in mind that the DHS had a shortfall (not enough money) during this biennium mostly due to changes in the Medicaid formula.
3. **The Governor recommended that the asset disregard under the Home and Community Based Waiver in Medicaid continue.** Within Senate Bill 2074 there is language that states "The Department of Human Services shall provide Medical Assistance benefits to children and family coverage groups and pregnant women without consideration of assets." This means assets would not be considered when determining medical assistance eligibility for the Extended Services, Supported Living, Day Supports and Family Support Services/In-Home Support)
4. The DHS was forced to eliminate Family Subsidy dollars to reach the 95% budget requirements. They asked for those funds to be added back into the budget in an Optional Adjustment Request (OAR). **The OAR for Family Subsidy was accepted and the funds for Family Subsidy were included in the Governor's budget.**
5. If approved by the legislature (no funding for the proposed budget is cut) families who use family subsidy dollars to pay for excess child care costs will continue to be able to do so. Incidentally only 2 of the 48 OARs that were sent to Governor Hoeven were included in his budget. The other OAR approved included funds to pay for extended employment.
6. At this time it appears that the spending levels necessary to meet minimum spending requirements and qualify the state to continue to receive Part C funds (federal) under IDEA were maintained in Governor Hoeven's budget. Part C funds pay for much of the early intervention services in the state of ND.

More Information about the Governor's Budget: The DHS asked that a \$1.50 an hour wage increase for DD provider staff (\$23,238,354 Total federal and state) be added to the budget and it was **NOT** added. The budget calls for only a 2.3% inflationary increase for DD providers each year of the biennium \$5,796,549 (total federal and state). **This means that it will remain very difficult for providers to hire and retain qualified staff.** The availability of

qualified staff on a continuous basis may impact the services and quality of life that young people with DD who need lifelong support experience.

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. That means that an individual (family member or private citizen) who meets DHS requirements as a “qualified individual provider” can be paid by the DHS to provide Family Support or Independent Supported Living Services (ISLA) to a person who is eligible for DD services. The Department of Human Services cannot force any consumer to use a qualified individual provider and it will be entirely up to the consumer or their family whether this option will work for them. Although this will be a new provider option for DD consumers receiving Family Support Services, this option has been offered for some time to consumer of aging services.

This gives families more flexibility especially when living in remote rural settings where providers are not available. It also represents a level of competition for providers that may act to improve services if the standards that both traditional and individual providers are required to meet remain high and equitable (fair). Hopefully details about the requirements for individual providers will be obtained and shared in future newsletters. To remove this option \$943,455 (total federal and state) would need to be restored to the budget for DD licensed providers. More about this in the next letter.

The 03-05 Governor's Budget Recommendation for DD services will **require all consumers to be eligible for Medical Assistance and meet federal requirements regarding level of support, in order for the Department of Human Services to pay for services on their behalf.** The level of support is determined by a Progress Assessment Review (PAR) conducted by DHS case managers. If a consumer does not meet the federal requirements they will need to privately pay for their services. This is an attempt by the state of ND to maximize the number of federal Medicaid dollars they can receive for any state dollars spent. It is important to remember two things:

- This works for all ND families raising children with DD only if the asset requirement for Medicaid eligibility is disregarded.
- ND must continue to have enough slots under the Home and Community Based Waiver for all families who request services.

Remember: THE LEGISLATURE COULD FAIL TO APPROVE OR MAY DECIDE TO CUT ANY OF THE BUDGETED FUNDS DURING THIS SESSION. The ND Legislature will be reviewing the full budget for the Department of Human Services next week. The schedule is listed below. Several families from FSP are interested in giving testimony. If you are interested in testifying on the benefits of

family support or family subsidy dollars or other issues related to families or children's mental health or special health care services, let me know.

Tuesday – Jan. 14th:

8:30 Introduction & Overview
9:30 Executive Office, Managerial Support
10:00 Subdivision 1 – Management: Information Management Division
11:00 Subdivision 2 – Economic Assistance: Economic Assistance Policy
2:30 Subdivision 2 – Economic Assistance: Child Support

Wednesday – Jan. 15th:

8:30 Subdivision 2 – Economic Assistance: Medical Services
10:30 Subdivision 3 – Program & Policy: DD Council
11:00 Subdivision 3 – Program & Policy: Aging Services
2:30 Subdivision 3 – Program & Policy: Children & Family Services
3:30 Subdivision 3 – Program & Policy: Mental Health & Substance Abuse

Thursday – Jan. 16th:

8:30 Subdivision 3 – Program & Policy: Disability Services
10:00 Subdivision 4 – Field Services: State Hospital
11:00 Subdivision 4 – Field Services: Developmental Center
2:00 Subdivision 4 – Field Services: Human Services Centers

Advocacy: The ND Disability Advocacy Consortium (NDDAC) is a 25 member consortium of advocacy groups that advocate for programs and services that benefits people with disabilities. Two important efforts that have received support from the NDDAC include:

- Working with the governor's office to divert funds from the long term care association to home and community based services and
- Supporting a ways for people with disabilities to buy into Medicaid

The **NDDAC Task Force for Children and Youth** supports the following initiatives:

- Fully fund IDEA to assure that all eligible students receive quality services.
- Fund early screening and diagnosis including newborn hearing and metabolic screenings, vision, developmental and mental health screenings.
- Fund early intervention/programs for children with special health care needs to the minimum amount needed to capitalize on federal matching dollars.
- Adopt necessary measures to assure that children who need them receive private and public health insurance coverage for the purchase of special communication devices and other durable medical equipment.

- Fund a State Children’s Health Insurance Program at \$185% of the Federal Poverty Level with the SCHIP program administered as a Medicaid expansion due to the rising cost of insurance premiums.
- Continue the disregard of the asset test so that family support funded through Medicaid is available to all children with special needs who qualify for services.
- Fund mental health programs for children so that mental health parity is achieved for children with both developmental and mental health needs.
- Fund enhanced transition services for youth before they graduate, through schools and Vocational Rehabilitation and for Independent Living Centers to assure a smooth transition into adulthood.

If you would like to serve on the Task Force for Children and Youth or learn more about its work, contact Donene Feist at (493) 233-2634.

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 decisions on important legislation. The topics are:

- | | | |
|-------------------|----------------|----------------|
| 1. Heroes | 2. Families | 3. Connections |
| 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 **EDUCATION**.

Please take 10 minutes to sit down and comment on the topic. It is not necessary to write out a full story. Just a few minutes each week will help the project collect the information it needs. To submit comments, just 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.

The Council on Quality and Leadership: <http://www.thecouncil.org/>

The Council creates opportunities for people to lead the lives they choose and to improve the quality of services/support for people with disabilities/mental illness.

Rural Civic Leadership by People with Disabilities:
<http://rtc.ruralinstitute.umn.edu/RuEcD/RuCmtLeadership.htm>

Rural Americans with disabilities and those who serve them experience problems with access to transportation and housing, employment and self-employment, independent living services, health and wellness facilities, and inclusion in community planning and activities. RTC's goal is to use scientific methods to develop solutions to these wide-ranging problems.

The ND IDEA Advisory Committee:
<http://www.dpi.state.nd.us/speced/idea/index.shtml>

The purpose of the Advisory Committee to make recommendations and to advise the Department of Public Instruction concerning the administration of, preparation of general regulations for, and evaluation of Special Education programs in ND.

Shaping Our Destiny: <http://www.aamr.org/ShapingOurDestiny/index.shtml>

This is a consumer guide that you can download for free. The guide outlines how people with developmental disabilities and their families can advocate for and evaluate quality services. The provider's guide details how service providers can provide quality supports that keep consumers' needs a priority.

