



## Leadership

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**Leadership:** Leadership is a weekly newsletter for ND families. *Leadership* is prepared by staff from the ND Center for Persons with Disabilities (NDCPD) at Minot State University. If you are interested in receiving a copy, contact Cathy Haarstad at [haarstad@minotstateu.edu](mailto: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. If you want to contact the leadership team in your region, email Cathy Haarstad at NDCPD. Bismarck, Minot, Grand Forks, Linton, and Fargo all have active teams planning local training on Leadership.

**Legislative News:** Most of our lives are busy. Those of us who are raising children with special needs are often busy and overwhelmed. Two notes recently came across my desk from a leader of the legislative working groups across North Dakota. They were:

The formal hearing for the Dept of Human Services budget - SB 2012 are over. The sub-committee will begin to make shifts, allocations, and changes next week. Any support of Home and Community Based Services would certainly be helpful. Contact your Senator with that simple message.

This week, people testified in support of increasing the Children's Health Insurance Program (SCHIP) funding from 100% to 200% of the poverty level (HB 1463). The bill received a do not pass on a 7 to 6 vote according to the sponsor - Rep. Niemeier. Support was quite light. Other than the bills' sponsors, only I and two others gave testimony in favor. No one spoke against.

The person who sent these messages is wise enough to know that unless families let their senators or representatives know how they want them to vote on a specific bill then the message that a certain resource is needed by YOUR FAMILY or A NEIGHBOR or FRIEND will be easy to ignore.

As a parent and citizen I understand the need to do this. As a busy, hectic mom whose child requires a lot of additional attention, I have difficulty carving out the time. I have asked myself how long it would take for me to communicate in writing with my senators or representatives by email or letter. Probably 30

minutes to sit down, get the addresses, compose a message or letter and send it electronically and mail it.

Now 30 minutes is not a lot of time until I try to squeeze it out of an already full day. That becomes harder because I don't always have 30 minutes that fall together when I am both free of other demands AND organized. On the other hand, I know I will find time to watch TV for a half hour sometime this week. And if I can with a simple note, say something that makes a difference for our family and others that would be good. So maybe I just need to get organized. Let's see! What information do I need and how long will it REALLY take. Remember 30 minutes is just a guess. I need to decide.

- How do I start the letter?
- How do I address the legislators properly?
- Where do I send it to make sure they get it?
- What format might I use for a letter?
- What should I say in the letter?
- What format might I use for an email message?
- Where do I keep the envelopes and stamps?

I know I can get some help with this from my legislative working group.

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**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: Families who pay taxes and are raising children with disabilities and who choose not to use Medicaid, should not have to support other families who are getting a free ride.**

**Facts:** Families who pay taxes and are raising children with disabilities and who choose not to use Medicaid are not the sole supporters of families on Medicaid. All taxpayers, not just the families who have children with special needs, contribute to Medicaid.

Only a small percentage of tax dollars paid by a family go towards Medicaid and an even smaller amount goes to support families who have children with special needs. Most of the increases in costs for Medicaid which we pay for with our taxes come from rises in the cost of prescription drugs and changes in the formula used to determine how many dollars a state will be allocated.

Families who are eligible to receive Family Support (a Medicaid funded program) because they are raising children with special needs and who choose not to apply for Family Support Services have made a choice. There is a difference between making a choice and demanding that all other families make the same choice so that my decision is easier.

Families with children who have special needs and who are using Medicaid are not getting “a-free-ride”. They have the same challenges that families who are not using Medicaid face. Families using Family support whether they pay taxes (and qualify because the asset test is waived) or whether they have low-income (and may not pay taxes) often contribute to their communities in other ways. They may be the neighbor who watches your child or serves on a committee or shovels the walk.

Many families who access Medicaid and are raising children with special need would buy into Medicaid (pay part of the cost just like an insurance premium) IF THEY COULD.

**Belief: Government run programs are expensive and not cost effective. Families should find other ways to get the support they need.**

**Facts:** Some government run programs are expensive and not cost effective. Others are relatively inexpensive and very cost effective. Using Medicaid dollars

to fund the Family Support Program in North Dakota has proven to be cost effective because:

- Medicaid staff work actively to keep medical providers from charging a high rate for services, something that families are not always able to achieve.
- For every family that signs up for Family Support the state of North Dakota is able to obtain new federal dollars and to free up other state dollars to serve other families. That is one of the reasons that the DHS has recommended that the asset test be waived.
- Many families receive services through Family Support that simply are not available through private health insurance including speech therapy, physical therapy and occupational therapy. Consider the cost to our state if these children were to go without these critical services into adulthood. How much more expensive would they be to serve without early intervention?

**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 again is BUDGETS. WE NEED TO HEAR FROM MORE FAMILIES! 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](mailto:haarstad@minotstateu.edu)

**Budgets:** Children with special needs often require specialized services that are not covered by private health care insurance, schools or other sources of support. Just like the state of North Dakota, families struggle to balance their budget each month while paying for medical transportation, medicines, therapies and supplies that are often a matter of life and death for their children with a disability. Other families while not on the brink of life or death do require these special services to enjoy the quality of life that most North Dakota families take for granted. Families are not looking for their neighbors through the state to pay for reasonable costs but they also do not want to see children suffer when the financial resources needed to pay for expenses are just not available.

**Example:** Our budget in the summer becomes very difficult. We pay \$80 a week for child care for a twelve year old with disabilities (about \$1,000 a summer). We also pay about \$100 a month for her medication year round (\$1200). Finally,

because she cannot handle group lessons, we have managed to pay for therapeutic riding or individualized art, swim or dance lessons. Now our daughter could survive without the lessons but these experiences have contributed a great deal to her personal development and self-confidence. Finally because of a history of seizures and upper respiratory infections our daughter must see a physician more frequently than typically developing children. These extra expenses stretch the budget. When a unique medical expense (i.e. new ear drums, braces, tooth extraction, hearing aids, eye glasses, eye surgery,) comes along in addition to routine costs, the budget is busted. Our daughter has exceeded her medical deductible every year since birth. We are not complaining just struggling at times to make end meet. These disability related expenses are very low compared to many other families we know.

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

Read about Promising Practices in Home and Community Based Services for Families at <http://www.cms.hhs.gov/promisingpractices/default.asp>

Find out about a new and innovative way of financing family support called an Independence Plus Waiver. Although there are a lot of unanswered questions about these options, being informed will put us in a better position to negotiate.

- <http://www.cms.hhs.gov/newfreedom/>
- <http://aspe.hhs.gov/daltcp/reports/Citarpt.htm>
- <http://whitehouse.gov/infocus/newfreedom/nfipprogress.pdf>

Noteworthy features: of the Independence Plus Waivers include:

- States must use a family or person-centered planning process
- Supports brokerage must be available
- Individual budgets are mandated
- Fiscal agent/intermediary can be claimed as a waiver service
- Flexibility in provider qualifications encouraged
- Families and individuals have the right to direct services and supports
- States must offer training/ information to families/consumers on self-direction
- Strong health and safety component
- Makes fiscal agent a Medicaid reimbursable service

