



**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:** Testimony on the Medicaid Buy-In bill was given to the Appropriations committee by Dr. John Uppal. This bill (if passed) would allow people with disabilities to buy into Medicaid much like another employee purchases health insurance from a private provider. New testimony will be provided this week as well. This bill Senate Bill 2194 is important to families because Congress is now considering similar legislation for families (Family Opportunity Act). This legislation may follow a similar path in the state legislature in the next biennium. If passed by Congress, a family which is unable to obtain coverage through an insurance company for a therapy or health care service could buy into Medicaid and obtain what they need. This would help families if the asset test is reinstated. This legislation may need to be passed by each state once passed by Congress because states match federal dollars with state dollars.

Senate Bill 2087 to repeal oral maxillofacial and orthopedic services thru Medicaid failed. This bill would have eliminated these services for Medicaid recipients in North Dakota and weakened their health care status significantly.

Senate Bill 2086 is an important bill to watch. This bill proposes that individuals receiving services under the Home and Community Based Waiver would have the right to choose which services they need. This relates directly on a court ruling (Olmstead) which strengthens the rights of individuals to live outside of an institution.

**About Families and Medicaid:** While a growing number of families have accessed the Family Support or Family Subsidy programs, many have not. Some

North Dakota families feel a sense of stigma in applying for programs that are funded through Medicaid (in the case of Family Support) or by the state (in the case of Family Subsidy). 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: Medicaid is intended to help only the poorest of the poor and those who need temporary assistance. If you are not poor, you should not get Medicaid.**

**Facts: Medicaid has been designed and revised to provide services to children and adults with disabilities as well as to people with limited income.** It is much less expensive and restrictive to provide home and community based support than institutionalized care. Families with children who have special needs often require these supports to participate in the life of the community.

- It Medicaid was originally designed to help families with limited income. It was hoped that the need for financial assistance would be limited or temporary for families with limited income however . . . .
- Congress also recognized that some groups experienced chronic unemployment or underemployment and/or chronic health care needs and deserved special recognition for long-term services. These groups included persons with disabilities and their families.
- Congress has amended the original Medicaid law many, many times over the years to address the needs of BOTH groups. Medicaid has two major components
  - **Health care services** (e.g., hospital and outpatient services, physician services, prescribed drugs, and laboratory tests)
  - **Long term services** (a) institutional services (nursing facility and Intermediate Care Facility for the Mentally Retarded (ICF/MR) services) and (b) **home and community services** (personal care/assistance, home health, case management, and home and community-based waiver services)
- Children and adults with developmental and other disabilities make up about 18-20% of all Medicaid beneficiaries. Medicaid benefits allow these individuals and families to **secure essential health care services that may not be available through private insurance.**

- Medicaid spending for home and community services has grown rapidly while spending for institutional services has declined.
- Addressing family needs through Medicaid allowed the government to provide a vital service without creating new levels of government.

**Belief: People who receive Medicaid often try to rip off the system and are a burden to taxpayers. They should have to pay a recipient liability and contribute like the rest of us.**

**Facts:** People who take advantage of the system have all levels of income. Although Medicaid fraud is a real concern in some states that has not been the case in North Dakota and certainly not among families raising children with special needs.

- Many people who receive Medicaid do not earn enough money to pay taxes or fees. A recipient liability for those families would be impossible for them to meet.
- Many other people who receive Medicaid already pay a substantial recipient liability.
- Families who receive Medicaid under the Home and Community Based Waiver and who have not been required to submit to an asset test are paying both Federal and State taxes that support Medicaid.
- Fraud in North Dakota (people who illegally claim benefits through Medicaid) is among the lowest in the nation. This is largely due to an active and rather vigilant county social service system.
- Evidence of fraud among families who are raising children with special needs in North Dakota simply does not exist.

**Next week we will look at two other beliefs.**

1. 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.
2. Government run programs are expensive and not cost effective. Families should find other ways to get the support they need.

**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:

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|-------------------|----------------|----------------|
| 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 BUDGETS. 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.

**Protecting State Medicaid Programs** – If you would like to read a report that explains how Medicaid relates to the economic well-being of your state, try this one. Although written in family-friendly terms, there is a lot of information to digest. Go to <http://www.familiesusa.org/> and click on Medicaid. Scroll down to Preserving Medicaid in Tough Times: An Action Kit for State Advocates, a 2003 Update and click on the title. Then scroll down to the first heading Protecting State Medicaid Programs. Or click on this link:

[http://www.familiesusa.org/Action%20Kit%20State%20Advocates/2003/1a\\_ProtectingStatePrograms.pdf](http://www.familiesusa.org/Action%20Kit%20State%20Advocates/2003/1a_ProtectingStatePrograms.pdf)

### **New Pamphlet on Students with Disabilities**

The Office for Civil Rights (OCR) in the U.S. Department of Education has prepared a pamphlet to inform students with disabilities about their rights and responsibilities and the responsibilities that postsecondary schools have towards them. This pamphlet, "Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities," is written in a Question and Answer format, addressing many pertinent questions that arise once a student leaves the public school system.

The pamphlet is available by clicking here or typing [www.ed.gov/ocr/transition.html](http://www.ed.gov/ocr/transition.html) into your browser. You may also request a print copy by contacting EdPubs via email: [edpubs@inet.ed.gov](mailto:edpubs@inet.ed.gov) or call 1-877-4-ED-PUBS (toll-free).

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