



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 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.

Legislative News: A hearing was held on January 14, 2003 by the Appropriation Committee of the North Dakota Senate. The meeting was held in the Harvest room at the State Capitol and filled with professionals from the Long Term Care Association and various DD service providers. The committee listened to a review of:

1. The ND budget for Medicaid (Department of Health)
2. The ND budget for DD services (Department of Human Services)

Important changes in the Governor's budget that may impact families included:

1. The budget proposes that only emergency dental costs will be covered under Medicaid beginning July 1, 2003.
2. The budget proposes no increase in wages for DD service providers either directly or for cost of living increases.
3. The budget proposes that the disregard for the asset test for families of children with disabilities continue.

Although many service providers and people from the Long Term Care association testified about services for adults and seniors only three family members testified about Family Support, Family Subsidy and the asset test. Although some members of the Appropriation Committee responded kindly, others made no comment at all and it was difficult to tell what they really thought.

If Family Support or Family Subsidy services are important to you, please take a few minutes to contact your State Senator by email or mail and express your point of view so that they have a sense of how many families might be affected and how important these programs are to families. Ask yourself, what would our

family do without this service? A copy of the testimony given by Cathy Haarstad is attached.

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.

At one time, our society responded to people with disabilities by putting them away from us in institutions. This decision resulted in terrible abuses (both physical and mental) that were life long and devastating. Abuse occurs when a few people with extraordinary power over others come to view them not as individuals with rights and capabilities but instead as the object of care. The cost of reversing our nation's commitment to institutionalization was fought and won in the court system and has been a very expensive lesson.

Some families rejected the notion of placing children in state institutions from the beginning and attempted to care for a son or daughter with special needs at home. Although some succeeded, many were overwhelmed by the medical and educational challenges and the disruption to family life. They sought support to continue to serve their sons and daughters at home through federal legislation.

In the early 80's, Congress considered the request of these families for home and community based life for their children and looked for a way to provide the service as an alternative to institutionalization. Instead of creating a new level of bureaucracy, Congress decided to use existing programs that were already designed to provide similar kinds of services at a county level. As a result special waivers to Medicaid were enacted into Federal law and made available to states. A waiver is an official document that allows a state to ignore or set aside rules in programs serving people with limited income, to serve a new class or group of citizens. North Dakota chose to apply for and received a Home and Community Based Waiver which is used to assist families with medical expenses, provide respite care and meet other special needs.

Unfortunately some unintended results occurred based on what families believe about government, Medicaid and being American. Some families have chosen to avoid asking for or accepting supports that are available because of how those supports are funded. Common beliefs about Medicaid will be reviewed against current information about North Dakota policy and services in the next several newsletters. Families are free to form their own conclusions. Some common beliefs are listed below:

1. 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.
2. 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.
3. 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.
4. Government run programs are expensive and not cost effective. Families should find other ways to get the support they need.
5. Families who do not meet the asset test for Medicaid have means and can buy the services they need. They should not get Medicaid.
6. Medicaid is funded with Federal dollars. North Dakota brings in more Federal dollars than we pay in taxes. When people raising children with disabilities use Medicaid funded programs, they are taking someone else's money.
7. 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.

Other Legislative News! The Medical Advisory Board for the Children's Special Health Care Services has recommended that they begin to provide some special supports for children who experience seizure disorders and some metabolic disorders. This will positively impact many families in North Dakota. They believe that this job can be done with the current resources budgeted. Because they are a division of the Department of Human Services they must obtain legislative approval for this change. Approval is anticipated.

Children will need to be screened for Medicaid services first or Health Steps. CSHS will fill in gaps when children are not eligible for these programs. Costs for children with seizure disorders do not include costs related to febrile seizures or surgeries but costs related to medicine, diagnostics, and lab work. For more information contact Children's Special Health Care Services at:

Children's Special Health Services
North Dakota Department of Human Services
600 East Boulevard Avenue, Dept. 325
Bismarck, ND 58505-0269
Phone: (701) 328-2436

Toll-free at 1-800-755-2714 (in-state)
TTY: (701) 328-3480
Fax: (701) 328-1645
E-mail CSHS at: dhscshs@state.nd.us

The number of individuals qualifying for DD services has gone up over the past biennium due to:

- Improved child find efforts
- Increased survival rate among children
- Increased birth rate in some counties (by Indian Reservations)

North Dakota DD providers indicated that staff turnover rate is 51% and higher in ICF/MR programs, possibly as high as 75% in the ICF/MR program.

Senate Bill 2257 introduces Universal Newborn Hearing Screening. This legislation would require hospitals to offer and conduct newborn hearing screenings. Research shows that when hearing loss is detected and appropriate intervention developed within the first six months of life, people with the hearing loss do not develop the significant delays in language and functioning experienced when early intervention does not occur.

House Bill 1463 Proposes an Increase in CHIPS funding for low-income families. This bill would increase the income level to access CHIPS to 200% of the Federal poverty level. This means that families who are considered to be part of the “working poor” would be able to secure health care for their children.

North Dakota Families: How Many ND Families Have Children with Special Needs? This question was asked just last week and data from the Department of Public Instruction was shared. 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.

This number is very different from the number provided to the North Dakota Legislature by the Department of Human Services. Currently North Dakota has 3, 987 service recipients (unduplicated count) for DD services. The DHS reported that 75 of those recipients received ISLA services (residential services typically provided in an apartment setting) and 100 recipients receive Family Support. Obviously not all of the students served in public schools are receiving DD services. This may be because their disabilities (speech or learning disabilities) don't meet the definition of Developmentally Disabled. Do you know what that definition is?

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 HEALTH CARE. 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 often require specialized health care services that many other families do not encounter. Providing these services in rural settings is a challenge that families appreciate. The Surgeon General and many Universities across America have pointed to a disparity in health care services for people with disabilities that may be growing. Most North Dakota families want to be able to find a physician, dentist and therapists in their home town who are readily available, familiar with the health care needs of their child with a disability and able to access the most current and best technology for treatment. Families also want health care providers to be familiar with options for family support and training and culturally competent. Right now North Dakota families often travel long distances for specialized services, experience long waits for some critical services, or juggle numerous health care appointments among several clinics.

Example: The hardest thing for us has been to obtain the services of a pediatric neurologist. We must travel 2-4 hours one way for an appointment. We recently found a local pediatrician who began to do all the work of consulting with the neurologist for us. What a blessing. Too bad our child was 12 years old before we found this service. We wonder about all the other families who don't have access to a pediatrician.

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

The North Dakota Center for Persons with Disabilities has an online class in Rights and Responsibilities that is designed to be taken by a young person with a developmental disability. The person finds someone who is willing to mentor him or her (discuss rights and responsibilities) and has an opportunity to put together a personal diary in class about his or her choices. The class features online discussion guides, a rights scrapbook, chat rooms, and discussion boards. The Rights included are:

1. Right to Free Association (Choosing Friends)

2. Right to Vote
3. Right to Own Property
4. Right to Spend Money
5. Right to Drive
6. Right to Use the Telephone
7. Right to Praise God and Attend Church

Right now, this class is only available to individuals served by adult DD providers. It could easily be used by high school students. The many pictures and icons at the sight make it effective for individuals with limited reading skills. If you would like to preview the site contact: Mary Mercer at 500 University Ave W., Minot, ND 58707 or call her toll free at 1-800-233-1737.

If you are interested in Leadership in Education, Check out the Institute for Educational Leadership at <http://www.iel.org/>