



## Leadership

02-14-03 # 7



**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](mailto:haarstad@minotstateu.edu)

**Leadership Teams:** If you are interested in forming or joining a leadership team in your region call Cathy at 1- 800-233-1737. Upcoming trainings include:

Bismarck	February 23, 2002	10:00 AM to 12:00 AM
Minot	March 25, 2003	5:30 PM to 7:30 PM
Grand Forks	March 11, 2003	6:00 PM to 9:30 PM
Linton	March 15, 2003	10:00 AM to 2:00 PM

## Legislative News:

Sadly, the **Senate Bill on Universal Newborn Hearing Screening** did not pass. This bill required hospitals to screen the hearing of newborns before they leave the hospital. (This simple test can be done while the infant sleeps). In fact the committee who heard testimony on this bill voted against it 5-1. Why?

At the last minute, the Department of Health attached what is called a fiscal note to the bill after previously assuring its sponsors that no note would be attached. Why? The fiscal note indicated to legislators that it would cost the Department 31,000 dollars to implement the software needed to track the follow-up for the screenings. In an arena in which the Legislature must balance the budget in the face of a huge shortfall, virtually nothing with a fiscal note is getting through.

It is sad that the impact of this decision will be that 50% of the new babies born with hearing loss in North Dakota will be missed if not screened at birth. The average age for detection is over two years old. When intervention is not provided before six months of age, children with hearing loss present from birth often develop a significant gap in language and cognitive functioning.

What can families do? While we cannot change this legislative decision for another two years we can send a strong message that the hospital of our choice must be one that provides this service. Note: All ND hospitals have the equipment and training, which was provided to them at no cost under a grant

from the ND Center for Persons with Disabilities and the Maternal and Child Health Bureau.

**Good News!** The Senate Bill for Medicaid Buy-In for persons with disabilities was unanimously passed by the Senate Appropriations committee. Waiting for the decision was a real knuckle-biter because the committee endured last minute negative testimony from Department staff who voiced fears about the cost of its implementation. However the evidence of savings for ND within this bill was too strong to be overcome by the voice of caution.

The full Senate will most likely pass the Medicaid Buy-In soon and then it will go over to the House. Passage of this bill means that YOUR son or daughter when they become an adult will be able to work and still keep any health care benefits that they need by buying into Medicaid. Hats off and much thanks to the advocates, staff and legislators who worked tirelessly to move this bill through the process and will continue to support it in the House.

**No News:** At the time this newsletter was written, we had not received any news about the Department of Human Service Budget. Information has not been obtained regarding the budget shortfall for this biennium or for the proposed budget. The big issues for families in the budget are continuation of early intervention, the amount budgeted for Family Subsidy and the continuation of the income disregard for Family Support.

**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 do not meet the asset test for Medicaid have means and can buy the services they need. They should not get Medicaid.

**Facts:** Families may have the means to buy a service but ironically the service may only be available for families who do not have the means. The Family Support program is a good example of this. Before the asset test was disregarded, the services of a trained care-giver were extremely difficult to find outside of the Family Support Program.

Even at a minimum rate of \$5.50 per hour, most middle and some upper income families cannot afford to purchase the services of a caregiver for the number of hours their child or family may need a week. Do the math.

Although families may have the choice or option of getting together with one or two other families in their area, pooling resources and hiring one person to work with their collective children, the logistics of advertising for, recruiting, and training the person as well as getting the children into one location is only going to work out on very rare occasions, especially for families who work outside of the home.

**Belief:** 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.

**Facts:** Although it is true that ND brings in more Federal dollars than we pay in taxes that does not mean that using Medicaid funded programs for family support means we are taking someone else's money. The amount of money paid in Federal Taxes in North Dakota is greater than the amount provided through Federal Taxes for Family Support. In fact, using this money means that you are actually accessing the tax dollars you contributed.

## **Home and Community Based Waiver**

ND has a **Home and Community Based Waiver (HCBW)** that waives typical Medicaid rules and allows ND to provide many services to families of children with special needs. The Departments of Health and of Human Services are part of the executive branch of government. Part of the role of this branch of government is to consider the current and future needs of families and to provide the Governor with an effective plan for service delivery.

ND's Medicaid Waiver is about five years old. States must reapply for the waiver annually and have several options for waived services. Because of the age of our current waiver, because of the need to optimize access to Medicaid dollars in the face of lowered state revenue and because the Federal government has made new options available to states for HCBW programs, the DHS may decide to change ND's HCBW possibly as soon as this spring. The impact of any decisions made by ND's legislature or Congress on our current HCBW as well as new options available to families will be considered.

Changes in the Medicaid Waiver are likely to impact a large number of ND families. The DHS is required to submit changes for public comment under a formal administrative rules process whenever significant changes are proposed. In addition, if changes are significant, the DHS is likely to hold focus groups to get more input from families. Finally the DHS will rely on its DD advisory committee to provide critical input into the decision making process. The window of time on decision- making to change the HCBW may only be a few months and it is very likely that the DHS is already looking into several options.

**It is very important that families get to the table when options are considered, that they be well informed about new options and services and that they weigh in on issues that impact their family before decisions are made!**

Families can meet this challenge in a variety of ways:

- Call your regional DD administrator and let him/her know that you are interested in providing input or serving in an advisory capacity.
- If you have young children, contact your Regional ICC committee with an offer to participate.
- Go to the Center for Medicaid Services website [www.cms.hhs.org](http://www.cms.hhs.org) and do a search using the key phrase Home and Community Based Waiver. Read up on new options for HCBW programs and think about how they might impact your family.
- Watch your local newspaper or other newsletters (including this one) for announcements about the Administrative rules hearings or focus group meetings and plan to send in written input or attend.
- Contact members of the DD advisory committee and let them know how new changes or current services are impacting your family.

**Families and Seniors with Disabilities:** Many ND families care for aging parents. Some parents live with a son or daughter in the family home. Other families make frequent visits to a nursing home to visit aging parents. The cost of nursing home care is high and takes a large percent of the ND state budget. More and more people in ND are aging and this issue impacts families who are raising children with disabilities in many ways.

Many senior citizens are raising children with special needs. As they age and some skills decline, most likely the overwhelming majority will wish to continue living in the community. Often seniors assist a family to provide supervision and childcare. Sometimes as their own needs increase, they themselves require care or even placement in a skilled nursing facility. As care requirements increase, families may experience an increased demand for time, energy and resources.

In 2000 the percentage of the total number of nursing home residents in North Dakota with ZERO/NO activities of daily living impairments was 32.8%; the total number of nursing home residents with ZERO/No cognitive impairment and/or only a "very mild cognitive impairment" was 35%; according to the Center for Medicaid Services.

What do these figures mean? It would seem that there are many people in ND who could live outside of a nursing home. The Supreme Court (Olmsted) ruled that people who want to live apart from institutional settings must be allowed to do so. As ND works to move more senior citizens outside of nursing homes, the funds used to serve them in that setting could be redirected into Home and

Community Based Services. North Dakota is being challenged to realign some of its services while the numbers of seniors are growing and then number of young families who contribute to the tax base is shrinking. That effort is bound to impact families who struggle with issues related to transportation, accessible housing, and support. Families will want to track the complex issues related to the Olmsted decision carefully.

**Families and the ADA** People with disabilities may sue an employer or a public business if they experience discrimination as a result of noncompliance with the Americans with Disabilities Act. What happens when a state is out of compliance? Although the U.S. Supreme court has ruled that people cannot sue a state for damages it is possible for an individual to sue the state.

How does that situation impact ND families? Most situations in which families encounter discrimination that impact children are related to IDEA (special education law) or 504 (Rehabilitation Act). ADA issues that impact families might relate to parent employment (if the parent has a disability) or access to public buildings.

There is a California case before the Supreme Court (the Hason Case) proposing that the Supreme Court overturn a lower court ruling that makes it possible for an individual to sue a state. In the California case the state of California has declared that a person with a mental illness may not practice medicine as a physician – even though they may be highly qualified in every other way required by the state. A lower court ruled that this practice was discriminatory. California is challenging that ruling. What does this have to do with North Dakota?

Sometimes states consider how a ruling might impact the people of their state and weigh in, sending a brief to the court (a brief is a form of written testimony based in law) that shows how a ruling would impact people and the government and outlines points they hope the court will consider in its ruling.

This is happening in the Hason Case. Some states are sending briefs that may strengthen the ADA and others are sending briefs that if followed would weaken the ADA. The Minnesota Attorney General is asking the U.S. Supreme Court to support a lower court's decision in favor of the ADA. North Dakota has the opportunity to join Minnesota, side with other states or do nothing. What do you think ND should do? North Dakota's Attorney General Wayne Stenehjem is now deciding whether North Dakota will join Minnesota in support of the ADA. Attorney General Stenehjem has supported disability causes but it is unknown whether he will join Minnesota in support of the ADA. If you have an opinion about this, you can contact North Dakota Attorney General Wayne Stenehjem:

1. Telephone 701-328-2210
2. Fax 701-328-2226
3. Email address [wstenehj@state.nd.us](mailto:wstenehj@state.nd.us)

The Attorney General serves all North Dakota residents, even people who did not vote for him. He can serve you best only if he gets your advice. If you **contact the Attorney General**, you must do so **immediately**. **His decision is due no later than this Friday, February 14.**

**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/nfiprogress.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