



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

Leadership Teams: Leadership teams face many challenges in reaching families. Challenges in providing local training identified by teams include:

- Finding someone the family trusts to make a phone call and not only invite the family to attend but indicate that the training may be very helpful.
- Offering training on a routine basis at a brown bag lunch or evening meeting so that if a family cannot make one session, they can make another.
- Using local newspaper and radio media wisely to reach as many families as possible. Sending the message early and often.
- Organizing events so that attending is very, very convenient for working parents.

Legislative News: It is important to remember that the final impact of any decisions made by the ND House and Senate will not be known fully until after the Legislative session ends and the Departments of Health, Education and Human Services are able to look at the amount of money appropriated and cut and then make final decisions internally about which programs, positions or services to keep or eliminate.

At this point, if no further action is taken by the House it appears that:

- If your child is between the ages of 0-3 he or she may continue to receive early intervention, because funding at a level that will allow ND to continue to receive Federal dollars was appropriated.
- If your child is eligible for DD case management services, then you will continue to receive any family and medical supports covered under ND's Home and Community Based Waiver.

- If you receive Family Subsidy, then you **may** experience a decrease in the number of hours available depending on how much is cut from the Department of Human Services' budget and how DHS responds to the cuts.
- Some Human Service Centers will lose funding for positions, meaning fewer DD case managers will be available and those who remain will have a higher caseload (increasing from 60 to 75 individuals).

If your child has a disability, but is not eligible for DD case management services (ADHD, Learning Disabilities, some Emotional or Behavioral Disorders) and your income is low enough for you to qualify for Medicaid, services, including dental services which would have been cut under the Governor's budget, have now been restored by the ND senate.

- If your child has a disability, but is not eligible for DD case management services and your income is low enough to qualify you for Medicaid, there are several services, which, if cuts initiated by the ND Senate are continued by the ND House, that you would no longer be able to receive. These include:
 1. Psychological services such as evaluation and counseling for your child with an emotional or behavioral disorder – unless you receive such counseling through your local human service center. This will probably mean a longer waiting period for services.
 2. Visits to an eye care professional will still be funded but the state would no longer pay for any eyeglasses that are recommended. You would have to obtain those funds on your own. It may be possible to obtain assistance through lending programs supported by your local Lions club.
- If your son or daughter with a disability is an adult, he or she would be able to work and still retain health care benefits covered under Medicaid by buying into Medicaid as long he or she works for at least 100 hours per month. The additional requirement that a person work for 100 hours, sometimes called the 100-hour rule was actually put in place on January 1, 2003.
- If your son or daughter has a disability but does not qualify for DD case management services and you do not qualify for Medicaid, you may continue to obtain medical insurance under the Healthy Steps Program for your son or daughter only if your income is at or below 140% of the Federal Poverty level. The ND Senate did not pass legislation that would increase insurance for families whose income was at \$200 of the poverty level even though they may do so under Federal guidelines. The legislature determined it would be too costly to come up with state general fund dollars. You may apply for services through Children's Special Health Care services. There is no guarantee that they will have sufficient funds to help all families.

- If you have an elderly parent or an adult son or daughter with a disability who has been receiving in-home and community-based services such as homemaker, chore services, respite, or personal or attendant care service funded under Service Payments for the Elderly & Disabled (SPED) they may no longer receive services. Legislation passed by the Senate changed the asset limit to \$20,000 in total assets (rather than liquid only) except for the individual's primary home. The DHS estimates that with the change in the asset limit from \$50,000 to \$20,000 – 376 fewer individuals will be served. This does not include the change from “liquid” to “total” assets. The effect of this is unknown at this time.
- If your son or daughter is receiving psychiatric care at the State Hospital and Jamestown, they may be negatively impacted by a significant reduction in operating funds. The cuts in funding are deep and will impact a number of children with special needs in ND.
- If your son or daughter is receiving services through the State Developmental Center at Grafton, they may be negatively impacted by a significant reduction (1 million) in operating funds. The cuts in funding are deep and will impact a number of adults with special needs in ND.

Several hearings on the DHS budget with opportunities for public comment will be held in the House in the next two weeks. Please contact your Legislative Working Group to find out times to testify on issues important to you and to get support or assistance in preparing testimony. The ND Disability Advocacy Consortium and AARP are planning joint news conferences and possibly a rally in Bismarck on April 1, 2003. We will keep you posted.

Federal Funding for Medicaid: Medicaid no longer only funds programs for persons with limited income. Medicaid is the major source of funding for services for families who have children with disabilities, for seniors and for adults with disabilities.

States like ND receive funding for Medicaid under a formula that considers average income and population. President Bush recently proposed changes in Medicaid funding for states in response to a widespread request for help as states experience shortfalls in their Medicaid budgets, nation-wide.

How would the changes proposed by President Bush impact North Dakota, especially families who are raising children with special needs? The truth is that no one knows because the changes are only proposed, they haven't been enacted yet and the results cannot be measured.

This newsletter gives leaders facts and information about the proposed changes so that families can decide for themselves whether these changes are good or

bad and take appropriate action based on their beliefs. Basically families need information that may help them to:

- Understand President Bush's proposed plan to change Medicaid
- Understand the political forces that will shape a response by ND
- Understand what ND's response may mean for YOUR family
- Understand what ND's response may mean for other families
- Understand what ND's response may mean for adults with disabilities

What President Bush Has Proposed:

The proposed reforms would cover a 10 year period.

Individual states may choose to participate. If a state participates they are obligated for all 10 years.

The proposed change would merge both Special Children's Health Insurance Program and Medicaid funds into a block grant. States would get two allotments, one for acute care and one for long-term care based on FY 2002 spending. Up to 15 % of each allotment is set aside for program administration and direct payments to hospitals.

States must continue to spend at least the same amount on Medicaid/SCHIP as they did in Fiscal Year 2002. States may be able to count other healthcare spending toward the requirement.

The proposal specifies a loan of additional funds to states initially, with states paying back the loan in years 8, 9, & 10 through reduced grants. States do not have to generate the pay-back revenue but take a reduction in Federal Funds to cover it.

States would have to pay for any annual overrun and would thus be encouraged to use cost sharing mechanisms, eligibility level changes and benefit reductions.

The proposal bases formula growth in funds on projections by the Congressional Budget Office, not on the level of services provided or enrollment numbers.

The proposal does not change mandatory population eligibility levels and also does not require states to maintain those either.

States would have the flexibility to alter benefits for "optional populations" including families with children who have disabilities without applying for additional waivers.

The Bush proposal would offer States the option of receiving some temporary relief to cover the shortfall beginning October 1. States would have two options:

States that choose not to participate would need to solve budget deficits without federal assistance by:

- Raising taxes
- Operating more efficiently
- Cutting services
- Moving seniors and persons with disabilities from nursing homes to less expensive community based services
- Those States that elect to take the block grant would receive a "federal loan" of \$3.25 billion in FY2004 and \$12.7 billion over 7 years.
- States would have to accept an overall cap on federal Medicaid spending over 10 years starting next year.

There are important questions to be answered about these proposed changes. They include and are not limited to:

1. Is ND in a position to solve its budget deficit without taking the money offered in President Bush's plan?
2. If ND decided today, that moving seniors and persons with disabilities out of institutions (nursing homes) and into community based services were a top priority, how quickly and effectively could ND achieve that goal?
3. What would be needed to make sure supports in the form of housing, transportation, home health care, and in home nursing care would be available in towns across ND?
4. What percentage of ND's nursing home residents could live in the community if appropriate supports were available?
5. How likely is it that ND will move from its current position of funding and supporting nursing homes (and the jobs they represent) to funding and supporting community based services (which may create new jobs or call for the realignment of skilled care into community settings)?
6. What is ND's history in planning and supporting community based care been like up to now?
7. Will the additional funding offered by President Bush be sufficient to overcome any barriers to achieving community based services in ND?
8. If the funds are accepted, how will ND respond if the needs of families require more funds than the cap allows?
9. What would the benefit of combining Home and Community Based Services under the Waiver along with the Children's Special Health Program into one block grant be to ND?
10. Would the "flexibility" block grants provide, result in decisions that retained the special protections that families now enjoy once their specific programs were eliminated? In an arena in which family support and early

- intervention are optional, would a block grant strengthen or weaken family access to needed support?
11. What might be done by ND to reassure families that the services provided under existing programs would remain intact in the face of proposed changes?
 12. How would capping Medicaid funding for ten years impact the rise in numbers of seniors and the general decline in ND's population?
 13. Would the Early and Periodic Screening, Diagnosis and Testing program continued under the proposed reforms?
 14. How reliable are projections from the Congressional Budget Office about proposed spending.
 15. Would families or persons with disabilities be able to absorb any increases in co-payments or reductions in services?

The Governor's have responded cautiously to this proposal saying more information was needed and setting up a committee to work with the White House on this proposal. It is being closely monitored by advocacy groups.

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

Fair Housing Accessibility First <http://www.fairhousingfirst.org/>

An initiative recently announced by the Department of Housing and Urban Development will allow homebuilders, developers, architects and designers to have access to the latest training and technical guidance on how to comply with accessible design and construction requirements of the Fair Housing Act.

NICHY Student Guides <http://www.nichcy.org/stuguid.asp#set1> Developed especially for older students with disabilities, these award-winning guides are actually a set of materials: a booklet for students, another for families and professionals, and an audiotape for everybody! Learn about student involvement in the IEP process.