



Leadership

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Leadership: is an online newsletter for ND families and family support specialists prepared by the ND Center for Persons with Disabilities (NDCPD) at Minot State University. If you want to subscribe, send your name, address, phone number, and email address to Cathy Haarstad at haarstad@minotstateu.edu Please indicate if you are the family member of a person with a developmental disability.

Leadership Teams: This section provides notes for regional leadership teams who are interested in developing leadership skills and sometimes provide training to families and providers about family support issues.

A team in Bismarck recently completed a local training on Applying for Medicaid for young families. If you are interested in getting some of their handouts or finding out why families interrupted their schedule to attend and learn, contact Roxane Romanick at romanick@bis.midco.net (BECEP). She has several good handouts that clarify information for families.

Leadership in Family Support: The ND Department of Human Services (DHS) is proposing a change in public policy. The department is proposing that families who receive family support (i.e. in home respite care) OR infant development services be required to apply for Medicaid and either be found eligible or pay for the services privately. This new policy will not impact family subsidy.

Why the change? This change is being proposed because of reductions in the DHS budget, passed by the North Dakota Legislature. Essentially the DHS has more families to serve and less money to spend. By requiring families to apply for Medicaid, the department can use dollars from the general fund as match to access more Federal dollars and serve more families. As part of the Executive Branch of government, the DHS has to seek realistic solutions to limited resources. The DHS hopes to bring in enough additional dollars to continue to serve families who are already receiving infant development services and new families as children are born.

Why Medicaid? Isn't Medicaid a program only for low-income families? No! Medicaid does fund Temporary Assistance for Needy Families (TANF) and it also funds Family Support Services (sometimes called in-home support or respite care by families) under North Dakota's Home and Community Based Waiver. Medicaid can also be used to fund many other family support or early intervention programs. Why? Because Congress, when putting the system to fund Family Support services in place decided to latch onto existing programs under Medicaid through Waivers (a plan that allows the state to bend the Medicaid rules to serve certain populations) rather than creating a

whole new program under some other name. Medicaid, through its Early Periodic Diagnosis Screening and Testing Program had a model that worked.

What will the policy change mean for families? This change will mean that **families** who have a child with a disability or developmental delay **who want to receive infant development services** will have to apply for Medicaid through their county social service program. The family can apply at the office in person or by phone and will be able to use a shortened application form. The DHS will disregard (not count) any assets or income that families have if their child has been found eligible for DD case management services. Because of the disregard, the DHS can require 100% of families to apply for Medicaid if they want services.

Families may have to provide documentation as to their income (often in the form of a pay stub) even though that income is not being counted, to be accepted into the Medicaid program. This allows the county to make sure the family does not qualify based on income. Families do not have to document assets because of the disregard.

If a family does not want to apply for Medicaid, they will either have to pay for infant development services out of pocket or go without those services.

How will this change impact families and the early intervention service system?

No one knows how this proposed change is going to impact families. The critical questions being asked by families and service providers are:

**Will families go without infant development
And other important early intervention services
Rather than apply for Medicaid?**

OR

**Will families apply for Medicaid if that is the only way
They can get early intervention for their child with
Special needs**

What do we know about the potential impact? Families who are already receiving infant development services need to know when the Medicaid application must be completed and whether a gap or delay in applying might impact services.

Hospital social workers, health care providers, DD case managers, infant development specialists and county social service workers need to work together to inform families about the Medicaid application process and make it as easy as possible for families to choose early intervention services. They must also work to assure that the procedures for applying are similar from county to county.

Barriers that keep families of older children from applying for Medicaid need to be identified and addressed if the DHS has reason to believe these same barriers may discourage new families from applying.

The DHS will need to review how infant development programs are paid or reimbursed since they may participate in intake or other screening activities and need funds to pay for the time they give to those activities. If a family is screened and then refuses to apply for Medicaid, how will the agency be reimbursed?

Are there any exceptions? When an infant or toddler is receiving Infant Development Services and has a large income (perhaps a parent or grandparent has left or set aside income for an infant) then the formula used to calculate the amount of Medicaid the child might receive would require the family to pay a large part of the cost (this fee is called a recipient liability). In that case, an exception to the requirement to apply for Medicaid may be requested from the DHS.

Is the policy change now law in North Dakota? Not yet! The DHS cannot make this policy change without obtaining public input through the administrative rules process. A memo attached to the Leadership newsletter describes how to give input to the policymakers. Basically families and early intervention specialists can:

- Attend a public hearing and express their point of view to DHS staff
- Send a written letter or email to the DHS staff or the governor
- Express concerns in writing to an infant development specialist or case manager
- Contact their representative in the state legislature

Who will decide whether this change in policy goes into effect? The final decision will probably be made by senior staff in the Department of Human Services, staff appointed by Governor Hoeven. Since this policy change is being proposed by the DHS, the policy most likely will go into effect unless public input brings to light important arguments that indicate the policy should be dropped or changed. In considering a policy change, the DHS must consider the risks of the change against the risks of doing nothing or doing something else. Important questions for families and early intervention specialists to ask themselves are:

- **Is the proposed change good for your family?** Do you have input to share on how the proposed change will help or hinder your family in obtaining services?
- **Is the proposed change good for North Dakota?** Do you have input to share on how the proposed change will help or hinder other families, neighbors, employers, and new families whose children are as of yet unborn?
- **Is the proposed change legal?** Do you know of a way that the proposed change would somehow violate rights or guarantees for children or families that are spelled out in other laws or legislation? Is there something the DHS has overlooked?

- **Is the proposed change going to work?** Do you know of any reasons why the proposed change might not work? Will the policy change create conditions that make it untenable for families to seek assistance or providers to do business? If so, what changes or alternatives can you recommend that will effectively address the need for additional resources?
- **Is the proposed change cost effective?** Do you know of some hidden cost to the new requirement that should be considered? Will the additional Federal dollars received by the state be offset by the cost of the required procedures?
- **Is the proposed change fair?** Do you know of some condition or circumstance inherent in the requirement that will be unfair or discriminatory to families who have children with special needs? Is the proposed policy fair to the people who will have to live with it? Will the proposed change leave children and families at greater risk or assure that families have the services they need?
- **Will the proposed change help us reach our goals?** Do you know of some way in which the proposed change supports or undermines other goals that the DHS has set for keeping families together and out of institutions?
- **Is the proposed change necessary?** Do you know of some other reasonable way in which the DHS could make up the budget shortfall and serve additional families? Again, is there something the DHS has overlooked?

Several actions can be taken by families that will assure this policy change is put into effect quickly. They are:

Do not become informed
 Don't think about it
 Be interested or concerned but say nothing
 Don't participate in the administrative rules process

Several actions can be taken by families and leaders that may check the DHS decision to implement the policy and lead to a different outcome. They are:

Become informed
 Think it over
 Be interested or concerned and speak up
 Participate in the administrative rules process

The choice is up to you!

Leadership Opportunities: The **Rural Special Education Strategist (RSES) project at Minot State has filled the parent positions on its new advisory group** to review curriculum and make recommendations for recruiting and training

teachers. RSES prepares teachers to obtain an Education Strategists credential which qualifies teachers to work with students who have any of the following disabilities

- Mental retardation
- Learning disabilities
- Emotional disturbance

Dr. Joan D. Bonsness has asked me to pass on the information that the vacancies **HAVE BEEN FILLED** and thank the many families who responded to the leadership opportunity by contacting her. If you have an opinion or suggestions for the RSES advisory council to consider, please forward them to Dr. Bonsness at bonsness@minotstateu.edu

The **North Dakota Federation of Families 5th annual conference** will be held at the Radisson Inn, 605 E. Broadway Avenue in Bismarck, ND one June 8th and 9th. The theme for the conference this year is "In a System of Care – Constructing a New Future." This is going to be a GREAT conference with an opportunity to obtain training in Leadership in Accessing Systems and Systems Change. If you are interested in registering please contact Carlotta McCleary, at 701-222-3310 by phone.

Leadership Links:

Families and Schools Together (FAST) is a multifamily group intervention designed to build protective factors for children (4 to 12 years old) and empower parents to be the primary prevention agents for their own children. Dr. Lynn McDonald developed FAST in 1988 to serve teacher-identified, at-risk 5- to 12-year-old elementary school youth and their families; however, universal recruitment is now the recommended strategy. A collaborative team of parents, trained professionals and school personnel recruit then deliver FAST program components to 5 to 25 families at a time. Team members do not lecture at FAST, but structure highly participatory, research-based activities with turn taking, experiential learning, and parent support. <http://www.wcer.wisc.edu/fast/>

Fiscal Agents: Under an Independence Plus Waiver, families may choose a fiscal agent to help them write checks and pay vendors according to their individual budget. One such fiscal agent is called acumen. Why not visit their web site at: <http://www.acumenfiscalagent.com/Acumen/external/consulting.asp#>

Access to the Regular Education Curriculum Are you interested in enhancing access to the general education curriculum for students with special needs? Would you like to know more about activities that students with special needs might do in a regular education setting that are meaningful, produce real learning and will really address your child's individual needs? Why not visit the Access Center at: <http://www.k8accesscenter.org/default.asp> Another helpful site on this same topic can be found at Center for Universal Design, North Carolina State University <http://www.design.ncsu.edu/cud/>

