



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 get a copy, 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: Notes for regional leadership teams who provide training to families and providers about family support.

Strategies for reaching parents

Wonder what are other teams are doing? A copy of the brochure sent out by the Region II team in Minot can be obtained to look over upon request.

Did anyone use the new checklist on **How To Reach Families** in planning? Did you find it helpful? Please let me know.

Shirley Rimer contacted us to indicate they may invite Stella Hegg from F2F to provide training on **Leadership in Accessing Systems** for families of children with emotional and behavioral challenges at the Federation of Families office in May or June of this year.

Who we need to hear from? Call Cathy toll free at 1-800-233-1737

Team D Dickinson – Connie Kathrein - Hope to hear from you soon
Team I Wahpeton – Scott & Tammy Emmons – Hope to hear from you soon

Getting the team together

Some teams have struggled to decide who will lead the team. Strong interest or knowledge does not mean that a group will accept a person's leadership. Sometimes one person takes the initiative to call a team together. He or she then assumes that they will be the group's leader. That does not always work out well. Small leadership teams or work groups operate best when *consensus* (shared decision making) is used for planning.

Leadership becomes a matter of **approachability** (how easy is it to contact the person, get a response, talk to them), **service** (is the person willing to do some but not all of the work), **style** (does the person suggest or direct others, does he

or she invite discussion or have all the answers) and **organization and follow through** (does the person complete activities in a consistent and timely manner, is he or she organized)? The person or persons who have most of these skills will be a person from whom the group will accept leadership. Leadership is both a skill that can be learned and a role that must be earned **and** accepted.

New Teams: New teams from unserved areas may be funded in the future. If you wish to start or join a team in your region – please contact the project director.

ND Family Support Project Update: A planning meeting involving partners and families concerned about the availability and quality of family support is being held in Bismarck on Thursday, April 3rd from 1 to 8 PM at the Comfort Inn. This time was selected to help partners who are active in the Legislative process to attend.

Partners will look ahead over the next two year period and plan:

- Outcomes & collaborative activities to enhance Family Support
- Recommendations for allocation of funding sources (new family support grant, state improvement grant, Part B & C funds) to achieve outcomes & complete activities

Partners are encouraged to bring one family member each to the planning meetings as their guest (costs will be covered by the project). The project does not have the funds to open this planning meeting up to all families. If you are interested in attending please contact any of the partners (DHS – DD Division, DHS-CSHS, DPI, NDCPD, F2F, TAT, SIG, P & A, FV, AUV, FOF, DCIL, PTI,) with which you are affiliated. (See list of full names for these acronyms at the bottom of the newsletter.)

Family Support Projects: The ND Family Support Project has developed or is working on several new technical assistance guides that will help family support specialists individualize their approach, build inclusive communities or reach more families. Please let me know if you or an agency that supports your family would like a copy. The products are:

N2K Website Brochure

Family Support Partner Brochure

Attending Training and Information Opportunities: A report on what ND families have to say

Planning to Reach Families Checklist

Supporting Families When Parents Have Intellectual Disabilities

Managing Supports At Home: Using Family Subsidy Dollars to Pay for FS

Supporting American Indian Families (Under production – available July 03)

Supporting New American Families (Under production – available July 03)

Leadership in Accessing Systems and System Change

New Partners in Family Support:

We will soon be inviting new partners to participate in the collaborative planning. Your specific suggestions for “other players” *who impact or are involved in family support* would be welcome.

We are also looking for new membership to serve on the Family Support Advisory Council. Alas we don't have a formal application process in place yet. In the interest of being fair we will try to develop one soon.

Medicaid Plus Waivers: ND has a Home and Community Based Waiver (HCBW) that allows our state to disregard certain Medicaid rules in order to effectively serve families of children with special needs using Federal dollars.

Federal dollars (with some state match) are used by ND to pay for services that help keep families together and prevent institutionalization. Services include and are not limited to in-home support or respite, help with medical expenses, payment for therapy, and much more. **ND has also chosen to disregard income when considering family eligibility for families who have children with special needs.** This means that many more families in ND can access these special services.

The Medicaid Waiver is not automatic. ND has to apply for the waiver annually, specify the changes in the rules that it wants and negotiate to obtain those changes.

One new option in Medicaid Waivers called an **Independence Plus Waiver** that was recently made available to states. An Independence Plus waiver has new options that allow individuals with disabilities, or their families, to direct the design and delivery of their own health care services and hopefully experience higher levels of satisfaction, avoid unnecessary institutionalization and use resources more effectively.

The new options come with a template that describes the features and decisions that must be made related to family support. Some of the requirements include:

- Developing a written plan of care for each individual under this waiver using a family or person-centered planning process that reflects the needs and preferences of the individual and their family.
- Developing individual budgets that include the value of the waiver services available to the family or individual to support the individual's plan of care. Only waiver services as defined by the State are included in the individual budget. The amount of money designated in the budget is established by a

methodology determined by the State and the amount is agreed upon with the family or individual.)

- Families and individuals will have flexibility to select qualified providers of their choosing within the criteria established by the State.
- Families and individuals will have the ability to direct the services and supports identified in the plan of care within the resources available in the established individual budget. Families will have maximum possible flexibility in the utilization of resources delineated in the plan of care and individual budget.
- The State has procedures to assure that families have the requisite information and/or tools to participant in a family or person-centered planning approach and to direct and manage their care as outlined in the individual plan of care.
- The State will make available and provide services such as assistance in locating and selecting qualified workers, training in managing workers, completing and submitting paperwork associated with billing, payment and taxation. Supports Brokerage and Fiscal/Employer Agent Services/Functions are required and should be provided by one or more entities.
- Upon family or individual request, the State makes available, at no cost, provider qualification checks, including criminal background checks.

States have the option of designating which populations may be included in the Waiver including persons with Mental Illness. States still have to come up with the required matching dollars to fund the services they agree to provide.

This information was taken from information at the Centers for Medicare & Medicaid Services website <http://www.cms.hhs.gov/independenceplus/>

Legislative News: A RALLY has been scheduled for APRIL 1st in Bismarck to show support for Home and Community-Based Services (HCBS). The primary sponsors are the ND Disabilities Advocacy Consortium and the AARP of ND. The rally will be on the front steps of the Capitol (if the weather cooperates) or in the Memorial Hall inside the Capitol (if it doesn't). The starting time is planned for 11:30 a.m. A large crowd is expected. Traffic will be congested and parking may be sparse. You are encouraged to take this into consideration when planning your arrival time at the Capitol.

The formal rally will last for 45 minutes to an hour. Following, it is hoped that participants will try to hook up with their legislators to pass on a positive message about Home and Community-Based Services. Individual legislators may or may

not be available. Participants are encouraged to bring a personalized note along to leave for each legislator in their district, just in case...

It is not too early to start organizing transportation and ride-sharing. If you (and/or a group of people) are planning to attend, it would be very helpful if you could let me or the NDDAC office know so we have an idea of how many people to expect. NOTE: It will NOT help the cause for HCBS to have a small crowd. PLEASE plan to attend!!!

Leadership Links: If you are interested in new web-sites as a leader, please check on the following links

North Dakota Foster Care Website <http://www.ndfosterparent.com/>

North Dakota Community Action Programs <http://www.ndcaa.org/>

Native American Food Guide <http://www.aaip.com/tradmed/tradmedfoodguide.html>

Acronyms for ND Family Support Partners:

DHS = The Department of Human Services – DD Division

CSHS = The Department of Human Services - Children’s Special Health Care Services

DPI = The Department of Public Instruction

NDCPD = The ND Center for Persons with Disabilities

F2F = The ND Family to Family Project

TAT = The Early Childhood/Tribal Education staff from the Three Affiliated Tribes

SIG = The ND State Improvement Grant

P & A = The Protection & Advocacy Project

FV = Family Voices

AUV = The Arc, Upper Valley

FOF = The Federation of Families for Children’s Mental Health

DCIL = The Dakota Center for Independent Living

PTI = Parent Training & Information Center called The Pathfinder Family Center