



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.

A recent phone conference with partners in the ND family support project indicated that families are looking for training that would enhance leadership skills. There are many different ways of showing leadership. Which of these ways interest you?

- mentoring another family that has a child with a similar disability
- mentoring a family in which a parent has an intellectual disability
- learning how to write a proposal or small grant to get funding for a project
- learning how to serve on an advisory board or committee
- becoming active in projects within my local school district
- becoming more effective in getting the IEP my child needs
- building a generic support network within my community
- building or joining a family support network for parents of children with special needs
- leading a faith-based initiative to support families in my local center of worship
- leadership in accessing systems that support children/families
- leadership in system change _____
- learning how to make use of the Internet to get information for our family
- learning more about a special topic _____
- other _____

Please copy this simple survey list, put an x by any areas that interest you and paste it into an email, returning it to Cathy Haarstad at haarstad@minotstateu.edu Share with other families as you like.

ND Family Support Project Update: A phone conference of family support partners was held

4. Use data-driven decision making to enhance family support in North Dakota

- Collaborate with the ND state Improvement Grant (SIG) and Kids Council to identify specific data to measure outcomes for families of children with special needs. Include this information with the annual Kids Count report.
- Develop a mechanism to continue collaborative planning among family support partners.

5. Increase access to information about family support

- Share curricula developed by the NDFSP with higher-education staff in ND
- Collaborate with the Parents as Trainers and Natural Allies programs to enhance access to information about family support.

Medicaid Plus Waivers: ND is actively exploring the implementation of an Independence Plus Waiver (IP+) that if granted would be an option for families along with the current Home and Community Based Waiver. Although there are two types of new waivers available to states, at this time ND has decided to pursue only the IP+ option. The other option (1115) would be difficult to carry out in the current fiscal climate and has a strong research component that the DHS would have difficulty in addressing with current resources. Here is some information about an IP+ waiver.

- An Independence Plus waiver is a Medicaid Home and Community Based Waiver (HCBW) option for family or individual directed community services.
- Families who opt for services under this waiver may be required to apply for Medicaid through their county social services. The asset test has been disregarded by the ND legislature.
- Medicaid is no longer only a social welfare program for persons with limited income but **a safety net to prevent institutionalization and unemployment** for families raising children with special needs.
- **Supports brokerage** services must be included that assist participating families to make informed decisions about what will work best for them that are consistent with their needs and reflect their individual circumstances. A family or person centered approach will be used that also addresses effective back up and emergency plans. Families will be offered practical skills training including information on recruiting, hiring and managing personal care workers.
- Fiscal/Employer Agent services must be included that will assist the family to manage and distribute funds contained in their **individual budget**. Families would not receive a direct cash allowance but an individual budget to be managed for them by a fiscal/employer agent. Fiscal agents perform activities such as issuing payroll checks, calculating federal and state tax withholding/payments, unemployment compensation fees, fiscal accounting and expenditure reports.
- Evaluation, level of care, choices of services, plan of care and quality assurance components would be similar to those already provided to families under the current HCBW.
- An IP+ waiver could include In-Home support activities AND most of the family subsidy areas of reimbursement. Services available through the state Medicaid Plan cannot be supported through an

Aside from supporting people by recruiting persons to assist with housing or serve as fiscal agents, microboards often serve as a circle of support for an individual with members spending time with the person as part of his or her individual circle of support.

The ArcLink: The ArcLink at www.TheArcLink.org offers any organization the opportunity to list information about upcoming training or networking events on a searchable database. The resource is free-of-charge as a public service to the disability community.

The calendar can be searched by keyword or by intended audience. More than 6,500 visitors use TheArcLink site each month for information about available services and supports for full community inclusion. TheArcLink Calendar adds a new tool, bringing more people together for education, information and interaction.

Organizations interested in placing events on the calendar should visit the website or send an email message to Calendar@TheArcLink.org.

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

Center for Rural Health <http://www.med.und.nodak.edu/depts/rural/> Look for the Family to Families' revised website at this location. ☺ The center is committed to providing leadership in rural health.

Child Development Media Inc. http://www.childdevmedia.com/catalog2.cfm?category_id=17 This site shows many wonderful videos for families on raising children with special needs.

Northwest Area Foundation <http://www.nwaf.org/> This foundation focuses its resources on helping communities in an eight-state region (including ND) reduce poverty. Because of this focus, the foundation no longer accepts requests for grants. Rather than supporting individual institutions, the NWAFF forms partnerships with communities working to develop long-term solutions to poverty.

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