



04-22-03 # 13

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.

One of the Bismarck leadership teams is planning training around the issue of applying for Medicaid and getting family support services. They are pulling in participants from county social services, parents and the Department of Human Services. It should be a good presentation.

Please remember to send this short survey to Cathy Haarstad at haarstad@minotstateu.edu We are studying new Leadership options for teams and would like your input ASAP.

- _____ mentor another family that has a child with a similar disability
- _____ mentor a family in which a parent has an intellectual disability
- _____ learn how to write a proposal or small grant to get funding for a project
- _____ learn how to serve actively on an advisory board or committee
- _____ be active in projects within my local school district
- _____ be effective in getting the IEP my child needs
- _____ build a generic support network within my community
- _____ build/join a family support network for parents of children with special needs
- _____ lead a faith-based initiative to support families in my house of worship
- _____ leadership in accessing systems that support children/families
- _____ leadership in system change _____

_____ learn how to make use of the Internet to get information for our family
_____ learn more about a special topic _____
_____ other _____

ND Family Support Project Update: A second phone conference was held to discuss the possibility of hosting a twice a year conference in North Dakota for families. A draft of the group's vision is described below. We'd be interested hearing your thoughts on this important topic.

Present: Cathy Haarstad, Marilyn Brucker, Sue Offut, Donene Feist, Margaret Fedje
Deb Balsdon

Purpose: To develop written information that may be shared among family support agencies and professionals regarding a bi-annual family conference.

Target Audience:

Families of children and adults with developmental delays and disabilities

Care givers, providers, therapists, educators, administrators and other interested people who work with children, youth and adults with developmental delays and disabilities

Individuals with disabilities

Goal:

1. To increase family attendance and access to information and training in a face to face format using a one-stop shopping model.
2. To build individual capacity on topics related to abuse/neglect prevention, education, transition, mental health, health care, developmental delays or disabilities, financial assistance (for health care and other needs), parenting, sibling, family support, early intervention, employment, independent living, male involvement, self-determination and advocacy, legal/legislative, leadership and system change.
3. To strengthen individual/family/professional partnerships by featuring individual/family and professional partners as presenters for all sessions and by encouraging family/professional teams to attend.
4. To give individuals/families an opportunity to network and gain understanding of the service delivery system.

5. To maximize the use of time and resources of both families and professionals and avoid duplication of services in a period of fiscal restraint.
6. To determine if using parent feedback on what it would take to bring families to a training and information conference really works by following recommendations provided through research with ND families.

Format: We will host two conferences - one in the spring beginning in 2004 on the eastern side of the state and one to follow in the fall also in 2004 on the western side of the state.

Planning for the first conference will begin almost immediately with costs to be covered using funds from both Part C and Part B dollars as well as funds from the Family Support Grant and other interested sponsors.

A planning committee comprised of interested partners from the ND Family Support Advisory Council will have oversight responsibilities for the conference. A budget will be set with a percentage of funds going to a professional group OR interested partner to coordinate or facilitate the conference proceedings. An RFP process will be used to give interested parties a chance to participate.

The conference would probably be scheduled to take place over a Friday/Saturday period with details to be worked out by the planning committee. The date would be scheduled to avoid conflicts with other conferences hosted at the same time. Stipend dollars from participating sponsors would go to support family, professional and individual attendance at the conference.

A portion of the Family Support dollars from the extension grant would be used to cover the costs associated with establishing the format. Specific planning would take place to assure that the conference is self perpetuating on an ongoing basis, using buy-in from service and corporate sponsors.

The planning committee will need to recruit participants or information about obtaining corporate sponsorship.

It is felt that the broad agenda will help to obtain fiscal and talent buy-in from many agencies, families and individuals across ND. The conference will provide a format in which many participating agencies will be able to meet their training agendas or requirements to invest in family support.

Sufficient buy-in will allow us to bring in a slate of national speakers. Because of the time frames involved, it is anticipated that the conference in the spring of 2004 will be slightly smaller than the conference in the fall of 2004.

Potential sponsors include: Head Start, Early Head Start, Center for Rural Health, UND School of Medicine, Centers for Independent Living, Department of Human Services, DD and VR divisions, Division of Mental Health, Children and Family Services, Children's Special Health Services, Medicaid, Robert Wood Johnson –Dakota Medical Foundations, Covering Kids, Department of Public Instruction, ND Mental Health Association, the Federation of Families for Children's Mental Health, ND Protection and Advocacy Project, ND Association of Community Facilities, Special Education Units, Child Care Resource and Referral, Tribal Education groups, Native American Training Institute, Kids Council, Children's Services Coordinating Councils, Children's Trust Fund, ND Center for Persons with Disabilities, County Social Services, Lutheran Social Services, Catholic Family Services, Pathfinder Family Center. Voices for Children, Children Caucus, ND Association for the Education of Young Children, Blue Cross/Blue Shield, NDAD, the Arc chapters in ND, the ND Disability Advocacy Consortium, Emergency Medical Services, First Sounds, ND Academy of Pediatrics, ND Occupational Therapy Association, ND Physical Therapy Association, ND Association of School Counselors, ND Association of School Psychologists, Anne Carlson Center, IPAT, ND Vision Services, ND School for the Deaf,

Another conference call will be held at 1:00 PM on Wednesday, May 7th.

Medicaid Plus Waivers: Under the Medicaid Plus Waiver, families will have new important service options. One is called supports brokerage. What does that mean? Here is a definition from the Federal Template.

Supports Brokerage: *Supports Brokerage is a service/function that assists participating families and individuals to make informed decisions about what kind of supports will work best for them. This service must be consistent with their needs and reflect their individual circumstances. Serving as the agent of the family or participant, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services. A family or person-centered planning approach is used. Supports Brokerage offers practical skills training to enable families and individuals to remain independent. Examples of skills training include providing information on recruiting and hiring personal care workers, managing personal care workers and providing information on effective communication and problem solving. The service/function provides sufficient information to assure that participants and their families understand the responsibilities involved with self-direction and assist in the development of an effective back-up and emergency plan. States may elect to fulfill the requirement of this service/function using a self-directed case manager or creating a distinct service. States may elect to fulfill this required service/function either as a service cost or an administration cost, but must clearly identify which method will be used. The services/functions included in Supports Brokerage are mandatory requirements of the template.*

New Hampshire is one of two states to receive a Medicaid Plus Waiver. Let's look at how they defined the Supports Brokerage service in their waiver. New Hampshire, decided to call this service Consolidated Developmental Service.

"The Consolidated Developmental Service will consist of a range of home and community-based services intended to improve and maintain the child's/individual's opportunities and experiences in living, socializing and recreating, personal growth, safety and health. It is anticipated that this service will support the family as the primary caregiver of the child/individual. The specific array of services within the Consolidated Developmental Service includes:

- *Enhanced Personal Care;*
- *Consultations; Respite;*
- *Environmental and Vehicle Modifications;*
- *Family Support/Service Coordination/ (Supports Brokerage)*

One or more of the above components may be authorized for each child/individual based on his or her needs. Providers must meet the requirements specified for each of the individual service components described below, and in addition, each applicant for employment must:

- *Meet the educational qualifications, or the equivalent combination of education and experience, identified in the job description;*
- *Identify former employers and agree to 2 reference checks;*
- *Meet certification and licensure requirements of the position, if any;*
- *Present documentation of a TB test performed within the past year or undergo a TB test;*
- *Agree to a criminal records check, prior to a final hiring decision, to ensure that the applicant has no history of a felony conviction; and*
- *Be a minimum of eighteen years of age. However on an individual basis, upon agreement between the family and the Area Agency, persons as young as fifteen may be chosen as a provider.*

Family Support/Care Coordination (Supports Brokerage) including:

- *Coordinating, facilitating and monitoring services provided under the waiver;*
- *Assessing and reassessing service needs;*
- *Assistance with recruiting, screening, hiring, and training in-home support providers;*
- *Identifying, providing information regarding and assisting families to access community resources and supports;*
- *Development, review, and modification of service agreements;*
- *Providing counseling and support; Skills and advocacy training for the eligible consumer or representative;*
- *Monitoring consumer satisfaction;*

- *Initiating, collaborating and facilitating the development of a transition plan at the age of 16, to access adult supports, services, and community resources when the child/individual turns age 21, and*
- *Creating and maintaining work registries;”*

It is interesting to look at what other states are doing and to think about how we would like services in ND to be defined. If you would like to see all of the New Hampshire Waiver why not visit the Center for Medicaid Services website at:
<http://www.cms.hhs.gov/medicaid/1915c/nh0397.asp>

Legislative News: A copy of the most recent legislative grid from Protection and Advocacy is enclosed. You can see some of the bills that have passed or failed. Committees within the House and Senate are still working this week to resolve issues.

As a result of legislative action, Infant Development projects are being asked to budget for services at the same level they used in 1990, thirteen years ago, regardless of the growth in numbers of families they serve today.

Leadership Opportunities: The Rural Special Education Strategist (RSES) project at Minot State is forming an 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

More information about this advisory group is attached. Contact Dr. Joan D. Bonsness at 1-800-233-1737 if you are interested.

Leadership Links:

Autism Conference:

Autism Asperger Publishing Company will be having its third annual conference in Grand Forks, North Dakota on August 4th & 5th, 2003. The conference will offer dual tracks for Asperger Syndrome and classical autism. Participants will have the option of selecting either one or two hours of college credit. The conference will be held at the Ramada Inn and Conference Center, Grand Forks North Dakota. Register online at www.asperger.net or call 913-897-2632 or mail to AAPC, PO Box 23173, Shawnee, Mission, KS 66283

Law Enforcement handbook for victims with a disability

The Department of Justice published this handbook for law enforcement officers on how to help crime victims with a disability. The handbook specifically addresses how to help those with a mental illness, mental retardation, or who are blind or visually impaired, deaf or hard of hearing. <http://www.ojp.usdoj.gov/ovc/publications/infores/firstrep/2002/welcome.html>

SSA collaborates on video and workbook with AAP

The Social Security Administration (SSA), in collaboration with members of the American Academy of Pediatrics (AAP), developed a video and workbook as educational tools for physicians who are advocates for their patients with disabilities. These tools describe the process by which SSA provides financial assistance as a safety net for disabled children. They explain the disability application and evaluation processes, and the importance of medical evidence of record to the adjudication of disability claims. The video and workbook also include information regarding the criteria for making disability determinations, and are designed to assist consultative examiners, treating physicians, and the medical consultants employed by SSA. CME credits are available through the AAP.

SSA Pub. No. 64-082; ICN 953854 Office of Supply and Warehouse Management, 239 Supply Building, 6301 Security Blvd., Baltimore, Maryland 21235, Phone: (410) 965-2039, Fax: (410) 965-2037, Email: oplmswrmrptorders@ssa.gov

Online Survey of Parent Employment Experiences

The Common Ground Project is interested in learning about how parents caring for children with emotional or behavioral disorders manage both employment and family responsibilities. The information collected will be used to inform employers and human resource professionals about the work-family experiences and needs of employed parents or those seeking employment who are caring for children with emotional or behavioral disorders (EBD). They will also provide suggestions and strategies for finding and keeping a job when a parent is caring for a child with an EBD. <http://www rtc.pdx.edu/pgPEsurvey.htm>