



FamNet Advocacy Platform

2008-2009

DRAFT

Organization

FamNet is a not-for-profit network of ND family support agencies. We are in the formative stage of development. We are committed to enhancing the well-being of families whose children have special health care needs or disabilities. Our office is temporarily housed at the ND Center for Persons with Disabilities at Minot State University.

Advocacy Theme

Each member of the Network has a unique mission and serves diverse rural families. We have chosen one, over-arching theme to guide our advocacy work and collaboration.

We advocate for family support across the life-span!

Family support includes formal and informal supports and services. Family support makes it possible for families to stay together, successfully raise and educate their children, provide necessary health care, get and keep a job, save for the future, overcome challenges associated with their child's special health care needs or disabilities and take part in the life of the community.

Values and Principles

Our definition of families is broad and honors individual choices and diversity.

We believe that most ND families want and need community-based care and support options, especially when traditional family life is at risk.

We understand that children and families need an appropriate mix of formal/informal supports to thrive.

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We believe that supports work best when they are individualized to meet the unique needs of the child and family and are delivered in natural settings (homes and community based support).

We promote family-centered principals and practices in all systems. We work to assure that families, youth and adults with special health care needs are involved as decision makers in all aspects of service planning and delivery.

We expect public/private service systems to be organized so families can use them easily.

Families should also be able to expect that systems have knowledgeable trained staff that are accessible.

Understanding your child's disability is key to a family's ability to accept and adapt. We support collaborative efforts to provide training/education to families. We also support overall awareness/education for communities because extended families, neighbors, churches, restaurants, and businesses need to have some degree of knowledge if the family is to feel supported in their community.

We believe that service systems and policies should work together for the well-being of families. They should not be in conflict with each other.

We advocate that youth with special health care needs (YSHCN) and their families receive the information and services they need to transition to all aspects of adult life.

We listen to and acknowledge statewide input from families in setting priorities for advocacy and strive to implement culturally competent services.

We believe that out-of-home placement should always be considered as a last resort; should be viewed as temporary and must be designed and implemented as an extension of the family.

We honor strategic partnerships and work together to achieve common goals; doing together what may not be done alone to enhance the well being of families with children that have special health care needs and disabilities.

Short Term Goals

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During the 2009 legislative session and throughout year 2 of our development phase, FamNet has agreed to direct our attention the following three priorities.

- 1) Legislative and policy initiatives that affect ND families of children with Autism Spectrum Disorders (ASD) and other children with developmental disabilities that effect adaptive behavior.
- 2) Legislation and systemic policy initiatives to enhance services for transition-aged youth at risk.
- 3) [Legislative initiatives for early newborn hearing screening and follow up.](#)
- 4) To be responsive to new and emerging legislative or policy issues which are aligned with our mission and values.

Action Plan:

- 1) Review numerous state plans on Autism and state legislation mandating insurance coverage for families of children with ASD.
- 2) Meet with BCBS to share concerns about the challenges in securing treatment for children with ASD and to find common ground.
- 3) To support the governor's budget or legislation to fund a Medicaid Waiver on Autism for ND.
- 4) To support legislation creating a task force comprised of public and private payers including families and people with ASD charged with developing an effective and affordable plan to coordinate statewide efforts to combat ASD.
- 5) To support legislation advocating a systemic response based on best-practices to at-risk youth of transition age that are not currently served within the DD system.
- 6) To strengthen early intervention service initiatives that fund salary increases for respite and child care providers, increase the income levels for medically needy families, and increase the availability and funding of child care nursing consultants.
- 7) To recommend a study that will help ND revisit our status as a 209B state.

Long Term Goals

- 1) To revisit the ND MR/DD definition

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2) To work for full implementation of EPSDT (Health Tracks)