



“Uniting for a Healthy Future: Integrating Systems for North Dakota’s Children, Youth, and Young Adults”

MEETING SUMMARY

**2008 North Dakota Integrated Services (NDIS) Stakeholder Symposium
Tuesday, December 9, 2008 (8:30 a.m. to 4 p.m.)
Best Western Doublewood Inn, Bismarck ND**

Purpose of the meeting: To develop collaborative partnerships for creating integrated, family-centered, culturally competent systems of care so that children and youth with special health needs have the full equal opportunity to thrive in body, mind, and spirit.

Goal of the meeting: to set the foundation for developing a collaborative leadership and creating humane systems of care.

Facilitators: Richard A. Aronson, MD, MPH
Deanna Askew, MPA, LRD

Meeting Participants:

Name	Agency
Barbara Schweitzer	Division of Family Health
Becky Bailey	ND Department of Health
Brenda Estes-Schmid	Family Representative
Brent Askvig	NDCPD
Cathy Haarstad	NDCPD
Cheryle Masset-Martz	ND Department of Health
Cynthia Salazar	NDCPD
Donene Feist	Family Voices of North Dakota
Gerry Teevens	ND Department of Public Instruction
Heather Lee	NDCPD
Janel Schmitz	ND American Academy of Pediatrics
Jen Restemeyer	Family Representative
Joey Huber	Dakota Center for Independent Living

Judy DeWitz	Protection & Advocacy
Kari Arrayan	NDCPD
Katherine Barchenger	Children with Medically Fragile Needs
Kora Dockter	NDCPD
Linda Rorman	ND Department of Human Services
Lisa Johnson	NDCPD
Malette Young	Family Representative
Murray Nelsen	Family Representative
Myra Quanrud	Innovis Health Clinic
Pat Conway	Center for Rural Health, UND
Phyllis Howard	ND Department of Health
Tabitha Morin	Independence Inc.
Tammy Gallup-Millner	Children's Special Health Services
Tricia Kiefer	Children's Special Health Services
Twyla Bohl	Family Representative
Vickie Brabandt	NDCPD
Wendy LaMontagne	ND Department of Human Services
Vicki Peterson	Family Representative
Carlotta McCleary	ND Federation of Families
JoshAskvig	ND Education Association
LeAnn Nelson	ND Education Association

SETTING THE STAGE

Dr. Brent Askvig, Executive Director, ND Center for Persons with Disabilities, welcomed the participants and provided a brief description of the ND Center for Persons with Disabilities. See <http://www.ndcpd.org>

Tammy Gallup-Millner, Division Director, Children's Special Health Services, shared North Dakota results from the National Survey of Children with Special Health Care Needs. This helped the participants understand the national indicators of Quality Services for children and youth with special health care needs. See: www.cshcndata.org

Donene Feist, Executive Director, Family Voices of North Dakota, shared information about Family Voices of North Dakota. See: <http://www.fvnd.org>

Family Panel: Personal stories were shared by the following participants: Donene Feist, Murray Nelsen, Twyla Bohl

PLANNING FOR THE FUTURE

Richard Aronson, MD, MPH introduced the methods to be used for the remainder of the day. Future Search <http://www.futuresearch.net> is a uniquely interactive planning tool, which is derived from research on how to get people to work together for the common good.

The following ground rules were established:

- All ideas are valid
- Listen to each other
- Use clear language that all understand
- Keep recorders accurate
- Think “community”
- Have fun!

Focus on the Present

MIND MAP:

The group identified trends affecting children and youth with special health needs and their families in North Dakota by developing a “mind map.” This allowed the group to consider the trends as they planned for the future. For a visual example of a mind map, see: <http://www.futuresearch.net/method/methodology/index.cfm>.

In the center of the mind map was “**Children and Youth with Special Health Needs and Their Families.**”

Items encompassing the entire circle were:

- Increased economy in ND
- Increased aging population

Trends identified:

Increased homeless/increased awareness of service needs

Increased divorce rates/financial burden

/increase emotional/access MH for whole family

Increased adolescents, adjudicated/meds

Increase complex needs

Increased technology/people have access to more info

/increase screening, diagnostics/decrease consistency tools

/increase use of online support

Increased number of families needing services, ages 3-21

Increased awareness transitional issues

Increased insurance coverage for medically fragile and workers with disabilities

Increased awareness pre-K

Increased centralized medical care/lost orthopedic surgeon ND

/decrease primary care providers

/Increase family docs, pediatricians treating emotional disorders

Increased autism

Increase family involvement/boards

/increase family inquiries about education

Increased economic distress

/increase drop-out school
/decreased tolerance in the workplace
/decreased benefits, wages
Increased costs of all and doing business
Increased awareness Native American population
/decreased funding for NA population
/increased birth rates NA
Increased number of parents with disabilities/cognitive, physical
Decreased insurance coverage/decrease funding autism
Decreased federal funding/MCH block grant
Decreased child care/no child care centers
/decreased availability of quality care
Decreased teaching positions/special needs
/decreased school nurses
Decreased enrollment higher education/MSU
Decreased availability of specialists/dental care/mental health

PROUDS AND SORRIES:

Participants were divided into groups. Each group identified their “prouds and sorries.” Prouds were defined as current efforts in North Dakota, of which they were proud, that focused on advancing four areas: 1) medical home 2) cultural and linguistic competence 3) family involvement, and 4) youth in transition to adulthood and work. Sorries were defined as things that they are sorry aren’t happening now.

Key “Prouds”:

- Medical Home implementation
- Collaborative efforts of staff and division (CSHN) around building medical home team
- Medically fragile waiver
- Collaboration toward developing infrastructure
- ND good framework for Medical Home
- Ability to “make things happen”
- Established Office on the Elimination of Health Disparities
- Advocates on reservations (P & A) (2)
- Relationships (3)
- Greater family involvement on committees, etc.
- Increased involvement of families/increased opportunity
- Inclusion! It’s working
- ND Parent to Parent Program NOW
- People’s willingness to work together
- Willingness of others to join a team and work together for the benefit of CSHCN

Key “Sorries”:

- What does medical home really mean?
- High turnover in providers
- Meeting involvement: meet needs of families and children (dev. Leaders)
- Lack of resources for power of attorney guardianship issues (1)
- Poor accessibility in rural areas
- Decreased specialists
- Unable to bridge services with Native American population
- Lack of rural services and the ability to support rural parents
- Medical providers and staff do not know of services in ND
- Healthcare is still segregated

Observations stated from the collective group, after each small group reported:

“It was neat to feel proud.”

“The sorry was a true sorry.”

“There’s real ownership.”

“We feel connected to one another through a day like this.”

“Still work is done in silos...through group like this, we can identify people to work with...”

“Interconnection today...”

Focus on the Future

Groups were asked to visualize their community and the whole state of North Dakota as a place in which children and youth with special health needs, and their families, thrive in the fullest sense. Each group selected a creative way to present their vision as it is happening now on December 9, 2018.

Four groups presented their future scenario:

1. News story, “Changes in Healthcare in a Tropical Nutshell”
2. “Who Wants to Be a Millionaire?”
3. Clinic scene with an anxious mother and baby, meeting the physician for the first time
4. News story about the Medical Home Initiative, with North Dakota leading the nation

Recurring themes were:

Medical Home

Care Coordination

Cultural Competence

Education and teachers – willingness to teach

Access

Family Support

Attitudinal Shift

Common Ground for the Future

Collectively, the participants brainstormed a list that reflected what they believed every person was willing to work on together. The group confirmed specific areas, with none of those identified being moved to the “not agreed” list.

The following is the entire list of common ground items: (Items identified with an * are the ones that the group agreed to be the most important.

- *Family-centered/family involvement (DONENE)
- *Coordinated Services (System) (CATHY)
- Care coordinators
- Health care access
- *Smooth transitions at all ages (MAURY)
- Practical community-based resources
- Teachers’ limited resources
- *Trained service providers (Medical Home) (MYRA)
- Best practices
- Improved funding streams
- Insurance coverage, newborn screenings, care coordination, medical caps
- Removal of bias re: people with disabilities, attitudinal change
- Planning for sustainability
- Involvement of stakeholders
- *Reduction in health disparities (PHYLLIS)
- Cultural competence
- *Care Coordination (CATHY)
- Need for public awareness
- *Attitudinal changes (PHYLLIS)

Action Planning

The following 5 groups were identified to be future working committees as a result of this stakeholder meeting: *(The person in parentheses following the group is the person who agreed to move these committees forward)*

1. Family-centered/Family Involvement (*Donene Feist*)
2. Coordinated Services/Care Coordination (*Cathy Haarstad*) ***(May be combined with Medical Home and Family Area)***
3. Smooth Transitions at all ages (*Murrey Nelsen*)
4. Medical Home- Trained Service Providers (*Myra Quanrud*)
5. Health Disparities/Attitudinal Changes (*Phyllis Howard*)

Kora Dockter (*NDCPD, contact information listed below*) will work with the identified leaders as stated above to coordinate the future meetings of these committees. Some areas may be combined with other groups. NDCPD can make the technical arrangements for the committee meetings (i.e., coordinate conference calls).

Each committee should:

- Determine a name for their committee
- Establish a chair, if different from the person identified above
- Maintain contact with Kora Dockter
- Work with Kora Dockter and staff to develop meeting schedule, determine goals for their committee that meet the needs of the Integrated Services Grant, as well as needs of group members
- Share goals between the committees to avoid duplication

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