



Early Intervention/Education and Disability Summit White Paper
July 22, 2009
Jamestown, ND

As part of the Developmental Disabilities Assistance and Bill of Rights Act, and with a strong belief that the American Dream belongs to everyone, three organizations formed a collaborative network to service individuals with developmental disabilities living in North Dakota. The network was named the North Dakota Developmental Disabilities Network (NDDDN), and includes: The North Dakota Protection and Advocacy Project, the North Dakota Center for Persons with Disabilities, and the North Dakota State Council on Developmental Disabilities. The trio strives to assure that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration, and inclusion in all facets of community life.

The activities of each entity belonging to NDDDN fall within core emphasis areas established at the federal level. Emphasis areas include:

- quality assurance activities
- education and early intervention activities
- child-care related activities
- health-related activities
- employment-related activities
- housing-related activities
- transportation-related activities
- recreation-related activities
- other services available/offered to individuals in a community, including formal and informal community supports that affect quality of life

To gather current input on these emphasis areas, a series of summit meetings were designed. The summits were structured to encourage discussion and input from participants, and to gather information from professionals working in the emphasis areas. Each summit meeting covered one emphasis area, began with a keynote speaker, involved the audience in small group work, and featured a panel of presenters who discussed their particular experience with some aspect of the emphasis area. During the small group work, participants developed lists of actionable steps that could be used by NDDDN agencies in planning yearly goals and objectives. Results of the summit meetings are published in white papers and broadcast through websites to make information available to a broader range of constituents.

On July 22, 2009, the Gladstone Inn in Jamestown, ND hosted the Early Intervention/Education and Disability Summit. The summit opened with an explanation of the NDDDN and its purpose. Participants

of the workshop were introduced, and asked to identify their expectations for the summit. Identified expectations included:

- Learn about ECE
- Statewide collaborations
- Build Family Partnerships between agencies for greater impacts
- Gap filling/information/em:supp

Challenges surrounding the early intervention/education and disability include:

- Identification = connection (referral form)
- Bridging Programs/How do we partner?
 - School/After School
 - Public/Private
 - What are families doing?
- Gaps in services for those who may not qualify for services
- Preservice education
 - More education/phil. family supports, etc. included
- Parents with DD who have children
 - Lack of trust
- Children with disabilities in a traditional daycare
- Gap in early intervention to traditional school (all support is lost)
- Loss of Medicaid due to not screen of DD waiver
- Disconnect (Social Services/Human Services)
- Health Insurance cap outs – babies
- Family decisions to obtain supports
 - i.e. divorce, etc.
- Service delivery systems are too complex
 - Need family navigator for the system
- Inequities – Why some people receive certain services and others don't
- Difficulty within the local area/state case managers
- Fragility of families
 - Family centered policies to focus on the gaps

Rhonda Eppelsheimer from the Anne Carlson Center was the keynote speaker. Ms Eppelsheimer presented an overview of the Anne Carlson Center community based service model and the importance of strong partnerships, communication, and collaboration between families, agencies and schools for effective service coordination

Based on the information presented by the keynote speaker, four main topic areas were developed and written on flow charts, which were then placed around the room. Following the keynote presentation, summit participants were directed to pick the topics they were most interested in, and spend fifteen minutes in discussion to identify actionable steps that could address each topic area. This process was completed three additional times, which provided participants the opportunity to discuss all topic areas. Topic areas and actionable steps identified during the small group work included:

Early Intervention:

State:

- Bring Safe Care training into ND and use Train the Trainer model to develop expertise across state.
- Expand developmental screening options and Child Find
- More money for advertising of programs that screen, like Right Track
- Transition to school and services streamlined
- Utilize family support organizations in addition to EP's.
- Good parent materials on EI that is easily understood
- NICU assist
- Fund EI to be viable and stay viable entities
- Provide more family supports across the board and fairly instead of letting it depend on who your case manager is.
- Serve "at risk" kids from Part C to Part B instead of going with two standard deviations below

Local:

- Expand Village Team concept used in several rural communities
- RICC's stay in place reciprocal with direction from state – circle for continuity
- Education with LEA's and be more interactive – to instill EI and its existence
- Smoother transitions from Part C to Part B
- Re-educate schools about "fiscal savings" by serving kids earlier than later, instead of "wait and see" approach.
- Let local programs purchase needed materials rather than state level

Connecting Programs:

State:

- Opportunities for training – cross agency training
- Encourage usage of program to include disabilities - Bridges to Benefits
- Increase Parent Navigators to lead family support as paid staff – Regional based – contract FVND
- Parent Teacher Organizations specific to Special Ed/IDEA in communities (SeptA)
- More mapping work with families
- Using technology to help connect families with their team members
- Connecting daycare providers to support services
- Listen to the people who are working in the trenches! ! !
- More Respite services and more flexibility in how they are used.

Local:

- Personal staff commitment to learn about other programs
- Regional parent navigators
- Increase collaboration of local partners to "play in sand box together" for best interest of child and family

- More mapping work with families
- More training for EP's

Complex Service Delivery Systems:

State:

- Make sure everyone is trained (consistent training) with same information, have information accessible to families and family organizations
- Help family organizations with money to increase outreach of programs.
- Empower case management to be able to do what needs to be done, what they can do and should do
- Statewide advertising for programs (e.g. brochures, billboards, TV/cable ads, etc.), keep websites current and user friendly

Local:

- Make sure everyone is trained (consistent training) with same information, have information accessible to families and family organizations – including making sure local people/entities have information not just state level staff

Both State and Local:

- Engage the medical community
- Lower caseloads
- Have agencies understand what each does and be willing to make referrals
- Parent to parent support for navigation in each region (as Navigators)

Gaps in Services:

State:

- Consider serving 3 year olds "at risk" at school level (Part C → Part B)
- Reconsider eligibility criteria for 2 yr 9 mo determination for DD
 - Rescreen at age 3
 - Then again at age 5
 - Again at age 12
 - Again at age 18
 - Again at age 21
- Gap in Medicaid coverage under new waiver regs i.e. 1) after 20 days of hospitalization child discharged from EI. 2) No longer can serve child in NICU so can't start receiving waived service until discharge.
- Increase P2P supports
- Increase Parent Navigator
- Behavior/HealthCare
- Consultation in Child Care (need state general fund money)
- Increase school nurses/social workers
- Agencies pool money for family leadership and to increase understanding of their rights and navigators/parents (P2P)

Local:

- Keep Advocating “begging” school districts to serve 3 year olds coming from Part C!
- Serve more children/families collaboratively through ID and center-based EHS.

Both State and Local:

- Someone to advocate for kids such as educational advocate so child does not get lost
- Help for young DD parents with children of parents with other disabilities

After completion of the small group work, a panel presentation took place. Panelists shared their perspectives and experiences, identifying challenges they face, unmet needs they have identified, and potential solutions for those needs. The panel, composed of a combination of professionals, included the following individuals:

Missi Baranko– Coordinator for ND Parent to Parent program with Family Voices of ND. Ms Baranko has served in an advisory capacity on a number of disability and early childhood related projects.

Roxane Romanick– State Family Liaison for the ND Early Intervention System through North Plains Special Education. Ms Romanick, in her personal and professional capacities, has had experience with direct parent support, program and policy development, advisory involvement and advocacy.

Rose Greer - Works at Community Action Head Start with children ages 0-3 and pregnant women. Previously she has facilitated, advocated and coordinated services for children and families. Ms Greer has worked in clinical nursing through Freedom Resource Center for Independent Living and Easter Seals Goodwill of ND.

Kathy Lee– Project Director for the Minot Infant Development Program. Ms Lee has worked in a variety of settings including public schools in regular education as well as special education programs, state institutions and a vocational workshop. She currently is on a state committee to establish Early Learning Guidelines for ND.

Outcomes/Lessons Learned:

Upon completion of the panel discussion, participants of the workshop were asked to vote on what they felt were the highest priority steps that had been identified during the earlier small group work. Each participant was instructed to cast three votes, and had the options of voting for three separate issues, or casting all three votes for one issue that they felt the strongest about. Actionable steps identified as highest priorities as well as the number of votes cast for each are as follows:

Number of votes:

7

Issue

- Reconsider eligibility criteria for 2 yr 9 mo determination for DD
- Rescreen at age 3
 - Then again at age 5
 - Again at age 12
 - Again at age 18
 - Again at age 21

4	Parent to parent support for navigation in each region (as Navigators)
3	Statewide advertising for programs (e.g. brochures, billboards, TV/cable ads, etc.) keep websites current and user friendly
3	Behavioral/Health Care consultation in Childcare (need state general fund money)
2	Transition to school and services streamlined
2	More Respite services and more flexibility in how they are used
2	Using technology to help connect families with their team members
2	Help family organizations with money to increase outreach of programs
1	More training for EP's
1	Connecting daycare providers to support services
1	Bridging programs/How do we partner? School/After School Public/Private What are families doing?
1	Bring Safe Care training into ND and use "Train the Trainer" model to develop expertise across state.
1	Provide more family supports across the board and fairly instead of letting it depend on who your case manager is.
1	Smoother transitions from Part C to Part B.
1	Consider serving 3 year olds "at risk" at school level (Part C → Part B)
1	Increase school nurses/social workers

The identified issues and proposed actionable steps can now be used to guide future strategic planning for the three partners of the NDDDN, providing the agencies with a road map of needs and priorities to reference when designing programs and work plans for the future. Although the summits were originally designed to elicit feedback from constituents on priority issues and actionable steps, indirect outcomes also resulted from the interactive group work, including:

- Networking among professionals from various agencies
- Education regarding services offered by agencies and programs
- Identification of new/increased priority areas for agencies
- Identification of possible funding sources for additional training
- Discussion of how agency personnel can collaborate on various issues

The primary objective of the Early Intervention/Education and Disabilities Summit to gather current information on issues and identify actionable steps was successfully met. As a result of the excellent interactive group work and lively discussion among attendees, participants unexpectedly identified individual action steps for themselves and their agencies.

NDDDN agencies now have current information to carry forward into planning processes. Using the information gleaned from the summit meeting, NDDDN members can structure work plans and design programs that are relevant to the needs of consumers and that ensure individuals with developmental disabilities have access to high quality programs and services that will promote self-determination, independence, productivity, integration and inclusion in all facets of community life.

Sponsored by the
North Dakota Developmental Disabilities Network (NDDDN)

