

Health Care and Disability Summit White Paper

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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 were published in white papers and broadcast through websites to make information available to a broader range of constituents.

On March 12, 2009, the Health Care and Disability Summit took place in the Missouri Room – Student Center – Minot State University, Minot, ND. The summit opened with an explanation of the NDDDN

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

- Access to remote rural areas
- Concerns about hospitalist concept and people with disabilities
- Access to dental care for people with disabilities
- Medicaid State Status
- Care coordination
- Where to refer
- Fitness/Weight
- Advocacy for healthcare
- People with disabilities – differences in obtaining healthcare
- ND Health Services Network
- Social Security and benefits in healthcare
- Work incentives
- Community transitions
- Health transitions to adults
- Prevention
- Disability as a culture in healthcare

To start the presenters' session, Kari Arrayan, program director of ND Disability Health project presented on her role of previously providing training to ND law enforcement agencies on disability related issues, peer coaching and behavior intervention.

From information presented by Ms. Arrayan, 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 ten to fifteen minutes in discussion to identify actionable steps that could be address each topic area. This process was completed two additional times, which provided participants the opportunity to discuss a total of three topic areas. Topic areas and actionable steps identified during the small group work included (with total number of votes received from the participants):

Obesity:

State:

- Educate people with disabilities and providers about importance/rights to be active throughout life span
- Insurance coverage to support groups to encourage participation (ex. Weight Watchers)
- Work with nutritionists and physicians to increase awareness of the effects of medications such as weight gain
- Educate and support case managers/support staff on nutrition/physical activity planning meals/prep
- Review effectiveness of MSU nutrition module
- Policy to increase health and wellness in school
- Employers encourage/promote fitness eg: encourage employees to get up and walk twice a day

- Assistance programs for people with fixed incomes to be able to afford healthy food (like WIC)

Local:

- Explore affordable transportation and accessibility to weight loss centers, Fitness/Health Centers
- Create adaptive fitness equipment center
- Picture/video guide to use when shopping/cooking for people who are unable to read
- Increase knowledge of how to lower caloric intake in small ways
- Work together with mental health and recognize that physical activity/mental health are linked
- Implement programs ex: ICDI to increase physical activity/nutrition
- Cognitive appropriate understanding of implement of fitness
- Training on healthy cooking/meal planning
- Curriculum in the schools when kids are young on the importance of fitness/eating healthy
- Promote peer support to exercise

Diabetes Awareness:

State:

- Make resources (materials, sites, classes) available to specific types of disabilities (cognitive, physical, etc) and family support organizations (MYPAD)
- In-Home support/coaching (Develop a model)
- Educate about secondary conditions ex amputation CVD
- Awareness of diabetes screening
- Develop information on availability of free or low cost diabetic supplies and resources
- Assure diabetic testing supplies are accessible and inform caseworkers, etc about the supplies and equipment
- State entities/support staff prioritize nutrition and testing devices
- Make testing monitor that talk – easier to use – more affordable for people with disabilities
- Educate youth and individuals at risk about prevention especially with Native American population

Local:

- Make sure local cooking classes are accessible and advertised at local agencies dealing with people with disabilities
- Tie into social clubs (ex. 2nd Story) where it is not seen as “education” and is non-threatening
- Include medical professionals in meetings, trainings, etc
- Work with tribal leaders/providers to reduce prevalence
- Use “Partner Up” mentoring/motivator to increase health wellness

Mental Health:

State:

- Program Funding for Mental Health medication
- One Stop resource level
- Insurance reimbursement for Hospital stays/transitional
- Fact Sheet – Benefits of taking medications
- Advocate for equal reimbursement for physical and mental health
- Sensitivity training for law enforcement
- ID high risks/localities
- ID prevalence of emotional distress in youth with disabilities

Local:

- Educate physicians to recognize mental health issues as a secondary condition
- Educate public
- Local Resource Center
- Peer supports
- Create peer support program statewide
- Educate regarding link of physical activity/mental health
- ID transitional services
- Encourage employers to utilize Employee Assistance Programs

Both State and Local:

- Educate legislatures

Tobacco Cessation:

State:

- Connect DD providers to cessation programs
- Using settlement dollars for North Dakota to be sure people with disabilities and disability issues are considered during development
- Smoke –Free public places
- Tie employee health incentives into cessation programming (include DD provider)
- Provide disability accessible material to ND Quit-Line staff
- Explore mentoring effect on cessation
- Saturate public with messages via media (include people with disabilities) include smokeless tobacco products
- Gather data on number of people with DD served by providers who use tobacco
- Find out if data exists regarding long term effects (financial and physical) on businesses – Make employers/providers aware
- Educate regarding fire hazards

- Educate/Data regarding second hand smoke and it's effect on people with disabilities
- Giving other choices in activities that are healthy (social life without smoking)

Local:

- Utilize public health for small group training

Both State and Local:

- Education

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:

Kora Dockter, R.N., B.S.Nc. – Kora is a registered nurse and holds a Bachelors of Nursing Science Degree from MedCenter One's College of Nursing. Kora has almost 15 years of pediatric nursing experience ranging from clinical to administrative nursing, most recently working with children with special health care needs at the state level.

Dawn Olson– Dawn Olson is a Consumer Liaison for NDCPD. She is responsible for coordinating the activities and meetings of the NDCPD Consumer Advisory Council, an advisory group to the Center.

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:

<u>Number of votes:</u>	<u>Issue</u>
4	Access to remote rural areas
4	Concerns about Hospitalist concept and people with disabilities
3	Access to Dental Care for people with disabilities
3	Explore affordable transportation and accessibility to weight loss centers, Fitness/Health Centers
2	Medicaid State Status
2	Care Coordination
2	Program Funding for Mental Health medication
2	Educate people with disabilities and providers about importance/rights to be active throughout life span

- 2 Insurance coverage to support groups to encourage participation (ex. Weight Watchers)
- 2 Create adaptive fitness equipment center
- 2 Picture/video guide to use when shopping/cooking for people who are unable to read
- 2 Connect DD providers to cessation programs
- 2 Make resources (materials, sites, classes) available to specific types of disabilities (cognitive, physical, etc) and family support organizations (MYPAD)
- 2 In-Home support/coaching (Develop a model)
- 1 One Stop resource level
- 1 Insurance reimbursement for Hospital stays/transitional
- 1 Fact Sheet – Benefits of taking medications
- 1 Advocate for equal reimbursement for physical and mental health
- 1 Educate physicians to recognize mental health issues as a secondary condition
- 1 Work with nutritionists and physicians to increase awareness of the effects of medications such as weight gain
- 1 Increase knowledge of how to lower caloric intake in small ways
- 1 Using settlement dollars for North Dakota to be sure people with disabilities and disability issues are considered during development
- 1 Smoke –Free public places
- 1 Educate about secondary conditions ex amputation CVD
- 1 Make sure local cooking classes are accessible and advertised at local agencies dealing with people with disabilities
- 1 Tie into social clubs (ex. 2nd Story) where it is not seen as “education” and is non-threatening

The identified issues and proposed actionable steps can now be used in strategic planning for the agencies belonging to NDDDN, providing the agencies with a road map of needs and priorities to look at when designing programs and work tasks for the future. Although the summits were originally designed to elicit feedback from constituents on priority issues and actionable steps, other 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 objective of the Health Care 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)

