

SAND (Support Autism in North Dakota)  
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**PROBLEM:** In North Dakota, children and youth with autism spectrum disorders are under identified, lack a coordinated support system for families, and have difficulties accessing diagnostic team evaluations. Much of this problem relates to our rural issues and lack of qualified personnel. Medical and related professionals need help in learning about and conducting early screening, and in developing and conducting team assessments. Families and professionals need access to accurate information and resources. Further the ND ASD Task Force lacks sufficient funding to implement components of its Strategic Plan.

**GOAL(S) AND OBJECTIVES:** Goal 1: By 2014, 75% of North Dakota children and youth will receive quality early and continuous screening services for ASD. Goal 2: By 2014, 50% more North Dakota children and youth will receive high quality (gold standard) interdisciplinary diagnostic assessments for ASD. Goal 3: By 2014, North Dakota families and professionals will report increased awareness of ASD issues and the services that are available. Goal 4: By 2014, 200 North Dakota families of children and youth with ASD who request information and resources will receive family support services that are culturally competent and promote the medical home. Goal 5: By 2014, North Dakota will have improved infrastructure (e.g., legislative policy and funding for autism services, state mandated insurance coverage for autism services, public policy directed toward increased ASD services) necessary to provide comprehensive, coordinated health care and related services for children and youth with ASD and other developmental disabilities into adulthood.

**METHODOLOGY:** The combined efforts of the ND ASD Task Force, ND CSHS, Family Voices of ND and SAND will address the needs of North Dakota children and youth with or suspected of having autism spectrum disorders. We will implement strategies to address early identification and screening, appropriate and effective practices, quality providers, infrastructure development, information access, and family support. SAND staff will train personnel on early screening and diagnostics processes of ASD. Of particular relevance here will be the use of telehealth technologies to bridge rural systems issues. Evidence-based information about ASD will be available to all ND citizens. Family Voices of ND will provide information and emotional family support to target families. And SAND staff will work with the ND ASD Task Force in ongoing infrastructure development to serve our children and youth.

**COORDINATION:** SAND staff will work with ND's Children's Special Health Services Division, Family Voices of ND, the ND Department of Human Services, and the ND ASD Task Force. SAND staff will participate in national grantee meetings as well as the federal learning collaboratives.

**EVALUATION:** SAND will conduct both impact and process evaluations. A key component of the evaluation plan will be to use an Evaluation Advisory Team made up of key partner representatives and two parents.

**ANNOTATION:** NDCPD will work with a collaborative partnership to increase the numbers of children screened and diagnosed with ASD. Staff will work with physicians, early childhood providers and others to increase these evaluations. Staff will train practitioners to use telehealth technologies to deliver interdisciplinary team assessments of ASD. Evidence-based information on ASD and its implications will be distributed throughout the state and particularly to policy makers. Family support services will be improved, and infrastructure development will occur with the ND ASD Task Force.

**Table 2. ASD Relationship between State Autism Plan, MCH, and SAND**

State Autism Plan Vision Statements	MCH Six Systems Indicators	SAND Project Goals
A. Early Identification and Screening	3.Early and continuous screening, evaluation and diagnosis, and intervention	SAND Goal 1, Goal 2
B. Appropriate and Effective Practices	3.Early and continuous screening, evaluation and diagnosis, and intervention	SAND Goal 2, Goal 3
C. Quality Providers	3.Early and continuous screening, evaluation and diagnosis, and intervention	SAND Goal 1, Goal 2
D. Funding Issues	4.Adequate public and/or private financing of needed services	SAND Goal 5
E. Information Access	2.Access to comprehensive health and related services through the medical home 6.Successful transition to all aspects of adult health care, work, and independence	SAND Goal 3, Goal 4
F. Family Support	5.Organization of community services so that families can use them easily	SAND Goal 4
G. Accountability	1.Family/professional partnership at all levels of decision-making	SAND Goal 5

**Table 4. Work Plan for the SAND Project**

<b>Goal 1: By 2014, 75% of North Dakota children and youth will receive quality early and continuous screening services for ASD.</b>			
<b>Activity</b>	<b>Timeline</b>	<b>Responsibility</b>	<b>Outcome/Product</b>
<i>Activity 1.1: Discover reasons for lack of screening use by medical professionals.</i>	Q1-3	PC1	Reasons will be identified
<i>Activity 1.2: Train individuals working directly with children to recognize the early signs of autism.</i>	Q1-12	PC1, PC2, TAL	At least 100 individuals will be trained
<i>Activity 1.3: Train individuals working directly with children to effectively utilize and interpret initial screening tools, such as the M-CHAT.</i>	Q1-12	PC2, TAL	At least 30 individuals will be trained
<i>Activity 1.4: Present information to ND pediatricians on the importance of ASD screening, methods of incorporating screening into existing practices, and follow-up options.</i>	Q1-12 on an annual basis	PI	At least 20 new pediatricians will be trained
<b>Goal 2: By 2014, 50% more North Dakota children and youth will receive high quality (gold standard) interdisciplinary diagnostic assessments for ASD.</b>			
<b>Activity</b>	<b>Timeline</b>	<b>Responsibility</b>	<b>Outcome/Product</b>
<i>Activity 2.1: Finalize team training materials.</i>	Q1-3	TAL	A list of materials will be compiled
<i>Activity 2.2: Recruit school, hospital, clinic and other interdisciplinary teams/team members for training.</i>	Q1-9	TAL	A list of new team members will be completed
<i>Activity 2.3: Deliver training to interdisciplinary teams.</i>	Q1-12	TAL, TS	Dates of team trainings will be compiled
<i>Activity 2.4: Project staff will provide technical support to interdisciplinary teams.</i>	Q1-12	PI	A list of technical support activities will be provided
<b>Goal 3: By 2014, North Dakota families and professionals will report increased awareness of ASD issues and the services that are available.</b>			
<b>Activity</b>	<b>Timeline</b>	<b>Responsibility</b>	<b>Outcome/Product</b>
<i>Activity 3.1: Disseminate information about ASD and the services available in ND to families and professionals through a statewide outreach campaign</i>	Q1-12	PC1, PC2	A list of dissemination activities will be compiled
<i>Activity 3.2: Develop a Road Map of "What's next" to guide families and professionals through screening, diagnosis, educational options, and family support.</i>	Q1-4	PC2, WS	The Road Map is developed and fully implemented online
<i>Activity 3.3: Partner with Children's Special Health Services (CSHS) to revise and disseminate the CSHS Autism Resource Booklet.</i>	Q1-12 on an annual basis	PC1	A copy of the CSHS Autism Resource Booklet will be provided

**Goal 4: By 2014, 200 North Dakota families of children and youth with ASD who request information and resources will receive family support services that are culturally competent and promote the medical home.**

Activity	Timeline	Responsibility	Outcome/Product
<i>Activity 4.1: Increase ASD information on the FVND website.</i>	Q1-8	PI	At least 20 new website posts will be provided
<i>Activity 4.2: Family Voices will host monthly conference calls for families.</i>	Q1-11	PI	A list of conference call dates, topic name, and attendees will be compiled
<i>Activity 4.3: Family Voices will provide individual family support via email, website, and telephone calls.</i>	Q1-12	PI	A list of family support activities will be provided; including number of activities and method of delivery

**Goal 5: By 2014, North Dakota will have improved infrastructure (e.g., legislative policy and funding for autism services, state mandated insurance coverage for autism services, public policy directed toward increased ASD services) necessary to provide comprehensive, coordinated health care and related services for children and youth with ASD and other developmental disabilities into adulthood.**

Activity	Timeline	Responsibility	Outcome/Product
<i>Activity 5.1: Maintain current partnerships and build new ones with individuals, groups, and organizations that have the capacity to support and positively impact the lives of families and individuals with ASD.</i>	Q1-12	PI	A list of partnerships and their roles will be compiled and reviewed annually. At least 5 new agencies will be added by the end of year 3
<i>Activity 5.2: SAND staff will work closely with the Autism State Task Force.</i>	Q1-12	PI	A list of Task Force meetings attended, type of support provided, and products developed through Task Force meetings will be compiled
<i>Activity 5.3: SAND staff will provide data, information and testimony to relevant legislative, policy and regulation discussions.</i>	Q1-12	PI	Copies of data and information presented will be provided

**Key:**

**Timeline:** Q1-4 = Quarters in Year 1; Q5-8 = Quarters in Year 2; Q9-12 = Quarters in Year 3

**Personnel:** PI = Principal Investigator (Lori Kalash), PC1 = Project Coordinator 1 (Angela Richter), PC2 = Project Coordinator 2 (Hilory Liccini), TAL = Team Assessment Leader (Christy Helwig), WS = Website Specialist (Chad Fenner), TS = Telehealth Specialist (Steve Peterson)