Autism Spectrum Disorder Task Force

STRATEGIC PLAN REPORT

DECEMBER 2012

AUTISM SPECTRUM DISORDER TASK FORCE:

STRATEGIC PLAN REPORT DECEMBER 2012

In 2011 Minnesota Legislative Special Session Laws, Chapter 9, Sec. 95 the Minnesota Legislature directed the Autism Spectrum Disorder Task Force to:

> develop an autism spectrum disorder statewide strategic plan that focuses on improving awareness, early diagnosis, and intervention and on ensuring delivery of treatment and services for individuals diagnosed with an autism spectrum disorder, including the coordination and accessibility of cost-effective treatments and services throughout the individual's lifetime.
>
> The task force shall submit its strategic plan to the legislature by January 15, 2013. The task force shall continue to provide assistance with the implementation of the strategic plan, as approved by the legislature, and shall submit a progress report by January 15, 2014, and by January 15, 2015, on the status of implementation of the strategic plan, including any draft legislation necessary for implementation.

The Minnesota Autism Spectrum Disorder (ASD) Task Force created a planning subgroup to carry out this work including parents of children with autism, providers, state agency staff, school district staff, University of Minnesota staff, and parent advocacy organizations. (The subgroup member list is included in Appendix A.) On behalf of the Task Force, the Minnesota Department of Health engaged the Minnesota Management & Budget Department's division of Management Analysis & Development to help plan, facilitate, and document the results of a Minnesota ASD strategic plan.

The subgroup met four times between August and November 2012 to draft the strategic plan. They also met twice with the full ASD Task Force to share working drafts and get feedback, and once with the governor to share progress and discuss possible next steps.

The planning subgroup drew on several previous plans and reports, including the Autism Spectrum Disorder Task Force January 15, 2012 Final Report and draft Minnesota Autism/ASD Summit Committee State Plan. This planning group differed from these earlier efforts in that it included members of all four state agencies charged with addressing ASD (Education, Employment & Economic Development, Health, and Human Services) along with representatives of community agencies and communities affected by ASD, and that its work is overseen by the legislatively mandated ASD Task Force.

The strategic plan includes a brief introduction, a three- to five-year vision for the state as it would be improved by the work coordinated through the ASD strategic plan, and broad strategies for achieving that vision. These were developed by the strategic planning subgroup and approved by the full ASD Task Force. This report also includes "possible implementation activities" along with many of the strategies. These were not reviewed or approved by the full Task Force, but are included in order to illustrate the action steps discussed during strategic planning, which may be considered as part of implementation planning.

[1]Complete legislation is included in Appendix A

[2] http://archive.leg.state.mn.us/docs/2012/mandated/120070.pdf

[3]http://www.ici.umn.edu/

INTRODUCTION

Autism Spectrum Disorder (ASD) is a complex developmental disorder that affects a person's ability to communicate, form relationships with others, and respond appropriately to the environment. Repetitive behaviors and restricted, narrow interests are common. Autism affects individuals differently, and because of the varying degrees of severity it is called a "spectrum disorder." The term "autism" is often used synonymously with "Autism Spectrum Disorder" and the term ASD will be used in this report to include related developmental disorders such autism, Asperger's disorder and PDD-NOS[4]. Individuals on the spectrum range from those who have cognitive impairments, inability to communicate, severe behavior challenges including self-injurious behaviors to those who have average to above average intelligence, yet impaired social skills and perspective-taking ability. Family income, lifestyle, and educational levels do not affect the chance of a child having autism. While ASD is a lifelong condition, significant improvements can be made with appropriate services and supports.

ASD is the fastest growing developmental disorder in the United States. In 2012 the Centers for Disease Control (CDC) reported that it affects one in every 88 children. It is five times more likely in males, affecting nearly one in 54 boys identified compared with one in 252 girls.

The Minnesota Department of Education (MDE) provides reliable statewide data regarding ASD categorical eligibility for special education services. According to MDE data:

- **Minnesota schools reported 15,378 individuals have met the educational criteria for ASD and were receiving special education services in 2011, 12 percent of the statewide special education population.**
- **The special educational identification of ASD in individuals aged birth to 21 years in Minnesota has increased more than 300 percent since 2001 (MDE, 2011).**

Among children who have ASD, access to adequate health care and educational services on a consistent statewide basis remain major challenges (i.e. early identification/ diagnosis, access to community services, education, medical treatment and transition preparation to adult life). Further, significant disparities exist across both socioeconomic and ethnic/racial groups in ASD diagnosis and access to intervention services (Liptak et al. 2008, Mandell et al., 2009).

The increase in ASD prevalence highlights the need for high quality, accessible services and supports that begin as soon as ASD is suspected and extend throughout the lifespan. Ongoing, effective supports are needed to enable not only young children, but also adolescents and adults, to live healthy and productive lives in their own communities. This strategic plan envisions that individuals with ASD receive individualized, evidence-based, culturally responsive, inter-disciplinary services and supports. However, ASD services and supports have been both vital and costly: The Autism Society of America estimates that the lifetime cost of caring for a child with autism ranges from $3.5 million to $5 million.

Research suggests that the cost of lifelong supports can be decreased by as much as two-thirds with early diagnosis, appropriate intervention, and effective coordination of services (Jarbrink & Knapp, 2001). Research also suggests that significant cost savings can occur if intervention is coordinated appropriately and if there is a good support match for individuals and families with ASD (AuSM, 2010).

The need for statewide leadership across professional disciplines, state agencies, higher education, autism organizations, and other service providers was recognized by the 2011 Minnesota Legislature in appointing task force members from all of these groups and charging them with developing a strategic plan. Having a statewide strategic plan will support the efficient use of state and federal dollars and an effective system of high quality, evidence-based, interdisciplinary, culturally appropriate services and supports for individuals with ASD in Minnesota.

[4]PDD-NOS = Pervasive developmental disorder not otherwise specified

MINNESOTA AUTISM SPECTRUM DISORDER STRATEGIC PLAN

V I S I O N

The elements here describe the desired outcomes in three to five years as a result of the work to implement the Minnesota ASD strategic plan. The vision is described in the present tense, as things would appear once these outcomes are realized.

A. Early, timely and continuous, accessible screening and assessment

Individuals with ASD and their families have early and timely access in every region of the state to a seamless, culturally responsive, high quality, evidence-based procedure for screening and assessment. They are served by a comprehensive, multidisciplinary identification system that coordinates education, social services, community supports, and physical and mental health systems. Referrals are made so that timely follow-up happens after needs are identified.

B. Well informed, empowered and supported families and caregivers

Families and caregivers have easy access to unbiased, culturally and linguistically appropriate information to answer questions, address concerns, and are able to easily navigate a road map to resources and supports. Families and caregivers are active, equal participants in the team, helping to drive the process.

C. Coordination of services

Coordination of services to individuals with ASD happens behind the scenes (system) and around the individual from birth through adulthood. A seamless, comprehensive service system coordinates a single individualized intervention plan that incorporates physical and mental health, educational and family needs and goals. Coordination includes key transition periods throughout an individual's life.

D. Transition to adulthood

Preparation for individuals' desired outcomes from school to post-secondary education, employment and independent living begins by at least ninth grade. Supports for transition to adult supports are seamless and comprehensive, and incorporate physical and mental health, educational and family needs and goals.

E. Access to services throughout the state

Evidence-based interventions and services are accessible and funded in all geographic areas in the state to all cultural and socio-economic groups across the ASD spectrum. All students with ASD have access to tools and technology to better accommodate their communication and learning differences.

F. Competent practitioners and supportive communities

Awareness of ASD exists among employers, landlords and the general public. Competency in ASD is an expectation for practitioners (pediatricians, family practice, teachers, paraprofessionals, mental health providers, child care providers, vocational rehabilitation counselors, etc.), trained first responders, and those involved in the judicial system.

G. Funding supports families

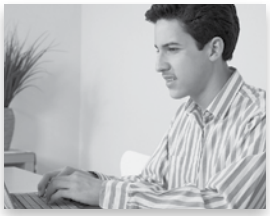
To enable the above outcomes to take place, all families of individuals with ASD have access to multiple sources of funding for necessary services.

H. Data-informed policy

Data is used to inform practice and policy. Data is regularly collected, reviewed and analyzed to inform improvements to the system, and a Minnesota-specific surveillance system exists.

I. Ongoing emphasis on implementation of the strategic plan

A structure is in place and functioning to follow through on and continually update the vision and strategies laid out in this strategic plan.



STRATEGIES

The 31 numbered items below describe the strategies designed to help achieve the vision outlined above, which were reviewed and approved by the full ASD Task Force. The possible implementation activities listed below each strategy suggest potential actions discussed by the planning subgroup, but which were not within their scope to decide. The full ASD Task Force, in its ongoing work through 2015, will design a process for overseeing plan implementation that accounts for the many diverse agencies, community groups and individuals that will play roles in carrying out the state's strategic plan.

The strategies are grouped along with the vision elements they respond to.

A. Vision: Early, timely and continuous, accessible screening and assessment

1. **Strategy: Intensify and expand public awareness of the early signs of ASD and educate the public on the benefits of early identification.**

Possible implementation activities include:

- Clarify for families the difference between screening and assessment
- Provide ways for families and care givers (families, extended families, child care, etc.) to get information about the signs of ASD. Examples could include:
  - Website to help people to know where to go for screening, assessment and diagnosis
  - One-stop website and family resource guide for ASD (see other states' models) with emphasis on serving people with concerns about their child's development, or just starting the diagnostic process
  - ASD Navigator online training tool and resource

2. **Strategy: Increase access to and quality of screening statewide.**

Possible implementation activities include:

- All children get developmental screening at ages consistent with AAP guidelines to identify developmental concerns
- Increase screening for ASD at 18 months and 24 months (CDC recommended ages) within the health care setting
- Add ASD-specific tools for screening to Minnesota's interagency approved list of screening tools, such as the CDC's "Learn the Signs. Act Early," American Academy of Pediatrics recommendations, etc.
- Promote consistency in referrals after positive screening
- Explore options for access to and sharing of screening results to improve practices and target resources statewide
- Promote one place for screening providers to go for guidance in making referrals

3. **Strategy: Investigate options for identifying a single evaluation process that serves multiple purposes (meets criteria for county services, special education eligibility, medical diagnoses and services).**

Possible implementation activities include:

- Explore use of electronic information and telecommunications technologies to support long-distance clinical health care, education services, patient and professional health-related education, public health and health administration
- Investigate feasibility and support for jointly planned and administered comprehensive multidisciplinary evaluations with shared resources, such as the Ohio Autism Diagnostic Evaluation Program (ADEP) model

4. **Strategy: Ensure continuous efforts to identify needs across the lifespan.**

Possible implementation activities include:

- Provide education for educators, families and the community about early warning signs of ASD and obligations for child find under Parts B and C of the Individuals with Disabilities Education Act (IDEA)
- Develop a website with screening and evaluation resources for diagnosis across the lifespan

B. Vision: Well-informed, empowered, and supported families and caregivers

5. **Strategy: Develop a Minnesota resource guidebook (print and/or website) for individuals, families and professionals.**

Possible implementation activities include:

- Develop criteria for what is included in guidebook
- Include options, including holistic, and research behind the options, so families can make informed choices
- Provide resources to teach parents ways to implement developmental and behavioral interventions with their children (See Florida State University's Autism Navigator)
- Make information about treatment options available immediately upon diagnosis; give families choices (not only medically based)

6. **Strategy: Provide culturally relevant options for different communities.**

Possible implementation activities include:

- Call on leaders of those communities to help identify and provide culturally appropriate education and services for their communities.

7. **Strategy: Promote parent-to-parent contact with initial diagnosis and throughout the lifespan.**

Possible implementation activities include:

- Provide immediate connection with experienced parents at time of diagnosis
- Expand availability of mentoring
- Develop training, such as, "If I knew then what I know now"
- Expand parent support group access
- Provide parent education such as established programs like "Positive Beginnings"
- Develop website registry of parents volunteering to serve as resources in communities across the state
- Offer hotline as part of website

C. Vision: Coordination of services

8. **Strategy: Define what service coordination means.**

Possible implementation activities include:

- Clarify existing models of coordination activities within health care, education, employment, social services and their application to people with ASD

9. **Strategy: Explore service coordination options.**

Possible implementation activities include:

- Explore having one service coordinator (see California's regional model)
- Explore what other states do that have similar state agency model to Minnesota's
- Coordinate private treatment and special education

10. **Strategy: Identify the best service coordination model or approach and implement it**

11. **Strategy: Explore and develop structure to coordinate state-level work on ASD.**

Possible implementation activities include:

- Continue Interagency ASD Workgroup
- Align with other collaborative structures, such as Minnesota State Interagency Committee (MnSIC), Interagency Collaborative Committee (ICC), health care reform activities, etc.

D. Vision: Transition to adulthood

12. **Strategy: Uphold Minnesota's standard that individualized transition to adult services should begin at ninth grade.**

Possible areas of focus could include:

- Coordination with higher education system on post-secondary education options for people with ASD
- Independent living
- Early start to getting job experience, work experience in school and at home (i.e. chores around the house, work experience classes in middle and high school, and working in the community for pay)

13. **Strategy: Transition partners (Vocational Rehabilitation Services, Minnesota Department of Education, counties, employers, community rehabilitation providers, nonprofit organizations, individuals with ASD) develop best practices to ensure a smooth handoff between school and training, post-secondary education and employment.**

For example:

- Preparation should begin at least two years prior to graduation

14. **Strategy: Expand best practices from pilots to statewide use to promote seamless, thoughtful process for transition in medical area from pediatric to adult systems.**

15. **Strategy: Provide parents information on transition and adult services (road map for transition to adulthood; things to do when child becomes adult).**

For example:

- Long-term supports and services (Medical Assistance eligibility)
- Options and opportunities for employment

16. **Strategy: Promote a range of safe, high quality living options for people with ASD.**

Possible implementation activities include:

- Review results of Minnesota Department of Human Services housing study and develop recommendations
- Develop best practices guidelines, such as:
  - Consider housing as well as other supports needed for living independently
  - Incorporate individuals' and families' preferences

17. **Strategy: Increase employment opportunities and supports.**

Possible implementation activities include:

- Convene a work group to explore barriers to full employment
- Educate parents and caregivers about the potential for people with ASD to work
- Provide work experience in schools
- Educate about the potential that people with ASD have; share success stories. Avoid underemployment
- Teach social skills and work skills needed to keep a job
- Provide coaching to help maintain employment
- Provide curriculum for building these skills

E. Vision: Access to services throughout the state

18. **Strategy: Partner with public and private entities to create a comprehensive, multi-system, statewide asset map of available services and supports for individuals with ASD at the local level.**

Possible implementation activities include:

- Create a resource guide that is updated and published (not only on Internet)
- Conduct outreach to get appropriate access to services for all, including populations and communities that are currently underserved

19. **Strategy: Use data to find and determine service needs of individuals with ASD throughout their lives.**

Possible implementation activities include:

- Build a registry that includes robust demographic data and data about ASD prevalence, diagnoses and treatments
  - Subcommittee on how to get this done
  - Identify benefits, understanding that individual patients, families and the public's health are better served with more information rather than less
- Develop baseline data on needs around the state; develop benchmarks: what do we want to know?
- Refer to Autism Society of Minnesota (AuSM) data
- Monitor trends

20. **Strategy: Create regional multi-agency centers of excellence that address ASD.**

Possible implementation activities include:

- Improve access for families not in metro area (outreach plan, increased access to information, telemedicine, etc.)
- University of Minnesota and Minnesota State Colleges and Universities help build capacity of rural and diverse providers
- Enhance service coordination

21. **Strategy: Promote the use of evidence-based practices across services.**

Possible implementation activities include:

- Refer to Minnesota Department of Human Services work to define standards for Medicaid services
- Ensure that individuals with ASD have access to tools and technology to better accommodate their communication and learning differences
- Ensure that service providers are prepared to understand and work with these tools and technologies
- Implement use of evidence-based practices in collaboration with the National Professional Development Center on ASD, utilizing on-line modules training and coaching

F. Vision: Competent practitioners and supportive communities

22. **Strategy: Examine the potential for a certificate for paraprofessional training and/or provider training in ASD.**

23. **Strategy: Offer education to increase awareness of ASD among community service providers (i.e. family members, law enforcement, judicial system, education, employers, medical personnel, housing providers, etc.).**

Possible implementation activities include:

- Explore established programs, such as "Autism in the Judicial System: What do we know and what do we need to know?"

24. **Strategy: Ensure preparatory and ongoing access to ASD training for students and the workforce appropriate to their field.**

Possible implementation activities include:

- Intentionally recruit diverse potential practitioners to serve rural and underserved communities
- Provide training in "ASD 101" or online via "Foundations in ASD"
- Teach skills for professionals on ways to interact with individuals with ASD
- Expand cultural competency training for providers
- Educate parents and providers about what resources are available
- Promote intentional integration of disciplines: education about others' disciplines approaches, who else is out there: i.e. Leadership Education in Neurodevelopmental Disabilities (LEND)
- Include bullying prevention as part of education

G. Vision: Funding supports families

25. **Strategy: Educate policy makers and payers about the return on investment of funding across the spectrum and across the lifespan.**

- Example: Authentic interagency funding could reduce other costs. Investment in the future
- Example: Assemble data to demonstrate benefits of early intervention
- Include existing data

26. **Strategy: Fund lifespan intervention services.**

Possible implementation activities include:

- Increase Medicaid, self-funded and private insurance funding of evidence-based autism services and interventions (such as early intervention therapies, behavior therapies, developmental-behavioral therapies, etc.)
- Include individuals across the ASD spectrum, including high-functioning (job supports, independent living skills training, social skills groups, etc.)

27. **Strategy: Encourage the legislature to explore new funding sources.**

- Examples include: accessing Medicaid funding, blending funding sources across existing programs, public-private partnerships, and fully funding early and continuous developmental screening, and basic and special education
- Meeting the needs of individuals with ASD is a complex and expensive undertaking. The recommendations in this plan will require new funding

H. Vision: Data-informed policy

28. **Strategy: Convene a working group of autism professionals to determine data that should be collected and establish benchmarks for monitoring progress in implementing State Plan.**

Possible implementation activities include:

- Determine ASD prevalence in Minnesota
- Determine treatment and service effectiveness in order to drive funding (knowing that outcomes will be different for different individuals)
- Collect and consider customer feedback

29. **Strategy: Create an ASD surveillance system to inform policy, funding, resource allocation, and research decisions, and to inform the public.**

Possible implementation activities include:

- Monitor progress toward benchmarks
- Determine prevalence
- Implement data-sharing structure and agreement across local and state agencies regarding data on screening and follow-up: e.g. Strengths and Difficulties Questionnaire (SDQ)-type data repository framework

30. **Strategy: Align information being collected and presented by multiple ASD organizations to streamline communications for policy makers: e.g., via ongoing ASD Task Force.**

Possible implementation activities include:

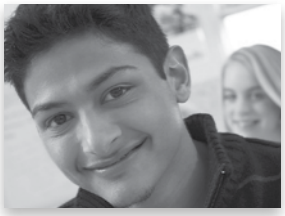
- Explore early education outcomes indicators and reporting model
- Apply for grants such as state implementation grant, Autism and Developmental Disabilities Monitoring (ADDM), etc.
- Drive agenda of community-based participatory research on ASD at university level

I. Vision: Ongoing emphasis on implementation of the strategic plan

31. Strategy: ASD Task Force continue to assist with implementation and oversight of the Minnesota ASD Task Force vision and strategies.

Possible implementation activities include:

- Annual reports to legislative committees and governor
- Continuation of ASD Task Force with eventual transition to commission status with formalized staff support and funding consistent with other citizen commissions



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APPENDIX A

MINNESOTA Session Laws, Chapter 9, Sec. 95. MINNESOTA AUTISM SPECTRUM DISORDER TASK FORCE.

Subdivision 1. Members. (a) The Autism Spectrum Disorder Task Force is composed of 19 members, appointed as follows:

(1) two members of the senate, one appointed by the majority leader and one appointed by the minority leader;

(2) two members of the house of representatives, one from the majority party, appointed by the speaker of the house, and one from the minority party, appointed by the minority leader;

(3) two members who are family members of individuals with autism spectrum disorder (ASD), one of whom shall be appointed by the majority leader of the senate, and one of whom shall be appointed by the speaker of the house;

(4) one member appointed by the Minnesota chapter of the American Academy of Pediatrics who is a developmental behavioral pediatrician;

(5) one member appointed by the Minnesota Academy of Family Physicians who is a family practice physician;

(6) one member appointed by the Minnesota Psychological Association who is a neuropsychologist;

(7) one member appointed by the majority leader of the senate who represents a minority autism community;

(8) one member representing the directors of public school student support services;

(9) one member appointed by the Minnesota Council of Health Plans;

(10) three members who represent autism advocacy groups, two of whom shall be appointed by the speaker of the house and one of whom shall be appointed by the majority leader of the senate; and

(11) one member appointed by each of the respective commissioners of the following departments: education, employment and economic development, health, and human services.

(b) Appointments must be made by September 1, 2011. The senate member appointed by the majority leader of the senate shall convene the first meeting of the task force no later than October 1, 2011. The task force shall elect a chair from among members at the first meeting. The task force shall meet at least six times per year.

Subd. 2. Duties. (a) The task force shall develop an autism spectrum disorder statewide strategic plan that focuses on improving awareness, early diagnosis, and intervention and on ensuring delivery of treatment and services for individuals diagnosed with an autism spectrum disorder, including the coordination and accessibility of cost-effective treatments and services throughout the individual's lifetime.

(b) The task force shall coordinate with existing efforts relating to autism spectrum disorders at the Departments of Education, Employment and Economic Development, Health, and Human Services and at the University of Minnesota and other agencies and organizations as the task force deems appropriate.

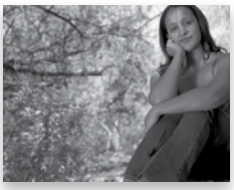
Subd. 3. Report. The task force shall submit its strategic plan to the legislature by January 15, 2013. The task force shall continue to provide assistance with the implementation of the strategic plan, as approved by the legislature, and shall submit a progress report by January 15, 2014, and by January 15, 2015, on the status of implementation of the strategic plan, including any draft legislation necessary for implementation.

Subd. 4. Expiration. The task force expires June 30, 2015, unless extended by law.

APPENDIX B

Minnesota Legislative Autism Spectrum Disorder Task Force

Dr. Jodi Milburn	Minnesota Academy of Pediatrics
Representative Nora Slawik	Minnesota House of Representatives
Representative Tara Mack	Minnesota House of Representatives
Abbie Wells-Herzog	Minnesota Department of Employment and Economic Development
Bradley Trahan	Advocacy Representative
Catherine Pulkinen	Minority autism community representative
Dr. David Griffin	Minnesota Council of Health Plans
Dawn Steigauf	Family representative
Heather Hanson	Family representative
Idil Abdull	Somali American Autism Foundation
Jody Manning	PACER Center
Philip Sievers	Minnesota Department of Education
Regina Wagner	Minnesota Department of Human Services
Renae Ouillette	Public School Student Support Services
Senator Chris Eaton	Minnesota Senate
Senator David Senjem	Minnesota Senate
Dr. Michael Reiff	American Academy of Pediatrics
Dr. Kimberly Klein	Minnesota Psychological Association
Barb Dalbec	Minnesota Department of Health
Lydia Uphus	Minnesota Senate staff
Dr. Troy Hanson	Sibley Medical Center
Amy Hewitt	University of Minnesota, Institute on Community Integration
Tim Moore	University of Minnesota, Institute on Community Integration
Jen Hall-Lande	University of Minnesota, Institute on Community Integration



The Minnesota Autism Spectrum Disorder (ASD) Task Force was created by the 2011 Legislature to develop a statewide strategic plan for improving awareness and ensuring treatment and services for individuals diagnosed with an autism spectrum disorder.

In addition to the specific recommendations contained in this report, the ASD Task Force also asked Governor Dayton and the Legislature to consider taking action in four additional areas: 1) explore autism private insurance reform, 2) create an autism-specific website, 3) introduce autism license plates to generate revenue to fund autism-related initiatives, and 4) creation of a permanent autism commission.
Note: These recommendations were supported by all members of the task force. State agency representatives who contributed to the work of the task force abstained from any discussion or recommendation on these items because the agencies have their own internal procedures for making policy and budget recommendations to the governor.

The ASD Task Force will publish annual strategic plan updates in 2014 and 2015. To provide input or to receive more information about the ASD Task Force and its recommendations, please contact:

Brad Trahan
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By email: rtautism@yahoo.com

Or by U.S. Mail:
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