Autism Spectrum Disorder Task Force
2013 Annual Report

March 11, 2014

Autism Spectrum Disorder Task Force Annual Report: 2013

In 2011 Minnesota Legislative Special Session Laws, Chapter 9, Sec. 95 the Minnesota Legislature directed the Autism Spectrum Disorder (ASD) 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, 2014. 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, 2015, on the status of implementation of the strategic plan, including any draft legislation necessary for implementation.

The following report highlights accomplishments made during the 2013 calendar year. These accomplishments include:

- In the first six months of the year, a facilitator from the Minnesota Management Analysis and Development was utilized to complete and plan for implementing the strategic plan. This plan is included in Appendix 4: ASD Legislative Task Force: Strategic Plan Implementation Recommendations.
- In April-May, members of taskforce worked with MDH to develop the State Autism Implementation Grant, in response to a HRSA Request for Proposal. In early June, dissention occurred between taskforce members over the language in the ASD Taskforce Letter of Support, written to accompany the HRSA grant. The taskforce chair, Brad Trahan, resigned in late June.
- Due to continued dissention, taskforce members contracted with a mediation service provider. An agreement was entered with the Conflict Resolution Center to facilitate the meetings. This agreement is located in Appendix 2 of this report. Members of the taskforce met with staff from The Conflict Resolution Center, on August 8th, September 10th, and October 3rd. The primary agenda item for these meetings was to create and discuss ASD Legislative Task Force Operating Procedures (see Appendix 5). Meeting materials can be found in Appendix 1 and Appendix 3 of this report. The operating procedures were approved on October 3, 2013.
- Abbie Wells-Herzog was voted in as Chair of the Task Force on, October 3rd. Ms. Wells-Herzog subsequently resigned as Chair on January 8th, 2014.
- Dawn Steigauf resigned as Vice Chair on March 3rd.
- The following scheduled meeting dates were not held: Nov. 7, and Dec. 5, 2013, Jan. 9, Feb. 6, Mar. 6, 2014.
- A meeting was called on March 11th to approve the required year-end report and implementation plan.

Appendix 1: August 8, 2013 Meeting Materials

Minnesota Autism Spectrum Disorder Task Force
Operating Procedures Development
August 8, 2013 Meeting Agenda

1. Introductions of facilitators and Task Force members
2. Overview of process for establishing operating procedures and agenda for this meeting
3. CRC Services Agreement
4. Clarification of facilitators' role and process
5. Establishment of Ground Rules
6. Round Robin Questions
    - Why is there a need for operating procedures?
    - What is working well?
    - What do you want to change?
7. Open discussion on Round Robin
    - Responses to what you heard
    - Brainstorming :
        - What concerns do operating procedures need to address?
        - What do want included in operating procedures?
8. Next Steps and Closing
    - Summary of where we are
    - Establish the working group and set timelines or Set second facilitated meeting
    - Review and confirm final decision on next steps

Appendix 2: Conflict Resolution Center Service Agreement

Service Agreement

The Conflict Resolution Center (CRC) is a non-profit organization whose mission is to bring people together to find lasting and effective solutions to conflict. The Minnesota Autism Spectrum Disorder Task Force (Task Force) is a legislatively mandated group charged by Statute to make recommendations and report on specific topics. CRC has agreed to provide services to the Task Force in accordance with the following terms:

Terms of Agreement:

1. CRC will facilitate a maximum of three two-hour Task Force meetings for the purpose of creating operating procedures. The operating procedures may include member's roles and responsibilities, behavioral norms, and conflict resolution processes. The first meeting will take place on Thursday August 8th, 2013 at 6 pm.

2. CRC and the Task Force will jointly establish enforceable ground rules for the CRC facilitated meetings, in order to facilitate meeting productivity.

3. Task Force members will be responsible for recording and distributing meeting notes. The Task Force is also responsible for convening a small work group to gather input and draft written operating procedures. CRC will not record meeting notes, participate in the work group, or participate in the actual drafting of the operating procedures. CRC will review draft operating procedures to determine that they accurately reflect areas of consensus.

4. CRC's role in the Task Force is to provide neutral group process facilitation and other mediation/facilitation services. CRC will maintain its role as a neutral and will not provide evaluation, advocacy, or legal advice.

5. Minnesota statute 595.02, Subdivision 1(l), makes testimony regarding any communications and documents made or used in the course of, or because of, mediation/facilitation inadmissible at subsequent legal or administrative proceedings. Staff, files and mediators of CRC cannot be subpoenaed to testify on behalf of any party. CRC shall be held harmless in the event of any legal proceedings that occur as a result of Task Force business or meetings.

6. CRC's will provide pro bono services for up to three facilitated meetings, including meeting preparation. Additional services, including group facilitation, mediation, conflict assessment, conflict consulting and training, are available on a sliding scale.

I have read and understand the information presented here. I agree to work collaboratively with CRC.

Participant: ______________________ Date: ______________________

Appendix 3: October 3, 2014 Meeting Materials

MINNESOTA AUTISM SPECTRUM DISORDER TASK FORCE

OCT. 3, 2013

300 NORTH SOB

MEMBERS PRESENT

Jody Manning
Abbie Wells-Herzog
Barb Dalbec
Dr. Catherine-Pulkinen
Anne Harrington
Dawn Steigauf (Jean Bender attend as proxy)
Phil Sievers
Rep. Kim Norton
Dr. Michael Reiff

MEMBERS ABSENT

Dr. Troy Hanson
Sen. Chris Eaton
Heather Hanson
Dr. David Griffin
Sen. Senjem
Idil Abdull
Dr. Kimberly Klein
Rep. Tara Mack

MINUTES

- Meeting was called to order at 1:20 p.m.
- Chair election - Abbie Wells- Herzog was unanimously elected chair.
- Written comments from Idil Abdull were submitted at 11:00 a.m. via email to task force members and will be addressed in each section of the ASD Task Force Operating Procedure and setting of meeting dates.

Operating Procedures Review

The task force started where we left off with term limits:

Term Limits

Member comments noted "*Removing or limiting anyone's term on the current task force is NOT part of our charge. Suggestion could be to write term limits into the next task force bill. Something like the*

state agencies are, this continues and the public members are 2 years, some 3 so that as some are getting out, others are getting in. And, hopefully this time minority community parents and advocates are part.

Discussion took place.

Decision: Term limits will match MN Statue 15.059 that provides staggered term limits. See adopted operating procedures. This will address concerns noted.

Resignation and Vacancies Discussion

Member comments noted: *Concern regarding removing members because of attendance. Some members are parents with young or multiple children with ASD who are not always able to come, some are doctors who have patients and can't always come and some are legislators who might be in busy especially during the session was noted.*

Member comments noted: "In addition, saying the chair sets the time, can cancel anytime and then if those that might have made plans to come will be removed when THEY can't come seems double standard. It seems punishing members for having a life outside of the task force whereby things can happen. Emergencies can't be foreseen and members should not be penalized for it nor removed."

Discussion took place.

Decision: Operating procedures will include a possible removal if 3 consecutive meetings or a total of 2/3 of the meetings in a year are missed. While the group understood the difficulties that are unpredictable, the group wanted to assure voices of all constituents are heard. And there will be added work groups where many voices could be heard and public comment in all Task Force meetings. See adopted procedures.

Chair duties

Member comments noted: *Cancelling a meeting that many might have planned on it and changed their own schedule seems harsh.*

Suggestion could be having Co Chairs so that at least one of them is present and committee business can continue because life happens and sooner or later the chair can't come. But the rest of the members don't suffer and committee task can continue. Also, we can limit the chairs time to one or two years so that he/she is not burned out. It might also be good to have at least one of the co-chairs an agency rep since they have more time and support from their respective agency.

Discussion took place.

Decision: It was decided that the previous chair and the chair elect could fill in for the chair as needed. The agency reps noted that they are not able to take on a chairmanship because their current level of job responsibilities. See adopted operating procedures.

Operating Procedures Adopted

Member Comments: *Finally, when we adopt some guidelines here - we can move to the important stuff of autism and families which we all care about. Maybe if there is time today, we can pick sub committees under the whole task force which will tackle the various strategic plan items the Barb Deming helped us with. It seems too many, but maybe if they are condensed so that 3 or 4 items can be*

tackled by each sub group, etc. And, the chair or co-chairs can help us through this process including which external experts to invite to help us achieve our final goal of a good statewide autism plan.

Discussion took place

Decision: Rep. Kim Norton motioned to adopt the MN ASD Operating Procedures. Catherine Pulkinen seconded the motion. Group Consensus was achieved with Operating Procedures being adopted.

Meeting Dates

Member comments noted: *Suggestion could be to have times and dates rotate and send out calendar doodle and let members pick their available times and the chair can pick whatever time/date most are available.*

Comments were taken into consideration and meeting dates were set for the next 8 months to allow for schedules to be adjusted. Times were rotated between evening and days so more members would be able to participate.

Future meetings will be the first Thursday of the month. A location will be determined in the future.

2013
Nov. 7 – 6:00 p.m.
Dec. 5 – 1:00 p.m.

2014
Jan. 9 – 6:00 p.m.
Feb. 6 – 1:00 p.m.
Mar. 6 – 6:00 p.m.
Apr. 3 – 1:00 p.m.
May 1 – 6:00 p.m.
Jun 5 – 1:00 p.m.

Appendix 4: ASD Task Force: Strategic Plan Implementation Recommendations

Autism Spectrum Disorder Task Force
Strategic plan implementation recommendations

The ASD Task Force charged state agency and University of Minnesota representatives with drafting implementation recommendations for consideration by the full ASD Task Force.

Minnesota Autism Spectrum Disorder strategic plan

Vision

The elements below describe the ***desired outcomes in 3-5 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 9th 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 and implementation steps

Implementation recommendation drafting process notes:

- *"Vision and strategies" column comes directly from the ASD Task Force Strategic Plan Report. Other columns incorporated material from the report, as well as ideas of the small group charged with drafting these recommendations.*
- *Measures/Indicators of progress are needed to go with every strategy.*
- *State agencies are listed as the champion but this effort will take effort from the individuals, community and other agencies that have a vested interest in improving systems that serve people with autism and their families.*

The **boldface items** below describe the strategies designed to help achieve the vision, which were reviewed and approved by the full ASD Task Force. The *possible implementation activities* listed alongside each strategy suggest potential actions discussed by the planning subgroup, but which were not within their scope to decide.

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
1. 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	Provide ways for families and care givers (families, extended families, child care, etc.) to get information about the signs of ASD. Clarify for families the difference between screening and assessment Examples could include: **I.** Website to help people to know where to go for screening, assessment and diagnosis **J.** 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 **K.** ASD Navigator online training tool and resource **L.** DB101	Existing activity M. Act Early Team N. Local public health – WIC, Follow Along O. Race to the Top P. Help Me Grow Q. AAP R. Early Childhood Screening S. IEICs T. Developmental Screening Task Force	MDH MDE DHS	Needs • One-stop website/common resource ○ • Above list needs to incorporate ASD warning signs/red flags and next steps to get to diagnostic • DB101
2. Strategy: Increase access to and quality of screening statewide	All children get developmental screening at ages consistent with AAP guidelines to identify	AAP, Health Plans	MDH DHS MDE	• Strategy 2 should be in place before doing strategy 1 • Barrier: Doctors don't get

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
	developmental concerns. Increase screening for ASD at 18 months and 24 months (CDC recommended ages) within the health care setting.			paid to do this/are not billing for it. • Developmental screening could be done in other venues (WIC, public health, social services, etc.)
	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.	U of M ASD Clinic MDH take lead with backing of ASD TF	MDH DHS MDE	
	Promote consistency in referrals after positive screening. Promote one place for screening providers to go for guidance in making referrals.		MDH DHS MDE	
	Explore options for access to and sharing of screening results to improve practices and target resources statewide.		MDH DHS MDE	AG would review current laws and advise what is recommended
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)	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 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	Fraser is looking at regional evaluation sites	MDH DHS MDE	Pilot use of single evaluation; If it works move it to regional or statewide implementation New autism bill is moving in this direction Look at where this has been done successfully.
4. Strategy: Ensure continuous efforts to identify needs across the	Provide education for educators, families and the community about	IHEs, Continuing Ed, U of M ICI	MDH DHS	Part C is included above. This group would start with high

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
lifespan	early warning signs of ASD and obligations for child find under Parts B of the Individuals with Disabilities Education Act (IDEA)		MDE	school/ transition age
	Develop a website with screening and evaluation resources for diagnosis across the lifespan		DEED DHS MDH MDE	
2. 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	Develop criteria for what is included in guidebook • Include options, including holistic, and research behind the options, so families can make informed choices • Make information about treatment options available immediately upon diagnosis; Give families choices (not only medically based)	AUSM already has a lot of this on their site	DEED DHS MDH MDE	Will require money Two-parts to website • Single point of entry accessible to anyone • Information sharing and education Needs to be accessible to non-English speaking users or include avenue to interpreter
	Identify resources to teach parents ways to implement evidence-based developmental and behavioral interventions with their children (See Florida State University's Autism Navigator)	Existing efforts: Fraser, AUSM, ARC, PACER, Family Voices	DEED DHS MDH MDE	• Look into purchasing access to Florida's website • Anyone coming into contact with family's needs professional preparation

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
6. Strategy: Provide culturally relevant options for different communities	Call on leaders of those communities to help identify and provide culturally appropriate education and services, and build advocates for their communities. Train people to do culturally appropriate outreach. Could extend LEND's community fellows outreach to Somali community and others. (Ensure that this effort includes service coordination)	Community outreach workers, CHWs, school districts, clinics LEND DHS SAAF Somali-American Parent Association Organizations of: Hispanic Hmong Native American Other identified disadvantaged groups	DEED DHS MDH MDE	• Community-based participatory research on autism and cultural resources is in process – U of M School of Public Health is in lead • LEND community fellows act as ambassadors to communities; increase awareness and education
7. Strategy: Promote parent-to-parent contact with initial diagnosis and throughout the lifespan	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."	PACER, Family Voices, Center for Engaging Autism AUSM, ARC, NAMI, ANSWER, ATAM (new organization of behaviorally based treatment providers), Social Odyssey	DEED DHS MDH MDE	Need to have statewide access to these resources.
	Develop website registry of parents volunteering to serve as resources in communities across the state		DEED DHS MDH MDE	
	Offer information telephone line as part of website	Community providers; 2-1-1; MNinfo.gov; PACER, Family Voices, etc.	DEED DHS MDH MDE	Not for crisis, but info resource
3. Vision: Coordination of services				
8. Strategy: Define what service coordination means	• Clarify existing models of coordination activities within health care, education,	MnSIC (3-21), ICC (B-3) at state agency level	DEED DHS MDH	• Important to clarify what service coordination is – everyone has different

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
	employment, social services and their application to people with ASD • *Begin with existing definition work by MnSIC and ICC* • *First: Clarify with families what the problem is that needs to be solved* • *Revisit existing/past structures promoting service coordination* • *Develop MOU to clarify definitions and roles of partner agencies* • Ensure attention to cultural, linguistic and geographic differences	Local agency involvement will be identified by work group – potentially CTICs, etc. Ensure that parents and cultural representatives are included	MDE	definition • Major agencies need to help define what coordination looks like (in consultation with families) • Revisit Gov. Carlson-signed agreement? • See requirement for interagency agreement • Three levels of coordination – state agency, local agencies, individual family
9. Strategy: Explore service coordination options	Explore what other states do that have similar state agency model to Minnesota's • Explore having one service coordinator (see California's regional model) • Some states have autism "tsar" or commission		DEED DHS MDH MDE	
	Coordinate private treatment and special education (part of understanding three levels of service coordination – see note above)		DHS MDE	
10. Strategy: Identify the best service coordination model or approach and implement it	• Put together information gathered in above strategies and facilitate opportunities for public and stakeholder input on options developed • Develop new infrastructure to make these coordination models connect (all three levels)		DEED DHS MDH MDE	Infrastructure would begin to address service coordination, data collection, funding

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
11. Strategy: Explore and develop structure to coordinate state-level work on ASD	Align with other collaborative structures, such as Minnesota State Interagency Committee (MnSIC), Interagency Collaborative Committee (ICC), health care reform activities, etc.		DEED DHS MDH MDE	
	Continue Interagency ASD Coordination		DEED DHS MDH MDE	
4. Vision: Transition to adulthood				Possible areas of focus could include: A. Coordination with higher education system on post-secondary education options for people with ASD B. Independent living C. 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)
12. Strategy: Uphold Minnesota's standard that individualized transition to adult services should begin at 9th grade.	D. Monitor potential changes to policy	Coalition for Children with Disabilities; MASE; PACER	DEED DHS MDH MDE	
13. Strategy: Transition partners (Vocational Rehabilitation Services, Minnesota Department of Education, counties, employers, community rehabilitation providers, nonprofit organizations, individuals with ASD) develop best	Support and encourage local communities of practice that would identify and share best practices specific to children and youth with ASD. Eventually review practices for possible statewide application.	Transition Community of Practice, CTICs, Fraser, AUSM	DEED DHS MDH MDE	Refer to ICI-created NASET Standards and Indicators for transition Lionsgate Academy is developing a transition program specific to ASD. Fraser is also

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
practices to ensure a smooth handoff between school and training, post-secondary education and employment.	*Example:* Dakota County (already interested in developing ASD Transition Community of Practice) *Best practice example:* • Preparation should begin at least two years prior to graduation			doing this. TRiO at Dakota County Technical College provides internships and supports for students with ASD. Project SEARCH scale-up to statewide (18-years-old and above)
	Investigate legislative action to reinvigorate Work-Based Learning and Career Technical Education programs to promote community-based employment experiences.	school districts, counties, employers, community rehabilitation providers, nonprofit organizations, individuals with ASD	DEED DHS MDH MDE	
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	Continue to provide resources to refine tools offered by National Health Care Transition Center for use in Minnesota, and spread best practices throughout state with certified health care clinics. Ensure ASD-specific focus.	AAP, MAFP, Family Voices, AUSM	DEED DHS MDH MDE	
15. Strategy: Provide parents information on transition and adult services (road map for transition to adulthood; things to do when child becomes adult)	Develop ASD-specific framework, referring to existing research and standards. *For example:* • Long-term supports and services (Medical Assistance eligibility) • Options and opportunities for employment	Outreach Work Group	DEED DHS MDH MDE	Thousands of publications already exist related to this. PACER's for example. ICI is repository.
16. Strategy: Promote a range of safe, high quality living options for people with ASD	Review results of Minnesota Department of Human Services housing study and develop recommendations	Fraser, counties, End of the Spectrum	DHS	Governor, DHS and legislature working on this Olmstead plan affects this, and many other areas

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
				Guidelines may include: • Consider housing as well as other supports needed for living independently • Incorporate individuals' and families' preferences
17. Strategy: Increase employment opportunities and supports	Based on recommendations of the National Collaborative on Workforce and Disability for Youth, all young people with ASD should have • career assessments to help identify individuals' school and post-school preferences and interests; • training designed to improve job-seeking skills and work-place basic skills • opportunities to engage in a range of work-based exploration activities such as site visits and job shadowing; • on-the-job training experiences (paid or unpaid), including community service, that are specifically linked to the content of a program of study and school credit; • opportunities to learn and practice soft skills; • opportunities to learn about the relationships between benefits planning and career choices; • opportunities to learn to communicate their disability-related work support and accommodation needs	School districts, ICI, PACER, Fraser, Lionsgate Academy, Transition Community of Practice, Independent Living Centers, Community rehabilitation providers, workforce investment boards, counties and businesses	MDE DEED DHS	NCWD/Youth recommendations parallel the NASET Standards and Indicators mentioned above in #13.
5. Vision: Access to services throughout the state				

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
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	Create a resource guide that is updated and published (not only on Internet) that is culturally, linguistically and geographically accessible Outreach Work Group develop template for local communities to complete the resource map	AUSM has resource directory, Local communities, DHS, MDH, MDE, DEED, nonprofit entities	DEED DHS MDH MDE	Connect with website (above) Local community = counties, school districts, etc.
	Conduct outreach to get appropriate access to services for all, including populations and communities that are currently underserved Identify key contacts in local areas to be point person for communications	Local communities (counties, school districts, trusted nonprofits partnering with schools, medical)	DEED DHS MDH MDE	1. Outreach to non-reading, non-English-speaking communities via local cable TV and local radio stations, sometimes provided by school districts 2. Look at national Help Me Grow model for key contacts
19. Strategy: Use data to find and determine service needs of individuals with ASD throughout their lives	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 • *Look at other statewide registries*	U of M	DEED DHS MDH MDE	1. MDH already has report of other state registries 2. SEMCIL pilot project is looking at outcome data on employment supports in the workplace 3. DHS is collecting and comparing data between children receiving early intervention benefit and others 4. Office of Early Learning Early Childhood Longitudinal Data System
	Develop baseline data on needs around the state; develop benchmarks: what research questions could the registry help to answer? • Refer to Autism Society of	MDE, Counties, MDH, DHS, U of M, DEED, parent groups	Contracted entity	

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
	Minnesota (AuSM) data • Monitor trends in resource availability • Clarify gaps in resources using locally developed resource maps (simultaneous with developing guide– don't delay guide development)			
	• Share baseline data across agencies		DEED DHS MDH MDE	Agencies are working to establish common terminology and data sharing agreements to enhance ability to share data and to affect policy
20. Strategy: Create regional multi-agency/disciplinary centers that address ASD	Increase access throughout the state to services, information, resources, telemedicine, etc. • Develop policy recommendations to support centers • Make sure services are available/ address geographic, racial and ethnic disparities • Check with families: Who needs this, what services are available where? (Don't assume)	Fraser, LEND, representatives of communities of color, such as SAPA, African American Family Center, CLUES, etc.	DEED DHS MDH MDE	• Fraser goal: Autism regional centers throughout the state • Center of Excellence refers to federally funded model
	University of Minnesota and Minnesota State Colleges and Universities help build capacity of rural and diverse providers	LEND, Act Early network	DEED DHS MDH MDE	
21. Strategy: Promote the use of evidence-based practices across services	Shed light on areas where there is agreement about evidence Refer to work under way in Minnesota Departments of Human Services, Education and Vocational Rehabilitation (DEED) to define best standards for practice while	private provider group of advocates, AAP, AuSM, stakeholder input group	DHS autism benefit advisory stakeholder input group (will include other agencies and parents)	• MDE refers to evidence-based practices in collaboration with the National Professional Development Center on ASD, utilizing on-line modules training and coaching

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
	respecting individual cultures and values			• Disagreement exists about what evidence says
	Ensure that individuals with ASD have access to tools and technology to better accommodate their communication and learning differences	MDE, PACER Center, DEED	DEED DHS MDH MDE	
	Ensure that service providers are prepared to understand and work with these tools and technologies	Communities of color, such as SAPA, others	DEED DHS MDH MDE	
	Develop infrastructure to coordinate ways of looking at outcomes across the lifespan		DEED DHS MDH MDE	• What are the valued outcomes that we agree on that would inform infrastructure?
6. Vision: Competent practitioners and supportive communities				
22. Strategy: Examine the potential for a certificate for paraprofessional training and/or provider training in ASD	*Look at 22, 23, and 24 together to develop training and education requirements for different groups, ensuring they are culturally appropriate.*	AuSM, Act Early	DEED DHS MDH MDE	• Training for consistency in how training is provided across the state • AuSM certification program for direct service providers
	Provide education for providers of adult services and the families of people being served (academic, vocational and social development + medical health care transition); Include person-centered needs assessment and planning. Need good tools for this.		DEED DHS MDH MDE	• Need to locate appropriate assessment tools and bring them to these groups. • Example: MN Choices
23. Strategy: Offer education to increase awareness of ASD among community service providers (i.e.	Explore established programs, such as "Autism in the Judicial System; What do we know and what do we		DEED DHS MDH	

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
family members, law enforcement, judicial system, education, employers, medical personnel, housing providers, etc.)	need to know?”		MDE	
24. Strategy: Ensure preparatory and ongoing access to ASD training for students and the workforce appropriate to their field	Intentionally recruit diverse potential practitioners to serve rural and underserved communities.		DEED DHS MDH MDE	
	Provide training in “ASD 101” or online via “Foundations in ASD”		DEED DHS MDH MDE	
	Teach skills for professionals on ways to interact with individuals with ASD		DEED DHS MDH MDE	
	Expand cultural competency training for providers		DEED DHS MDH MDE	
	educate parents and providers about what resources are available		DEED DHS MDH MDE	
	Promote intentional integration of disciplines: education about others’ disciplines approaches, who else is out there (i.e. Leadership Education in Neurodevelopmental Disabilities (LEND)		DEED DHS MDH MDE	
	Include bullying prevention as part of education		DEED DHS MDH MDE	

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
7. 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	*Look at 25, 26, 27 together to develop funding approach, priorities and recommendations*	State agencies, parents, providers, advocates, individuals with ASD, Legislative representatives	DEED DHS MDH MDE	Measuring outcomes relates to this Explain meaning of "spectrum" (throughout work groups) Legislative representatives advise on approach, priorities and recommendations For example: Authentic interagency funding will 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	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.)	DHS, MDE, MN Commerce Dept.	DEED DHS MDH MDE	
	Include individuals across the ASD spectrum, including high-functioning (job supports, independent living skills training, social skills groups, etc.)	DEED, MDE, DHS	DEED DHS MDH MDE	
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	Parents, advocates, providers, individuals with ASD	DEED DHS MDH MDE	Meeting the needs of individuals with ASD is a complex and expensive undertaking. The recommendations in this plan will require new funding.

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
	developmental screening, and basic and special education. Apply for grants (state implementation grant, Autism and Developmental Disabilities Monitoring (ADDM), etc.)			DEED, MDE, DHS, MDH explore new funding sources through grants
8. 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.	Work groups determine ways to measure progress and data collection needs for entire strategic plan implementation, to make each vision element measurable. Examples: • Determine who is being served and what services they are accessing. • Collect and consider customer feedback	Work groups created in this plan	DEED DHS MDH MDE	State plan = ASD strategic plan
29. Strategy: Create an ASD surveillance system to inform policy, funding, resource allocation, and research decisions, and to inform the public	Review other states' systems, determine feasibility and cost. System would: • Determine ASD prevalence in Minnesota • Monitor treatment and service effectiveness in order to drive funding (knowing that outcomes will be different for different individuals) • Monitor progress toward benchmarks		DEED DHS MDH MDE	
	Implement data-sharing structure and agreement across local and state agencies regarding data on screening and follow-up (example: Strengths and Difficulties Questionnaire		DEED DHS MDH MDE	

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point Agency	Notes
	(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)	Look at existing sources of data and develop key messages Example: Explore early education outcomes indicators and reporting model		DEED DHS MDH MDE	
	Drive agenda of community-based participatory research on ASD at university level	U of M School of Public Health, SoLaHmo, Confederation of Somali Community of Minnesota	DEED DHS MDH MDE	
9. Vision: Ongoing emphasis on implementation of the strategic plan				
31. Strategy: ASD Task Force oversight and focus continue to provide assistance with implementation of the ASD vision and strategies in the state of Minnesota	Annual reports to legislative committees and governor		DEED DHS MDH MDE	
	Determine structure that would best promote successful implementation of state plan vision and strategies. Possibilities include: • Continuation of ASD Task Force • Transition to commission status with formalized staff support and funding consistent with other citizen commissions		DEED DHS MDH MDE	HRSA state ASD/DD implementation grant potential funding source

Appendix 5: ASD Legislative Task Force Operating Procedures

AUTISM SPECTRUM DISORDER LEGISLATIVE TASK FORCE

Operating Procedures

Approved October 3, 2013

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STATUTORY PURPOSE

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 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. 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. 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.

2. MEMBERSHIP, APPOINTMENTS, RESPONSIBILITIES

a. Membership: The Autism Spectrum Disorder Task Force, stated as Task Force throughout document, is composed of 19 members, appointed as follows:

- **i.** two members of the senate, one appointed by the majority leader and one appointed by the minority leader;
- **ii.** 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;
- **iii.** 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;
- **iv.** one member appointed by the Minnesota chapter of the American Academy of Pediatrics who is a developmental behavioral pediatrician;
- **v.** one member appointed by the Minnesota Academy of Family Physicians who is a family practice physician;
- **vi.** one member appointed by the Minnesota Psychological Association who is a neuropsychologist;
- **vii.** one member appointed by the majority leader of the senate who represents a minority autism community;
- **viii.** one member representing the directors of public school student support services;
- **ix.** one member appointed by the Minnesota Council of Health Plans;
- **x.** 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
- **xi.** one member appointed by each of the respective commissioners of the following departments: education, employment and economic development, health, and human services.

b. Terms of Appointment:

i. **Appointed members:** The terms of the members of the advisory councils and committees shall be four years. The terms of one-half of the members shall be coterminous with the governor and the terms of the remaining one-half of the member shall end on the first Monday in January one year after the terms of the other members. If there is an odd number of members, the smallest possible majority of the members shall have terms coterminous with the governor. If the membership is composed of categories of members from occupations, industries, political subdivisions, the public or other groupings of persons, and if the categories as specified in statute have two or more members each, the appointing authority shall appoint as nearly as possible one-half of the members in each category at each appointment date per Minn.Stat. § 15.059.

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ii. **Alternate members**: The term of alternate members coincide with the term of the primary member.

c. **Term Limits:**

i. A**ppointed members:** Appointed members can reapply at the end of their term, but are limited to two consecutive terms except as required in D.1.

ii. **Alternate members:** The term limit for an alternate member coincides with the term of the primary member. If an alternate becomes a commissioner appointed, their term limit is governed by the provisions for that member category.

d. **Resignations and Vacancies:**

i. Members may serve until their successors are appointed and qualify. If a successor has not been appointed by July 1 after the scheduled end of a member's term, the term of the member for whom a successor has not been appointed is extended until the first Monday in January four years after the scheduled end of the term per Minn.Stat. § 15.059.

ii. Each member will receive notification of the expiration of his or her term at least sixty-days prior to the termination date. Notification will also be sent to the chair.

iii. Certificates of Recognition will be presented to all departing members during the last meeting of the year of the ending term.

iv. If a member misses two consecutive meetings without notifying the chair of need for being excused, the staff supporting the Task Force will notify the member in writing that the member may be removed for missing the next meeting.

v. Vacancies for appointed members are filled in the same membership category. Applications are made through the Secretary of State's Office of Open Appointments.

e. **Responsibilities and Expectations of Task Force Members:**

In accepting appointment to the Task Force, members are to promote the task force mission and expected to:

i. Attend Task Force meetings.

ii. Share responsibility for the group's success and work on behalf of positive outcomes for individuals with ASD and their families statewide.

iii. Acknowledge the value of other members and give genuine consideration to others' ideas.

iv. Promote an atmosphere of respect and collaboration both at Task Force meetings and in the public domain.

v. Treat all Task Force members in a professional and respectful manner that positively influences the vision for those with ASD outlined in the Minnesota ASD Strategic Plan.

vi. Serve on committees or work groups.

vii. Prepare for active participation in discussions and decision-making by reviewing meeting materials.
viii. Act as a liaison when appropriate between constituent groups and the Task Force.
ix. Inform constituent groups of Task Force activities, actions, and issues.
x. Abstain from voting where a conflict of interest may exist. A conflict of interest exists if one of the following conditions applies 3

1. Member has a direct financial interest in the matter under consideration.
2. Member has an indirect financial interest in the matter under consideration and is not so free from personal bias, prejudice, or preconceived notion as to make it possible for her/him to objectively consider the evidence presented and base her/his decision solely on the evidence.

f. **Staff Support:**

i. The Legislative Members will make available staff, space and other resources as appropriate and available to support the work of the Task Force.
ii. Staff support for the Task Force will be provided by legislative assists

g. **Chair:**

i. The chair serves a four-year term as per Minn.Stat. § 15.059.
ii. The duties of the chair are to:

1. Preside at all full Task Force meetings
2. Provide sufficient structure so that every task force member is heard while keeping the meeting agenda moving for timely adjournment;
3. Develop a meeting agenda prior to each meeting of the Task Force. Provide to members of the Task Force and place on the Task Force Website (http://www.lcc.leg.mn/asd/);
4. Ensure that meeting minutes are provided to all Task Force members and are posted on the Task Force Website (http://www.lcc.leg.mn/asd/);
5. Be the spokesperson and representative for the Task Force;
6. In order for the Task Force to be representative of the constituents it serves, and a sound resource on topics identified by the Task Force, additional individuals or organizations may be invited by the chair, Task Force approval, to be ex-officio members and serve on the Task Force or working groups;
7. Serve as past chair for one year.

h. **Chair-Elect:**

i. The chair-elect serves a one-year term.
ii. The duties of the chair-elect are to:

1. Preside at the Task Force meetings in the absence of the chair;
2. Assist the chair as requested;
3. Serve as the next Task Force chair.

i. **Past Chair:**

i. The past chair serves a one-year term.
ii. The duties of the past chair are to:

1. advise the chair and serve as a resource to the Task Force;
2. preside at Task Force meetings in absence of the chair.

3. ELECTIONS

The Task Force by consensus will nominate a member of the Task Force who has served at least one year on the Task Force, to serve as chair-elect. The nomination will be voted on by the Task Force at the last meeting of the calendar year before the chair-elect is to take office. The Task Force must approve the nomination by a majority of the members present at the meeting. A candidate for chair-elect whose remaining term on the Task Force is less than the two year term of chair for which they are nominate must be willing and eligible to serve another two year term on the Task Force.

4. MEETINGS

This section applies to meetings of the ASD Task Force, subcommittees, and work groups, unless otherwise noted.

a. Frequency:

The task force shall meet as requested by the chair in consultation with past chair or chair-elect as frequently as necessary and at least six times a year per legislative statute. Meeting dates for the Task Force for the upcoming year are selected at the prior summer Task Force meeting.

b. Cancellations:

Meetings of the Task Force may be canceled and rescheduled by the Chair in consultation with past chair or chair-elect. Task Force members will be notified of cancellations in as timely a manner as possible.

c. Quorum:

The presence of fifty (50) percent of filled Task Force members constitutes a quorum at meetings. Once a quorum is established it is maintain until the meeting is adjourned to mirror current legislature practice. This excludes alternate members, unless the alternate is attending in place of the primary member.

d. Public Meetings:

All Task Force meetings are open to the public and are posted on the public website for notification.

5. GENERAL PROCEDURES

a. Order of Business:

The business of the Task Force will include the following:

i. Call to order, welcome and introductions by the chair;
ii. Review and approval of the minutes of the previous meeting;
iii. Review and approval of agenda;
iv. Announcements;
v. Members news and new issues;
vi. Reports of subcommittees and workgroups;
vii. Other reports and presentations;
viii. Other business; and
ix. Public comment
x. Adjournment.

Agendas may deviate from the above format at the discretion of the chair.

b. **Conduct of Business:**

i. Task Force members will receive the agenda, past meeting minutes and other pertinent information at least four working days prior to each meeting.
ii. Minutes will be kept of all Task Force meetings and maintained according to establish records retention schedule. Minutes will be prepared and forwarded to Task Force members in advance of the next meeting. Approved minutes and agendas will be available on the Task Force website.
iii. Task force will strive for consensus. If consensus cannot be reached, decisions will be made when a majority of voting members present reach agreement on a given matter.
iv. Dissenting opinions will have an opportunity to be heard and be noted in the meeting minutes.

c. **Communication**

i. Task Force members will communicate at the Task Force meetings as well as externally in ways that support the collective work and mission of this group.
ii. Task Force members will bring any issues or concerns related to the function of the Task Force and its' mission, to the Task Force to resolve.
iii. Task Force members will communicate with one another during the meetings and outside of the meetings, related to the Task Force's work, in a respectful, professional manner and refrain from engaging in negative personal attacks in any verbal or written communication regarding the work of this group.
iv. Task Force members will refrain from reporting the opinions of other members without permission.
v. Task Force members will let the Task Force know of media contacts or concerns related to the Task Force efforts.
vi. Task Force members will accurately characterize to the public, decisions made by the Task Force.
vii. Task Force members will provide information from the Task Force to the organizations/constituents they represent and in turn bring the input of these groups back to the Task Force.

d. **Voting:**

i. Whenever possible, decisions requiring a vote by the Task Force will be indicated in the meeting agenda, which will be distributed to the members prior to the meeting.
ii. Fifty (50) percent of filled membership must be present at a given meeting. Decisions can be made when a majority of voting members present reaches agreement on a given matter.
iii. Voting will normally be done by a show of hands and will normally be recorded as the number of ayes, number of nays, and number of abstentions. When specifically requested by a member of the Task Force, the Chair will take a roll call, and individual votes will be recorded.
iv. Votes by members attending the meeting by technology are acceptable and add to the quorum.
v. Ex-officio participants are allowed to participate but do not have decision-making or voting privileges. They are not appointed to the formal Task Force membership.
vi. Voting privileges for absent members are as follows

1. Members participating by technology are allowed to vote.
2. Absent members may submit proxy votes to the Chair or another member beforehand if a topic was already discussed at previous meetings and notification went out ahead of time. The proxy statement will declare her/his approval or rejection of the issue that will be under discussion.

3. Absent members may submit proxy statements to the Chair or another member beforehand. The proxy statement will declare that a specific member, who must be present, serves as the absent member's delegate and has full authority to vote on a particular issue.
4. Absent members are not allowed to designate an alternate to attend a particular meeting and vote on (either specific or all) arising issues during the meeting on their behalf.

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6. SUBCOMMITTEES AND WORK GROUPS

Subcommittees and work groups will be established to assist the Task Force in accomplishing their purpose. The chair will ask for volunteers or appoint members based on their expertise and interest to serve on a subcommittee or work group. Subcommittees and work groups will be given a specified charge and period of time to fulfill that charge, and will present a final report or recommendations to the full Task Force for approval at completion of its charge.

The chair may ask persons who are not appointed Task Force members, or alternates to serve on subcommittees or work groups as necessary to fulfill a specialized or technical charge.

7. ANNUAL REPORT

The Task Force prepares and present to the House and Senate a brief annual report based on the strategic state plan and work plan.

8. AMENDMENTS

Amendments to these Operating Procedures may be made only after notification of the ASD Task Force at least two weeks in advance of a regularly scheduled meeting. Amendments require a vote of two-thirds of the members present. Suspension of operating procedures must be by majority of present members and does not constitute amendment to operating procedures.