Autism Spectrum Disorder Task Force Strategic plan *draft* 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 *draft* 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.
- The full ASD Task Force will need to consider and approve or revise these recommended implementation activities.
- A work group structure was envisioned as a way to engage stakeholders outside of the ASD Task Force in ongoing implementation work. Work groups are listed at the end of this document.

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. 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.

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point person	Notes
A. Vision: Early, timely and continuous, accessible screening and assessment				
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: • Website to help people to know where to go for	Existing activity Act Early Team Local public health — WIC, Follow Along Race to the Top Help Me Grow AAP Early Childhood Screening	Screening and Early Identification Work Group	Needs One-stop website/common resource Above list needs to incorporate ASD warning signs/red flags and next steps to get to diagnostic

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point person	Notes
	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 DB101	 IEICs Developmental Screening Task Force 		• DB101
2. Strategy: Increase access to and quality of screening statewide	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.		Screening and Early Identification Work Group address all of Strategy 2 • AAP, Health Plans • MDH and Help Me Grow (WIC, public health, social services, Head Start, Part C, schools)	 Strategy 2 should be in place before doing strategy 1 Barrier: Doctors don't get 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	U of M ASD Clinic MDH take lead with backing of ASD TF	Screening and Early Identification Work Group	

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	"Learn the Signs Act Early," American Academy of Pediatrics recommendations, etc.			
	Promote consistency in referrals after positive screening. Promote one place for screening providers to go for guidance in making referrals.	Help Me Grow, Part C (MDE), MDH, DHS	Screening and Early Identification Work Group	
	Explore options for access to and sharing of screening results to improve practices and target resources statewide.	Help Me Grow, Part C (MDE), MDH, DHS	Screening and Early Identification Work Group	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	Screening and Early Identification Work Group	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.

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4. Strategy: Ensure continuous efforts to identify needs across the lifespan	Provide education for educators, families and the community about early warning signs of ASD and obligations for child find under Parts B of the Individuals with Disabilities Education Act (IDEA)	IHEs, Continuing Ed, U of M ICI	Screening and Early Identification Work Group	Part C is included above. This group would start with high school/ transition age
	Develop a website with screening and evaluation resources for diagnosis across the lifespan		Outreach workgroup	
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	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	Outreach Work Group above	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	Existing efforts: Fraser,	Family education	Look into purchasing

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		parents ways to implement evidence-based developmental and behavioral interventions with their children (See Florida State University's Autism Navigator)	AUSM, ARC, PACER, Family Voices	work group	 access to Florida's website Anyone coming into contact with families needs professional preparation
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	Family Education Work Group	 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	PACER, Family Voices, Center for Engaging Autism AUSM, ARC, NAMI, ANSWER, ATAM (new organization of behaviorally based treatment providers), Social Odyssey	Family Education Work group	Need to have statewide access to these resources.

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	education such as established programs like "Positive Beginnings."			
	Develop website registry of parents volunteering to serve as resources in communities across the state		Outreach Work Group	
	Offer information telephone line as part of website	Community providers; 2-1-1; MNinfo.gov; PACER, Family Voices, etc.	Outreach Work Group	Not for crisis, but info resource
C. Vision: Coordination of services				
8. Strategy: Define what service coordination means	 Clarify existing models of coordination activities within health care, education, 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 	MnSIC (3-21), ICC (B-3) at state agency level Local agency involvement will be identified by work group – potentially CTICs, etc. Ensure that parents and cultural representatives are included	Service Coordination Work Group	 Important to clarify what service coordination is – everyone has different definition Major agencies need to help define what coordination looks like (in consultation with families) Revisit Gov. Carlsonsigned agreement? See requirement for interagency agreement

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	 coordination Develop MOU to clarify definitions and roles of partner agencies Ensure attention to cultural, linguistic and geographic differences 			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		Service Coordination Work Group	
	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 		Service Coordination Work Group	Infrastructure would begin to address service coordination, data collection, funding

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	models connect (all three levels)			
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.		Service Coordination Work Group	
	Continue Interagency ASD Coordination		State agencies	
D. Vision: Transition to adulthood				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)

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12. Strategy: Uphold Minnesota's standard that individualized transition to adult services should begin at 9 th grade.	Monitor potential changes to policy	Coalition for Children with Disabilities; MASE; PACER	ASD Transition Work Group	
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.	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. 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	Transition Community of Practice, CTICs, Fraser, AUSM	ASD Transition Work Group	Refer to ICI-created NASET Standards and Indicators for transition Lionsgate Academy is developing a transition program specific to ASD. Fraser is also 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.	Vocational Rehabilitation Services, Minnesota Department of Education, school districts, DHS, counties, employers, community rehabilitation providers, nonprofit	ASD Transition Work Group Lead Partner: Key legislator	

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		organizations, individuals with ASD		
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, MDH	ASD Transition Work Group	
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	ASD Transition Work Group	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 Guidelines may include: Consider housing as well as other supports

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				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	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.

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	 benefits planning and career choices; opportunities to learn to communicate their disability-related work support and accommodation needs 			
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	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	Outreach Work Group	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)	Outreach Work Group	 Outreach to non-reading, non-English-speaking communities via local cable TV and local radio stations, sometimes provided by school districts Look at national Help Me

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				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, MDH, DHS, MDE	Data Management Work Group	 MDH already has report of other state registries SEMCIL pilot project is looking at outcome data on employment supports in the workplace DHS is collecting and comparing data between children receiving early intervention benefit and others 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 Minnesota (AuSM) data Monitor trends in resource availability Clarify gaps in resources using locally developed resource	MDE, Counties, MDH, DHS, U of M, DEED, parent groups	Contracted entity	

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	maps (simultaneous with developing guide–don't delay guide development)			
	Share baseline data across agencies		State agencies	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, DHS, LEND, representatives of communities of color, such as SAPA, African American Family Center, CLUES, etc.	Service Coordination Work Group	 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	[See vision area F]	
21. Strategy: Promote the use of	Shed light on areas where there is	DHS, Health Services	DHS autism benefit	MDE refers to evidence-

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evidence-based practices across services	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 respecting individual cultures and values	Advisory Committee, private provider group of advocates, AAP, AuSM, stakeholder input group	advisory stakeholder input group (will include other agencies and parents)	based practices in collaboration with the National Professional Development Center on ASD, utilizing on-line modules training and coaching • 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	ASD TF	
	Ensure that service providers are prepared to understand and work with these tools and technologies	Communities of color, such as SAPA, others	Capacity-building work group	
	Develop infrastructure to coordinate ways of looking at outcomes across the lifespan		Data Management Work Group	What are the valued outcomes that we agree on that would inform infrastructure?
F. Vision: Competent practitioners and supportive communities				

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point person	Notes
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	Capacity-building work group	 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.		Capacity-building work group	 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. family members, law enforcement, judicial system, education, employers, medical personnel, housing providers, etc.)	Explore established programs, such as "Autism in the Judicial System; What do we know and what do we need to know?"		Capacity-building work group	
24. Strategy: Ensure preparatory and ongoing access to ASD training for students and the workforce appropriate to their	Intentionally recruit diverse potential practitioners to serve rural and underserved communities.		Capacity-building work group	

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field				
	Provide training in "ASD 101" or online via "Foundations in ASD"		Capacity-building work group	
	Teach skills for professionals on ways to interact with individuals with ASD		Capacity-building work group	
	Expand cultural competency training for providers		Capacity-building work group	
	educate parents and providers about what resources are available		Capacity-building work group	
	Promote intentional integration of disciplines: education about others' disciplines approaches, who else is out there (i.e. Leadership Education in Neurodevelopmental Disabilities (LEND)		Capacity-building work group	
	Include bullying prevention as part of education		Capacity-building work group	
G. Vision: Funding supports families				
25. Strategy: Educate policy	Look at 25, 26, 27 together to	State agencies, parents,	ASD Task Force	Measuring outcomes relates

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makers and payers about the return on investment of funding across the spectrum and across the lifespan	develop funding approach, priorities and recommendations	providers, advocates, individuals with ASD, Legislative representatives		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.	ASD Task Force	
	Include individuals across the ASD spectrum, including high-functioning (job supports,	DEED, MDE, DHS	ASD Task Force	

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	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. Apply for grants (state implementation grant, Autism and Developmental Disabilities Monitoring (ADDM), etc.)	Parents, advocates, providers, individuals with ASD	ASD Task Force	Meeting the needs of individuals with ASD is a complex and expensive undertaking. The recommendations in this plan will require new funding. DEED, MDE, DHS, MDH explore new funding sources through grants
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.	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.	Work groups created in this plan	ASD TF	State plan = ASD strategic plan

Vision and strategies	Possible implementation activities	Possible partners	Champion/Point person	Notes
	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	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		Data Management Work Group	
	Implement data-sharing structure and agreement across local and state agencies regarding data on screening and follow-up (example: Strengths and Difficulties Questionnaire (SDQ)-type data repository framework)		Data Management Work Group	
30. Strategy: Align information being collected and presented by multiple ASD organizations to streamline communications	Look at existing sources of data and develop key messages Example: Explore early education		Data Management Work Group (see how data aligns)	

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for policy makers (e.g. via ongoing ASD Task Force)	outcomes indicators and reporting model		Communications for Policy Makers Work Group (develop messages for policy makers)	
	Drive agenda of community-based participatory research on ASD at university level	MDH, U of M School of Public Health, Solahmo, Confederation of Somali Community of Minnesota	U of M School of Public Health	
I. 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		ASD Task Force	
	Determine structure that would best promote successful implementation of state plan vision and strategies. Possibilities include: Continuation of ASD Task Force		ASD Task Force	HRSA state ASD/DD implementation grant potential funding source

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	Transition to commission status with formalized staff support and funding consistent with other citizen commissions			

Draft implementation structure

- 1. ASD Task Force
- 2. Screening and Early Identification Work Group
- 3. Outreach Work Group (including website and other methods)
- 4. Family education work group
- 5. Service Coordination Work Group
 - ICC (physicians, Early childhood educators, other providers)
 - Parents and families
 - Early childhood people already mandated to do service coordination
 - County representatives
 - Local school districts
 - State agency representatives
- 6. ASD Transition Work Group
- 7. Data Management Work Group
- 8. Capacity Building Work Group
- 9. Communications for Policy Makers Work Group