

# Autism Spectrum Disorder Task Force



January 15, 2012

Final Report

## **Task Force Members**

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## **Introduction**

### **Legislative Charge**

This report was prepared by the Minnesota Autism Spectrum Disorder Task Force in response to the following charge in Laws of Minnesota 2009, chapter 79, article 7, section 25.

“(c) The task force shall develop recommendations and report on the following topics:

- (1) ways to improve services provided by all state and political subdivisions;
  - (2) sources of public and private funding available for treatment and ways to improve efficiency in the use of these funds;
  - (3) methods to improve coordination in the delivery of service between public and private agencies, health providers, and schools, and to address any geographic discrepancies in the delivery of services;
  - (4) increasing the availability of and the training for medical providers and educators who identify and provide services to individuals with ASD; and
  - (5) treatment options supported by peer-reviewed, established scientific research for individuals with ASD.
- (d) The task force shall coordinate with existing efforts at the Departments of Education, Health, Human Services, and Employment and Economic Development related to ASD.
- (e) By January 15 of each year, the task force shall provide a report regarding its findings and consideration of the topics listed under paragraph (c), and the action taken under paragraph (d), including draft legislation if necessary, to the chairs and ranking minority members of the legislative committees with jurisdiction over health and human services.
- (f) This section expires June 30, 2011.”

## **Overview**

The Minnesota Task Force was convened October 13, 2009, meeting once or twice a month through June, 2011. The task force reviewed information from the Centers for Disease Control (CDC) and the Interagency Autism Coordinating Committee (IACC), and the work of Autism Task Forces/Councils in other states. Members reviewed information from various autism publications and research studies. Presenters included Minnesota Department of Human Services, Minnesota Department of Education, Minnesota Department of Employment and Economic Development, Minnesota Health Department, state office holders, providers of early intervention services, parents, schools, doctors and Project Search, a job training partnership.

It is the goal of Minnesota Autism Spectrum Disorders Task Force that all Minnesotans with Autism Spectrum Disorder (ASD) regardless of age, race, gender, religion, ethnicity, income, or geography receive appropriate and timely individualized, inter-disciplinary, evidence-based, culturally and linguistically responsive, services and supports throughout their lifespan.

### **Autism Spectrum Disorder in Minnesota**

Autism Spectrum Disorder (ASD) is the fastest growing developmental disorder in the United States. In 2009, the Centers for Disease Control (CDC) reported that it affects 1 in every 110 children. It is 4 times more likely in males, affecting nearly 1 in 70 boys. Every 21 minutes a child is diagnosed with ASD. Since 1993 there has been an increase of more than 1600% in the prevalence of ASD between the ages of 6 and 22 years in Minnesota (CDC, 2010). Minnesota's Dec.1, 2010 Child Count data indicates that there are presently 14,646 students identified with ASD as their primary disability in MN schools from Birth to 21 years and who are receiving special education and related services in our schools. This number has continued to increase from 3,759 which represented 3.3% of the total special education population in 2001 and now individuals identified as eligible under ASD represents 11.5% of all students receiving special education services. 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.

Autism 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; as there are varying degrees of severity thus it is a "Spectrum Disorder". 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, life-style, 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.

### **Parent Perspective on living with ASD**

Imagine having a son who cannot communicate with you what he needs or wants, he cannot tell you if he is in pain or ill. He often repeatedly bangs his head hard enough to cause injury if you don't intervene. He eats/chews non food items constantly and often only sleeps 4-5 hours. Or perhaps your daughter can't

tolerate having clothes on her body, her hair brushed or even a hug from you because of her severe sensory issues. Your son gets 100% on every test but has a low grade because he does not feel he should do homework on information he learned 4 years ago. Maybe your daughter is bullied because of her “social awkwardness” but you don’t know until she tries to commit suicide when she is 15. Your body has bruises and bite marks from trying to care for your child. Your son or daughter has no sense of danger and you must vigilantly prevent him or her from wandering away, not just when they are young but for their entire life. Autism affects every aspect of your life. You will not have time for friends or recreation, you will spend every free minute learning about ASD because you need to learn quickly to navigate a complicated system to figure out what services and treatments your child needs, and how to get them. You will soon learn you need a PhD to sort through all the information because there are literally 1000’s who want to sell you something. You know your child’s best hope for improvement depends on the choices you make. You may have to quit your job because there is no one able to care for your child or you will be fired because of too many “emergencies” with your child. Your family may have to move to acquire services for your child. You may have to make the difficult decision to place your child out of your home if there are not services to help keep him/her living with your family. You are terrified what will happen to your child when you are no longer able to care for him/her, and often hope your child does not outlive you. These are the stories of Minnesota parents.

### **Treatment Options**

“It is important to match a child's potential and specific needs with treatments or strategies that are likely to be effective in moving him/her closer to established goals and greatest potential. A search for appropriate treatment must be paired with the knowledge that all treatment approaches are not equal; what works for one will not work for all, and other options do not have to be excluded. The basis for choosing any treatment plan should come from a thorough evaluation of the strengths and weaknesses observed in the child.” (Autism Society of America, <http://www.autism-society.org/>) “Individuals with Autism Spectrum Disorders (ASD) require individually designed interventions that meet the distinct need of the person. It is important that parents, health care, social services and school professionals, working together as a team, select teaching strategies and methods based on peer reviewed, empirically based, valid evidence. To say that a methodology is grounded in scientifically based research means there is reliable, independent evidence and current knowledge that a given program or practice works for an individual with autism. Each individual with autism deserves no less.” (Washington Guidebook, [http://here.doh.wa.gov/materials/autism-guidebook/13\\_AutismGd\\_E10L.pdf](http://here.doh.wa.gov/materials/autism-guidebook/13_AutismGd_E10L.pdf))

### **Practices**

According to the National Professional Development Center on Autism Spectrum Disorders, a multi-university program funded by the United States Department of Education, Office of Special Education Programs, the following are Practices with Confirmed Evidence Base for Individuals with ASD (10/24/2008):

- Antecedent-based intervention
- Computer-aided instruction

- Differential reinforcement
- Discrete trial training
- Extinction
- Functional behavior assessment
- Functional communication training
- Naturalistic interventions
- Parent-implemented interventions
- Peer-mediated instruction/intervention
- Picture Exchange Communication System
- Pivotal response training
- Prompting
- Reinforcement
- Response interruption/redirection
- Self-management
- Social skills training groups
- Speech generating devices/VOCA
- Structured work systems
- Task analysis
- Time delay
- Video modeling
- Visual supports

### **Recommendations**

**The task force recommends developing and implementing a statewide autism early identification and information awareness campaign. Additionally every county would have a standard screening and follow up program for all preschool-aged children.**

- Because early identification and intervention of ASD is critical, an identification campaign would teach community members the signs to look for and where to go for an assessment and evaluation. MN already has universal preschool screening for children ages 3-5. A Follow Along screening program for children B-3 is available in the majority of counties and expansion to all counties would be relatively simple and inexpensive. In addition, the screening tool used in Follow Along (Ages and Stages Questionnaire/Social Emotional) has been shown to identify signs of ASD and indicate which children should have further evaluation for ASD. ([www.nectac.org/~pdfs/pubs/queries/queries\\_asdscreening.pdf](http://www.nectac.org/~pdfs/pubs/queries/queries_asdscreening.pdf)) ([www.firstsigns.org/screening/tools/rec.htm](http://www.firstsigns.org/screening/tools/rec.htm))

**The task force recommends that early intervention in Minnesota follow the guidelines below from the American Academy of Pediatrics. Because public schools provide legal access to services for all children with ASD we recommend Individual Family Service Plans and Individual Education plans address all the criteria for early intervention below.**

There is a growing consensus that important principles and components of effective early childhood intervention for children with ASD's include the following:

- Entry into intervention as soon as an ASD diagnosis is seriously considered rather than deferring until a definitive diagnosis is made;
  - Provision of intensive intervention, with active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate educational activities designed to address identified objectives;
  - Low student-to-teacher ratio to allow sufficient amounts of 1-on-1 time and small-group instruction to meet specific individualized goals;
  - Inclusion of a family component (including parent training as indicated);
  - Promotion of opportunities for interaction with typically developing peers to the extent that these opportunities are helpful in addressing specified educational goals;
  - Ongoing measurement and documentation of the individual child's progress toward educational objectives, resulting in adjustments in programming when indicated;
  - Incorporation of a high degree of structure through elements such as predictable routine, visual activity schedules, and clear physical boundaries to minimize distractions;
  - Implementation of strategies to apply learned skills to new environments and situations (generalization) and to maintain functional use of these skills; and
  - Use of assessment-based curricula that address: functional, spontaneous communication;
  - Social skills, including joint attention, imitation, reciprocal interaction, initiation, and self-management;
  - Functional adaptive skills that prepare the child for increased responsibility and independence;
  - Reduction of disruptive or maladaptive behavior by using empirically supported strategies, including functional assessment;
  - Cognitive skills, such as symbolic play and perspective taking; and
  - Traditional readiness skills and academic skills as developmentally indicated.
- (PEDIATRICS Volume 120, Number 5, November 2007)

Assessment and interventions should follow evidence based data or expert consensus guidelines/recommendations from reputable peer reviewed medical, mental health, and/or educational sources. Interventions should be intensive for at least 25 hours per week and include curricula that address functional communication, social skills, functional adaptive skills, disruptive or maladaptive behaviors, cognitive skills, and academic readiness skills (when appropriate). Interventions may include developmentally based models; direct applied behavioral models, and/or structured teaching models; while providing ongoing measurement and review of progress/outcome, generalization to new environments, and inclusion of active family/parent component. There should be established certification criteria and credentialed oversight guidelines for all therapists/providers working directly or indirectly with children having autism spectrum conditions.

**The task force recommends the development of a Minnesota Guidebook for ASD.**

- Navigating through the system to find the appropriate services and treatments for individuals with ASD can be daunting. Several states have developed guide books, the task force recommends using the guide book from the state of Washington as a model. Both printed and electronic copies should be made available to individuals, families and professionals. Ideally it

should be reviewed and updated if necessary every three years. This guidebook should be made available in Spanish, Hmong, Somali, and other languages upon request.

**The task force recommends implementation and funding of an autism service coordinator for at least one year for children ages 3 to 5 and for school age children where deemed appropriate.**

- Service coordination for children age's birth-3 is already mandated in federal law. Expanding services to all children for one year after they are diagnosed with ASD would provide families with a case manager/service coordinator who is knowledgeable about ASD and has ongoing training in "recommended practices".
- Service coordinators have training to assist families in understanding what autism is, what kind of interventions are recommended practice, what providers exist in their local areas, and how families can access the services. Comprehensive training available to any professional working with families of young children will ensure that the families of children who are over three years can access service coordination through their educational providers, county or community social workers, public health nurses, etc.
- Care coordination support would ensure access to timely assessment and intervention. This would include entry into early intervention as soon as ASD diagnosis is considered without deferring until definitive diagnosis is made. This would include up to date family resources for assessment, intervention, family care support and education, and financial assistance.
- The MN Department of Education permits Interagency Service Coordination as an allowable expense for students older than age 3. School districts in MN may choose to allocate funding for service coordination for students who would benefit.

**The task force recommends increase training for physicians, pediatricians, etc. so that children with ASD are receiving an early diagnosis. Establish a standard practice for autism diagnosis.**

- Physician Screening - It is recommended that every child in Minnesota have access to a primary health care professional for establishing a medical home. Within this relationship, it is recommended that each child receive developmental surveillance and screening throughout early childhood for all developmental domains, including autism spectrum conditions based on American Academy of Pediatrics guidelines. This should occur within routine health care maintenance as well as whenever a parent or provider concern is raised. These activities should be coordinated with tracking and intervention services within the local community.

**The task force recommends to the legislature that all Pediatric and Family Practice residencies located in Minnesota provide their trainees with didactic and clinical exposure to normal and abnormal childhood development.**

- The understanding of the presentation and natural history of Autism Spectrum Disorders should be an expectation of graduates of these residencies. Appropriate topics in the curriculum should include: screening tools, associated medical conditions (and their presentations), treatment modalities, training for medical staff to screen for disorders and presentations of available community resources. In addition, recommended guidelines from the AAP for both developmental screening/surveillance and Autism Spectrum Disorders should be a part of that curriculum.
- The Department of Health and other relevant agencies must work with current practicing physicians to educate doctors through CE programs and residents in how to identify medical issues and resources for treatment.

**The task force recommends the development and implementation of medical screenings of Children after age 4.**

- The MCHAT is the current screening tool used by primary care providers (peds and family med) to screen children up to age 4 for autism. Because there are no current screening tests for autism or Aspergers beyond age 4, and many children with higher functioning autism and Aspergers are not diagnosed until school age, the task force recommends the development of an autism screening tool and standardized screening recommendations for primary care providers to utilize during well exams for school age children.

**The Minnesota Autism Task Force recommends the state and federal government fully fund special education programs and services.**

- Because schools are the only legally mandated provider of services they are the only entity providing free and appropriate public education to all children with ASD.
- When Congress first passed the Individuals with Disabilities Education Act (IDEA) in 1975, the notion was that Congress committed to pay up to 40% of the national average per pupil expenditure (APPE) to offset the excess cost of educating children with disabilities. It is vital to continue to urge Congress to increase its commitment to funding so as to fully meet its obligation to support the appropriate education of students with disabilities

**The task force recommends that Paraprofessionals receive specific training in ASD.**

- The Minnesota Autism Task Force recommends Paraprofessionals working with students who receive educational services under ASD receive training in ASD. If a student attends regular education classes he/she is often supported by a Para in the classroom. While the student may have a teacher trained and knowledgeable about ASD, often the student spends more time alone with the Para. Too often situations arise because the Para does not have the skills, especially in behavior management, to effectively support the student's inclusion.

**The task force recommends that all school professionals receive training to recognize the risk factors and/or warning signs of ASD and that districts have personnel who are trained to screen students with milder ASD in educational settings.**

- There are a substantial number of students with milder forms of autism who have not been identified. These milder forms can have adverse effects on students' learning, behavior and social skills, effecting classroom performance. Because school staff do not recognize the signs of ASD many of these students receive multiple labels and are placed in inappropriate school settings.
- Increased autism awareness training and teaching skills training for teachers in mainstream classroom. Many higher functioning kids with autism or Aspergers have little or no special education services and spend most of their time in the mainstream classroom. Teachers need to know how to recognize and work with these children.

**The task force supports an Autism Spectrum Disorders Teacher License.**

- Currently special education teachers can graduate from Minnesota colleges/universities with very little information about ASD. Without an ASD license teachers are not required to have knowledge or skills to teach students with ASD. The volume of calls that come into Arc, Pacer, SAAF and AuSM regarding school issues for students with ASD tells the crisis this causes for these students and their families. Many teachers who are placed in classrooms of students with ASD end up going back to school for additional class work to acquire the skills and body of knowledge required to serve ASD students successfully. In the last decade there has been much research and knowledge acquired in the Autism field yet in Minnesota we have not added this information to our preparation of teachers. As the number of students with ASD continue to rise, Minnesota must prepare our teachers with the knowledge and skills specific to ASD before they are teaching our children. As teachers get licensed in ASD our districts will be able to reduce the amount of staff development resources that are spent training their teachers in the ASD field. Our children deserve to be taught by teachers who understand their disability, know how to communicate with them and have the skills to effectively teach them.

**The task force recommends the establishment and enforcement of anti-bullying policies for students with disabilities.**

- Minnesota needs to enforce existing policies and create strong policies where none exist to protect students with ASD. Research indicates that children with ASD, with their characteristic social deficits, are especially vulnerable to bullying. A child with ASD often has an inability to "read" the social signs that someone doesn't have her best interest at heart, can be easy to manipulate, and may have the tendency to say what he or she thinks without a full understanding of consequences. ([www.iancommunity.org/cs/articles/bullying](http://www.iancommunity.org/cs/articles/bullying))

**The task force recommends that First Responders are trained to recognize ASD and how to work with individuals with ASD.**

- A person with ASD may not respond appropriately. They may not understand requests, run away, hide, act aggressive, or may not feel pain if they are injured. First Responders must be trained to recognize ASD and how to interact with an individual with ASD. First responders should be trained in de-escalation strategies that are specific to individuals with ASD.

**The task force recommends that health insurance companies and such other insurers, both public and private, as may be applicable in Minnesota, be prevented from excluding coverage for evidence or expert consensus based services provided to individuals with autism.**

- Many health insurers in Minnesota exclude coverage for services for the treatment of autism. The task force supports parity of coverage for individuals with ASD.

**The task force recommends policies that would reduce waiting time for home and community based services and use public resources more effectively. Recommended strategies include: Supporting interagency community programs that blend funding for better outcomes. Expanding consumer-directed options for adults with autism, and developing individual budgets designed to meet individual needs controlled by the consumer.**

- With limited funding for adults with disabilities and waiting lists for services, an individualized approach to allocating resources is essential. The current human services system relies heavily on programs that may over-serve or under-serve individuals with autism. An individualized approach will ensure that resources are allocated appropriately and efficiently.
- One model for an individualized approach is Lutheran Social Services My Life, My Choices initiative whose goal is to reform services to give greater choice, freedom and responsibility in the decisions that shape quality of life.

**The task force supports expanding transition program options and employment opportunities for teens and adults with autism, particularly innovative community-based programs (e.g., Project Search--[www.projectsearch.us/](http://www.projectsearch.us/)) that better meet the unique needs of this population.**

According to Autism NOW ([autismNOW.org](http://autismNOW.org)), recommended practice for transition program includes:

- Transition services that are tailored to meet the individual needs of students preparing for postsecondary goals
- Ongoing transition assessments that help students determine what their preferences, strengths and challenges are, as well as to measure the skills they need to pursue employment goals
- Guidance to develop individualized postsecondary education, employment and independent living goals for life after high school
- Comprehensive and interagency transition internships and competitive employment
- A work-based learning plan between the student, employer and job specialist that requires discussion about agreed upon work goals and ongoing evaluation

- Job hunting skills (i.e., resume writing, cover letter writing, interviewing skills) in collaboration with local one-stop career centers
- Connections to adult agencies well before leaving high school (i.e., vocational rehabilitation, developmental disabilities agencies, independent living)
- Training and opportunities to practice self-advocacy and self-determination skills in work and college settings services that will ensure they meet employment goals
- A course of study that is directly related to their postsecondary aspirations
- Job and college awareness opportunities including informational interviews, job shadowing, college tours
- Training on disability disclosure and workplace accommodations
- Work experience in community-based settings including service learning,
- Postsecondary education experiences while still in high school via dual enrollment opportunities.

**The Task Force recommends the development of a higher education (college living) program modeled after University of Iowa's REACH program.**

- Program to focus on independent living, social and basic communication skills for young adults with a variety of skills. The students in the Reach program have the opportunity to experience campus life with their “typical” peers.

**The task force recommends developing policies to ensure that Minnesota Workforce Center personnel are educated in autism so that they recognize the unique strengths and needs of those with ASD and the appropriate accommodations to make available.**

“Vocational Rehabilitation (VR) agencies have a variety of services available to help an individual get and keep a job. These include:

- Eligibility determination to figure out if the person qualifies for services
- Assessment of vocational needs to learn more about the person’s interests, skills and the services and supports that would be needed
- Development of an Individualized Plan for Employment that outlines the person’s goals and the services s/he will receive
- Coordination of services to help the individual reach his/her goal
- Post employment services to help the person keep the job once s/he gets it.
- Once found eligible and accepted for service, each individual will work together with his/her VR counselor to develop a plan called an Individual Plan for Employment (IPE) that will identify the services necessary to reach the person’s goal; services available vary widely depending upon the state but they may include: vocational counseling and guidance, job placement assistance, college or vocational training, skill training, transportation, or assistive and rehabilitation technology among other services. Services will be provided directly by the VR counselor, coordinated with other services or purchased by the VR agency on the individual’s behalf. The diversity of people with autism spectrum disorders is so great that diagnoses alone are not very helpful to VR professionals. This reality reinforces the

importance of an individualized approach to helping individuals reach their employment goal.” (autismnow.org/on-the-job/vocational-rehabilitation)

**Expand community-based housing options for people with autism.**

- Minnesota currently has a moratorium on group homes and no consistent method of funding housing programs for adults with disabilities. As with other adult services, MN needs to have a more individualized approach to providing support so individuals with autism can live in their communities.

**The task force recommends decreasing disparity for minority and immigrant children with ASD by assuring that all state agencies train their staff to follow the federal CLAS guidelines and provide services and resources in a manner that is culturally and linguistically appropriate.**

- Although Minnesota has long been one of the healthiest states in the country, some Minnesotans tend to experience much worse health in several areas. Overall, Populations of Color and American Indians experience shorter life spans, higher rates of infant mortality, higher incidence of diabetes, heart disease, cancer and other diseases, and poorer general health. At this point Minnesota does not have autism prevalence data, so it is difficult to provide autism-related disparity information.

**It is the recommendation of the task force to develop a comprehensive statewide system to accurately identify the number of individuals with ASD in Minnesota.**

- The Autism Society of America estimates that the prevalence of individuals in the population with autism may be as high as 1 in 110. There is no comprehensive statewide system for accurately calculating the number of individuals with autism in Minnesota. We have the statistics from the Minnesota Department of Education but it does not include adults, students in private schools, home schools, private therapies (children not in public schools), doesn't include children with co-morbidities. Accurate prevalence data are essential to plan and provide resources for services that are needed for individuals with autism.

**The task force recommends that higher education, research institutions and state agencies conduct and write proposals for grants and do research on the area of autism.**

- Specific research is needed on prevalence, causation, genetic predispositions and environmental exposures. Expansion of research in the areas of immunology and gastroenterology is greatly needed since there are few providers in the state that specializes in these areas for autism. There is ongoing need for research into which interventions/therapies are the most beneficial to individuals with ASD.

## **Links/Resources**

MDH Autism and the Somali Community – Report of Study

<http://www.health.state.mn.us/ommh/projects/autism/reportfs090331.pdf>

The National Professional Development Center on Autism Spectrum Disorders

[http://www.wsti.org/documents/Conference%20Handouts%202010/Session%208/NPDC%20on%20ASD%20Flyer\\_1-20-10.pdf](http://www.wsti.org/documents/Conference%20Handouts%202010/Session%208/NPDC%20on%20ASD%20Flyer_1-20-10.pdf)

AAP Management of Children with Autism

<http://www.aap.org/pressroom/issuekitfiles/ManagementofChildrenwithASD.pdf>

2010 MN State Statute on Service Coordinator

[https://www.revisor.mn.gov/statutes/?id=125A.023&year=2010&keyword\\_type=all&keyword=Service+coordination+special+education](https://www.revisor.mn.gov/statutes/?id=125A.023&year=2010&keyword_type=all&keyword=Service+coordination+special+education)

Help Me Grow Website

[www.MNParentsKnow.Info](http://www.MNParentsKnow.Info)

Washington Guidebook on Autism

[http://here.doh.wa.gov/materials/autism-guidebook/13\\_AutismGd\\_E10L.pdf](http://here.doh.wa.gov/materials/autism-guidebook/13_AutismGd_E10L.pdf)

Autism Society of America

<http://www.autism-society.org/>

Interagency Autism Coordinating Committee

<http://iacc.hhs.gov/>