REPORT OF THE MINNESOTA SENATE AUTISM TASK FORCE

Submitted to

Majority Leader Lawrence Pogemiller
and
Governor Tim Pawlenty

Cc: Senator David H. Senjem - Minority Leader & Autism Task Force
Senator Terri E. Bonoff - Autism Task Force
Margaret Anderson Kelliher - Speaker of the House

March 2009

MINNESOTA SENATE AUTISM TASK FORCE

MARCH 13, 2009

Lawrence J. Pogemiller Majority Leader Minnesota State Senate 235 State Capitol 75 Rev. Dr. Martin Luther King Jr. Blvd St. Paul, MN 55155	Timothy J. Pawlenty Office of the Governor 130 State Capitol 75 Rev. Dr. Martin Luther King Jr. Blvd. St. Paul, MN 55155

Dear Majority Leader Pogemiller and Governor Pawlenty,

I am pleased to submit to each of you the initial report of the Minnesota Senate Autism Task Force adopted by a voice vote on May 17, 2008 [S.R. 176-Chief Author Senator David H. Senjem] in the 2007-2008 Legislation Session. [Senate Resolution Copied].

It was the sense of the Senate of the State of Minnesota that an autism task force be established to study and make recommendations to the Legislature regarding the growing incidence of autism and ways to improve the delivery and coordination of autism services in the state. This task force soon realized that the scope of work was greater than what could be accomplished within the time allotted. The task force first met on October 7, 2008 and took on a rigorous schedule, meeting bi-weekly thereafter until March 11th, 2009.

Each task force member worked extremely hard and put in many hours of dedicated volunteer service. It was clear early on that everyone shared the same passion to improve current Minnesota autism services. There is great concern as to how people in need can better navigate the system and more efficiently obtain services.

Autism is a very complex disorder with many unanswered questions. Many Minnesotans are depending on the existing task force as well as any future autism task force[s] to help them utilize Minnesota's existing services in a much more efficient manner, as well as to make recommendations regarding how to improve services.

On behalf of the task force, we would like to thank Senators David H. Senjem and Terri E. Bonoff for their support and guidance. We would also like to thank Majority Leader Larry Pogemiller and Governor Pawlenty for allowing our efforts to go forward and for giving us the ability to serve on the Minnesota Senate Autism Task Force [S.R. 176] these past six months. We truly hope that this work will continue in some way.

Regards,

Bradley D. Trahan, Chair
Minnesota Senate Autism Task Force

MINNESOTA SENATE AUTISM TASK FORCE

Member's of the Task Force

S. R. 176

2007-2008 Legislative Session

Senator David H. Senjem
Senator Terri E. Bonoff
Brad Trahan-Parent Advocate Representative [Rochester, MN]
Darren Schuler-Public School Representative [Delano, MN]
Dr. Eric Larsson-Therapy Provider Representative [Minneapolis, MN]
Jacki McCormack-Advocacy Representative-Arc of Minnesota [Saint Paul, MN]
Amy Dawson-Parent Advocate Representative [Minneapolis, MN]
Dr. Allison Golnik-Medical Field Representative- U of M [Minneapolis, MN]
Heidi Kluzak-Autism Society of Minnesota [Saint Paul, MN]
Virginia Richardson-PACER Center [Bloomington, MN]

Technical Advisors to the Task Force:
Karen Mickelson-Minnesota Department of Human Services
Phil Sievers-Minnesota Department of Education
Maggie Diebel-Minnesota Department of Health

Staff:
Lucas Nesse [Senator Senjem's Legislative Assistant]
Jonathan Eichten [Senator Bonoff's Legislative Assistant]
Lydia Uphus [Senate Republican Research]

MINNESOTA SENATE AUTISM TASK FORCE

Table of Contents

INTRODUCTION

According to the Centers for Disease Control, autism affects 1 in 150 births (roughly 1.5 million Americans are believed to have some form of autism). The Autism Society of America [ASA] estimates that the prevalence of autism could reach 4 million Americans in the next decade.

Autism is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting the areas of social interaction and communication skills. Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions and leisure or play activities. Autism affects each individual differently. Studies have shown that early diagnosis and early treatment is effective to improve autism symptoms.

Autism knows no racial, ethnic, social, economic, lifestyle, or educational boundaries and can affect any family and child. It is four times more prevalent in boys than girls.
A recent national survey revealed that children with autism had more challenges receiving good health care compared to children with other types of special health care needs. Specifically, children with autism have more unmet needs, delayed or foregone care and difficulty receiving referrals, less family support services and less family centered care. Additionally, families of children with autism were under greater financial stress compared to families of children with other special health care needs. Families of children with autism were more likely to report financial problems, need additional income for the child's medical care, reduce or stop work because of the child's condition, spend more than ten hours per week providing or coordinating care, and pay more than $1000 in the previous year for the child's care (Kogan, *Pediatrics*). [Report available on-line per request of forwarding link to the web site link].

The number of individuals identified with autism in Minnesota is growing, but it is difficult to gather data that provides the true incidence since our state does not have a registry or surveillance system for autism. The best figures available are from education data that is reported annually. Minnesota school districts report their Dec. 1 Child Count data to the Minnesota Department of Education to fulfill Federal reporting requirements. In 2008, the state total for individuals (birth-21 years) who were identified as meeting the Special Education eligibility requirements for Autism Spectrum Disorders (ASD), was 12,704. This is an increase over the previous year and the percent of increase in each of the past 5 years has been between 12-17%. While the increase in those identified as eligible for Special Education services under the ASD criteria is increasing in all states, this figure is generally believed to be an under estimate of the true prevalence, as some children are reported as eligible for services under different disability categories.

Parental and professional advocates have pushed long and hard for a task force to study and make recommendations to the legislature regarding the growing incidence of autism and ways to improve the delivery and coordination of autism services in Minnesota.

<u>CHARGE</u>: [S.R. 176]

1] Appoint a Chair within its membership.
2] Review the available literature and consult with experts to gain an understanding of the causes of the disorder and its incidence in Minnesota.
3] Assess the availability of services currently provided for early screening, diagnosis, and treatment of the disorder.
4] Assess the availability of services to assist families and individuals with autism.
5] Review the effectiveness of programs and services provided to individuals with autism and their families.
6] Review other issues and concerns that the task force believes would be helpful in arriving at sound policy recommendations; and
7] Complete its review and submit its recommendations to the appropriate policy and fiscal committees of the legislature and the governor by January 1, 2009. [Note: Extended by Task Force to March 13, 2009].

PUBLIC FORUM #1 [FAMILY PERSPECTIVE]

To begin to address the charges called for in the Resolution, the task force decided to host two public forums. The first forum titled, *Family* Perspectiv*es*, was held on Thursday, November 13, 2008 at the Capitol, Room 123, and focused on the issues that individuals, parents, guardians, grandparents and siblings are facing with autism. There was standing room only with an attendance of approximately 200 people who shared their stories and support for this cause. Oral testimony was taken from 46 people and, in addition, another 66 individuals shared stories via our e-mail address, autismtaskforce@senate.mn.

This was an emotional and moving 2 hours and 45 minutes. The task force heard from individuals with autism spectrum disorder (ASD) who indicated that they are struggling in school and have a difficult time making and keeping friends. Some of them expressed concern as to what they are going to do once they graduate from high school. Others shared that, despite their autism, they can be productive in the community and are proud to be employed and attending college.

We heard from parents, grandparents and guardians who literally "cried for help", and from those who are simply worn out and frustrated because it is so difficult for them to navigate the system, as each of the 87 counties operate differently. Other parents spoke about the financial strain caring for an individual with autism puts on their families. Furthermore, we heard testimony about the stress autism places on marriage and the higher divorce rates for parents of children with ASD.

The task force listened to the frustration that many expressed with regard to the private and/or self-insured who are not provided with necessary coverage for medically prescribed therapy. In addition, many expressed their frustration in what they believe is a lack of ASD related education in our communities, public schools and medical professions.

We also heard from those who traveled a great distance to participate in this public forum. It was made loud and clear to the task force that rural and greater Minnesota is struggling due to the lack of services provided to them. In an e-mail the task force was asked, "To look into how our kids are supported, when they most need our help, when they are in a crisis." As one writer wrote, "We live up north but that doesn't mean there isn't autism up here."

The task force also heard a story about how the sibling of a child with autism quit school only to see her brother with ASD graduate. She was so moved by his "can do" attitude that she went back to school to obtain her GED. We also heard from individuals who said the diagnosis of a sibling with autism is very emotionally difficult. One sibling wrote, "No one ever thought to ask me how I felt and how I dealt with things that came up like bullies, teasing, ignorance and understanding my brother. I was overlooked."

According to parents and guardians of children with ASD, children do not receive enough vocational skills to prepare them for survival outside of the school setting. They need more training as they transition from child, to teen, to adult, and begin to integrate themselves into community settings. The task force learned that, while many schools are being praised for their work, some parents/guardians are frustrated to the point of home schooling their child with ASD.

The task force read about family stresses such as receiving a medical diagnosis of autism from their family physician and still having to go through another testing process in order for the school team to determine if their child would be eligible for Special Education. Today an individual can have a medical diagnosis for autism bust must still be evaluated for eligibility for Special Education. A medical diagnosis and Special Education criteria are not equivalent and families are confused and frustrated by the different requirements of these systems.

Many families are concerned about the welfare and safety of their children in school and the community. People with ASD often wander off without any fear of harm. Families and professionals are pushing for statewide technology to be implemented that would help find, in a timely fashion, vulnerable loved ones who wander off.

People spoke of the many therapies available including ABA, RDI, floor time, occupational/physical therapy, speech, biomedical treatment, music therapy, and nutritional therapy for food allergies and intolerances. They also spoke of the challenges related to finding the "right" therapy, as well as the complexity of managing the array of therapies. Children with ASD frequently have other medical issues resulting in additional frustration for parents. Families also expressed concerns of not being able to find providers to treat their children, and when they do, they usually cannot afford the treatments prescribed or face a long wait to obtain those services.

Much frustration was expressed regarding financial stress and parental fees. There are evidence-based therapies available that result in significant progress for individuals with ASD, but the programs are very expensive. Some parents and guardians told us that, although their child had been on Medical Assistance, parental fees became so high they had to quit this service all together. As a result, they were not able to save for their own retirement or their children's future. Parents spoke of taking out a second mortgage on their home in order to pay for just for one month of therapy for their child.

The task force learned of major family stresses related to organizing transportation, other family members not accepting their situation, maintaining employment for one or both parents, and the lack of sleep in households that have a child or children with ASD.

While much of the forum focused on challenges and areas needing improvement, we heard many success stories about individuals who were making great strides in their public school setting. With early and intense therapy tailored to that individual, progress was being made. Individuals with ASD, no matter the severity of the diagnosis, can be taught and we should never give up on them!

In the closing comments of this public forum a testifier stated, "Of all the challenges we encounter throughout our day, one of the most challenging, frustrating, and heart-breaking is the number of people who are unaware of autism and/or are reluctant to listen, learn, change, and accept individuals with ASD. Many families live in fear of the unknown, and at the same time, struggle and fight for their child until they are physically and emotionally worn out.

PUBLIC FORUM #2 [PROFESSIONALS PERSPECTIVES]

The second public forum was titled, *Professionals Perspective*, and took place Wednesday, January 21, 2009 from 6:30 to 8:30 at the Capitol, room 123. The task force invited physicians, education professionals (support services, teachers, para-professionals), social service and therapy providers, extended home care providers, and autism specialists to speak. There were about 100 people in attendance. The task force heard testimony from 16 people and received written testimony from another 34 who wanted to express their views but could not attend. (Note: public forum #2 was videotaped and can be viewed by going to the Minnesota Senate Media Services Web Page. Click on Audio and Video Archives, Special Events, 2009 Video, January 21st, and then click, A Senate task force created to study the devastating impact of autism on individuals, families and society conduct a public forum.)

The first public forum generated tremendous emotion as we heard of the many challenges faced by families. In the second forum, the professionals echoed these challenges and sent a common message that better collaboration and coordination in addressing all aspects of ASD is critically needed. They also expressed the need for uniform standards of care, evidence-based approaches, and best practice guidelines, as well as more research and better data to guide our collective efforts. In addition to a focus on early intervention, the task force heard that increased emphasis should placed on issues related to transition (vocational training, housing, transportation), as kids with autism become adults with autism. We also heard about the need to ensure the availability of services – including expanding provider training – not only in the metro area, but in rural areas as well.

The task force heard from Early Childhood Special Education (ECSE) teachers who, despite the challenges, have learned to celebrate even the smallest accomplishments of students with ASD. With continued education, these children can achieve great success. Some of the teachers stated they had gained so much from individuals with autism, more than they ever would have in college or graduate school. Other professionals felt that special education teachers working with children with ASD should be required to obtain special certification. Currently, our teachers are getting hands-on training by working directly with ASD students, but there is no specific, formal education for teachers who work with ASD kids. Special education teachers themselves are calling for autism certification as well as special training for para-professionals. The professionals all agreed that early identification and intervention is extremely important. It was also suggested that the state should have regional resource and training centers with expertise in autism spectrum disorders to provide training and support for local schools.

One testifier focused on the poor reimbursement for mental health services which seriously limits available ASD services, and the task force learned of the challenges facing therapy centers that rely on third party payments to stay alive financially. They are frustrated with the lack of health care coverage for certain important therapies and with insurance companies in general.

The task force heard from a developmental and behavioral pediatrician who has been in practice for over 30 years and has diagnosed children from a 9 month old girl who was inordinately focusing on the spots on her mother's dress, to a 17 year old high school senior whose aspergers disorder had not been previously diagnosed and who had recently been hospitalized three times for depression and suicide because he felt so lonely. This testifier stressed, again, the importance of coordination among the various service providers, the need for changes in the payment system that would encourage coordination, and highlighted the need for continued ASD research and consumer education. We also heard testimony about the rising number of first generation Somali Americans being identified as having autism. (Note: The Minnesota Department of Health is currently studying the available data to better understand this situation.) In the Somali community, the isolation experienced by many families dealing with autism is compounded by what is felt by Somalis to be a cultural divide in dealing with the medical and educational systems in our state.

Social service providers compared the rise in cases of autism to a tsunami. ASD individuals now comprise up to one half of the total caseload. Social service providers across our state share the fear that if we do not do something to help our ASD population, more and more kids will end up in out-of-home placement, adding to the economic woes of our state and country.

The testimony given in our *Professionals Perspective* forum reinforced many of the concerns expressed by the individuals and families in the first forum, and proved an education for us all. Of particular note was the expressed need for better collaboration and coordination among us all. It is clear that the many young children in Minnesota who are identified as having autism spectrum disorders are receiving inadequate programming to address their developmental needs. There are evidence-based therapies that have been proven to work, and medical experts are trying to garner support for reimbursement of those therapies. Ensuring the availability of appropriate services will maximize the likelihood of individuals with ASD to become productive and independent citizens.

MINNESOTA AUTISM TASK FORCE SURVEY

A total of 1,407 Minnesotans responded to questions regarding autism in Minnesota. The great number of people who completed the 19 question survey (between January 5th to February 15th) without any incentives demonstrates the importance of autism issues in Minnesota.

Respondents included:

Individuals, parents/guardians, family members, educator, behavior therapists, speech/OT/physical therapists, physicians, community service professionals, government professionals, those affiliated with insurance companies and an "other" category!

Networks used to send out the survey were, but not limited to;

Various advocacy groups, Autism Society of Minnesota, ANSWER, St. Davids, Therapy for Me, student advocates, PACER, MN Secondary Principals Association, MN Elementary Principals Association, Arc of Minnesota, Arc Greater Twin Cities, Autism Discussion Group List Serve which covers professionals and MD's working with children in autism, MN-AAP, BEAT-MN, Statewide Network for Autism Spectrum Disorders [teachers & related service providers for individuals with ASD B-21], Minnesota Interagency Autism Planning Group [MN-IAPG, Regional Low Incidence Projects, Minnesota Autism Network representatives, ASD/Institution Higher Education Research Group [ASD/IHE], Early Childhood Special Education Practitioners [ECSE], Interagency Early Intervention committee chairs [IEIC], Speech Language Pathologist for Birth-5 years, Minnesota Administrators for Special Education [MASE], Minnesota Association of School Administrators [MNASA], Minnesota School Psychologist Association [MSPA], Minnesota Chapter American Association of Pediatricians, Governor's Council on Developmental Disabilities, Posted on MDH-MN Children with Special Needs website, and a variety of other websites and parent support groups.

Results

A full analysis will require additional time and resources to organize and analyze responses and over 2100 open-ended answers. The following are highlights that the Task Force would like to bring to the Governor's attention;

Financial Impact

- Seventy-Seven percent (77%) feel that obtaining **affordable autism therapies/treatment** is a great problem (rating it a 4-5 in a 1-5 scale of problems).
- Ninety-percent (90%) of families reported that their family has faced moderate to a great deal of **financial stress** related to an autism diagnosis.
- Seventy-six percent (76%) reported that a family member has had to **stop/decrease work** due to autism.

Physician Education

- Ninety-four percent (94%) reported that **physicians education** about early diagnosis of autism is very important (rating it a 4-5 in a 1-5 scale of importance).

- Ninety-four percent (94%) reported that **availability of physicians specializing in children with autism** is very important (rating it a 4-5 in a 1-5 scale of importance).

Treatments/Therapies

- Ninety-one percent (91%) reported that **autism therapy issues** are very important (rating it a 4-5 in a 1-5 scale of importance).
- Ninety-two percent (92%) reported that **navigating county systems** is a very important challenge (rating it a 4-5 in a 1-5 scale of importance).

Transition to Adulthood Services

- Ninety-four percent (94%) reported that **transition to adulthood** issues (including Vocational Skills Training) are very important (rating it a 4-5 in a 1-5 scale of importance).

Rural Issues

- Ninety-four percent (94%) reported that care for children with autism in **rural settings** is a very important challenge (rating it a 4-5 in a 1-5 scale of importance).

Educational Issues

- Ninety-two percent (92%) reported that **education of public school staff regarding autism** is very important (rating it a 4-5 in a 1-5 scale of importance).
- On a positive note, 59% feel that there is only *little* to *moderate* need for improvement in family involvement in the Individual Educational Program [IEP].
- Additionally, 47% feel that there is *little to moderate* need for improved options for inclusion in general education classroom vs. separate/specialized classrooms.

MINNESOTA CURRENT LEGISLATION RELATED TO AUTISM

- H.F. 0025/S.F. 0066 *Children's therapeutic services and supports modified*
- H.F. 0173/S.F. 0407 *Map of money used to support children required*
- H.F. 0266/S.F. 0711 *Parental fees modified for services for persons with developmental disabilities*
- H.F. 0359/S.F. 0312 *Autism spectrum disorders coverage required*
- H.F. 0516/S.F. N-A *New mandated health benefit moratorium established*
- H.F. 0622/S.F. 1138 *Local law enforcement agency grant established to develop or expand lifesaver programs that locate lost or wandering persons who are mentally impaired, task force authorized, and money appropriated*

While the legislation is being proposed concurrent with the submission of this report, the Minnesota Senate Autism Task Force has unanimously voted and requested from Senators Senjem and Bonoff that a joint task force be formed between the House and Senate. [Note: State employees on the task force abstained from all voting issues to avoid conflict of interest].

In addition, rather than being proposed as a resolution, we asked this to be submitted as a formal bill. It is the hope of this task force that one day in the near future the joint task force can be formed into an advisory council or commission. Representative Slawik previously initiated a bill for a joint task force, but is supportive of the current legislation being drafted and will be the chief House author upon its completion.

SUMMARY

The task force recognizes the current economic situation and feels that a report of recommendations containing fiscal implications is simply not practical.

While there will always be differing opinions on a variety of issues relating to autism, one thing has been made very clear to this task force. Much more work is not only needed, rather, warranted. The task force supports medical professionals and scientists as they continue to research the causes and best treatments for autism. Autism is the fastest growing developmental disability in our nation. It costs United States tax-payers up to $90 billion dollars annually to care for our individuals with ASD; an amount that can be reduced by up to two-thirds with early and intense therapy.

The task force hopes that the work accomplished these past six months will be a reflection of what is yet to come, and that one day our children and family members can better navigate the complex system, which would alleviate much stress on families. It is also our hope that Minnesota will work in unison to coordinate its ideas and resources to better help our children and their families.

RECOMMENDATION

It is imperative that the State of Minnesota act to fulfill the original charge of this task force. We strongly recommend that the Legislature and Governor act to establish a task force with a longer time frame that will be able to make a full range of in-depth recommendations and assist the State in coordinating inter-agency and intergovernmental efforts to address issues of concern related to autism and its effects on individuals, families, schools, and units of government.