

REPORT OF THE SAN MATEO COUNTY BLUE RIBBON TASK FORCE ON AUTISM

July 11, 2007

Executive Summary

The current autism crisis poses a tremendous challenge to San Mateo County's school system. Today, 1 in 150 children are diagnosed with autism, a complex neurobiological disorder that impairs an individual's ability to communicate and relate to others. School districts are struggling to hire and train staff, and develop appropriate programs, to serve over 550 children in the County who have been diagnosed with this disorder. The autism crisis also has caused enormous budgetary strain for school districts as it is not uncommon for a child with autism to require services costing in excess of \$50,000 per year.

In September 2006, the San Mateo County Office of Education (SMCOE) and the San Mateo County SELPA (SELPA) convened the Blue Ribbon Task Force on Autism to examine the issue and provide recommendations. The Task Force included a broad range of individuals involved with autism, including parents. The Task Force met eight times over the course of the 2006 – 07 school year to prepare this report.

The Task Force believes that all children with autism deserve and require evidence based interventions and services that will allow them to reach their potential and participate as fully as possible in family, school, and community life. At the same time, the Task Force recognizes the fact that such interventions and services must be cost effective so that school districts can maximize the limited special education funding that is available and optimize educational services for all children.

After researching developments in the field of autism at the national, state and local level, the Task Force believes significant autism specific funding is likely to become available in the years ahead. For San Mateo County to secure this funding, the Task Force believes that San Mateo County must act now to put in place a comprehensive plan for serving children with autism. This plan should include the "best practices" enumerated in this report relating to interagency collaboration, communication, services, and staffing/training.

The Task Force recommends the following steps be taken to develop and implement the comprehensive plan that will be needed to successfully compete for future funding: (1) establish a standing San Mateo County autism commission; (2) hire an Autism Resource Coordinator and an Autism Specialist at the county level; and (3) aggressively pursue public and private funding that is now available. This effort will require an initial start-up investment of approximately \$250,000, which the Task Force hopes can be funded by the SMCOE and SELPA.

A. The Autism Crisis

Autism is a complex neurobiological disorder that impairs a person's ability to communicate and develop social relationships with others, and is often accompanied by rigid routines and behavioral challenges. Autism is commonly referred to as a "spectrum" disorder as symptoms can range from very mild to quite severe. Throughout this report, the word "autism" will be used to describe a category of conditions, including full symptom autism, Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), which as a group are known as "autism spectrum disorders" or "pervasive developmental disorders."

1. Autism has emerged as one of the major public health crises of our time. The scope of the problem, and its rapidly growing national focus, is comparable to what the nation experienced with AIDS in the 1980s and breast cancer in the 1990s.
 - a. Autism is now diagnosed in 1 in 150 children born in the United States (Center for Disease Control, February 2007 report).
 - b. More children will be diagnosed with autism this year than with AIDS, diabetes & cancer combined (Autism Speaks).
 - c. The number of autism cases in San Mateo County has climbed to 553 in 2005-06, a 134% increase from 2000-01 (California Education DataQuest website). Of the 553 children with autism, 278 (about 50%) are between 3 and 8 years old. As a result, middle schools and high schools will soon see a sharp increase in the number of children with autism that they serve.
 - d. Each individual with autism is predicted to cost society \$3.2 million over his or her lifetime when service costs and lost productivity are both taken into account (April 2007 issue of Archives of Pediatrics & Adolescent Medicine).
2. School districts are struggling to hire and train staff, and develop appropriate programs, to serve children with autism. This challenge is compounded by two facts: First, San Mateo County has 23 school districts, many of which are quite small and therefore more limited in their ability to develop internal expertise. Second, appropriate programs and therapies must be tailored for each individual child given the broad range of deficits experienced by children with autism.
3. The budget strain on school districts caused by the autism crisis is enormous and growing. For example, in the 2005 – 06 school year, the Burlingame School District spent in excess of \$700,000 with nonpublic agencies (NPAs) to serve 27 students with autism which equates to almost \$26,000 per child. It is not uncommon for a child with autism to require services costing in excess of \$50,000 per year.
4. Our understanding of best practices and service models for children with autism is evolving. Existing evidence-based research on autism services is limited, but this will change in the years ahead given the growing number of researchers in the field.

B. The Blue Ribbon Task Force and its Vision

In September 2006, the SMCOE and the SELPA convened the San Mateo County Blue Ribbon Task Force on Autism. The Task Force was comprised of: SMCOE and SELPA senior administrators; special education directors from several local school districts; SMCOE special education teachers, program directors and managers; Golden Gate Regional Center (GGRC) representatives; the president of a local school board; PARCA's Director of Family Support Services; and parents of children diagnosed with autism (see attached list of members).

The Task Force met eight times over the course of the 2006 – 07 school year to develop policy recommendations for individuals with autism from infants through 22 years of age. In addition, the Task Force formed the following four sub-committees: Early Identification and Preschool; Elementary School; High School/Transition into Adulthood; and Next Steps/Resources. Each recommendation was discussed in detail, in both subcommittee and full committee sessions, until a consensus was achieved.

The Task Force believes that all children with autism deserve and require evidence based interventions and services that will allow them to reach their potential and participate as fully as possible in family, school, and community life. To achieve this goal, San Mateo County must develop a comprehensive system of programs and services that meet the various and unique needs of children with autism. This system will be most effective and cost efficient if it fosters collaborative and cooperative working relationships between the SMCOE, the SELPA, school districts, other governmental agencies, NPAs, and community partners.

The Task Force believes that San Mateo County must be proactive and bold in addressing the autism crisis and establish itself as a state leader in serving children with autism. To that end, this report sets forth a series of “best practices” policy proposals. It also recommends a structure and an initial start-up investment of \$250,000 from the SMCOE and the SELPA to: (i) begin the process of enhancing services for children with autism in San Mateo County; and (ii) position the County to successfully compete for significant autism specific funding that the Task Force believes is likely to become available in the years ahead.

C. Best Practices and Service Delivery

1. Interagency Collaboration:
 - a. Develop and maintain collaborative and cooperative working relationships between the SMCOE, the SELPA, the GGRC, school districts, other governmental agencies and NPAs so that students and their families can benefit from all available services.
 - b. For example, the Task Force believes it is important to improve collaboration between the GGRC, school districts and the SMCOE so that:
 - (i) services are not disrupted when the school system assumes financial responsibility for education related services when children turn three; and
 - (ii) school districts and the SMCOE can develop appropriate plans for

serving incoming students. The GGRC, school districts, and the SMCOE should maintain regular communication about the number of children with autism from birth to three receiving services.

2. Communication:

- a. Develop and implement a consistent communication system among each student's support team. A multidisciplinary team should be actively involved from initial assessment until after the student exits the education system, with special attention paid to all transition periods. The team should include everyone who is involved in the student's Individual Family Service Plan (IFSP) or Individual Education Plan (IEP), such as teachers, paraprofessionals, specialists, NPAs, families, and, when appropriate, the student. This team should meet on a regular basis and not just for the annual IEP or IFSP.
- b. Ensure that culturally competent communication systems are developed and implemented to serve San Mateo County's diverse population, particularly for individuals with limited English proficiency.
- c. Design and implement online resources (e.g. training modules, links to programs, etc.) for service providers, families and other stakeholders.

3. Services:

- a. Explore the possibility of developing a school based infant autism program along the lines of the Sonoma County and Orange County programs.
- b. Through the SMCOE, school districts, and/or consortia formed by school districts, support a full range of placement options that meet each student's individual needs and abilities. These placement options must offer quality programs that are "evidence-based" and include diverse teaching strategies.
 - 1) Evidence-based programs include:
 - Floor time.
 - TEACCH (structured teaching).
 - Applied Behavioral Analysis (ABA), Discrete Trials (DT) and Pivotal Response.
 - Relational Development Intervention (RDI).
 - Picture Exchange Communication System (PECS).
 - Alternative and Augmentative Communication (AAC).
 - Assistive Technology (AT).
 - SCERTS (Social Communication, Emotional Regulation, Transactional Supports).
 - Sensory Integration.
 - Positive behavior management.
 - Social skills training.
 - 2) Teaching strategies include:
 - Supporting each child's ability to communicate, regardless of the communication system, across all settings.
 - Interactive learning.
 - Focusing on the generalization of skills from one setting to another, including community-based settings.

- Providing opportunities for self-initiation, self-direction, and practicing new and emerging skills.
 - c. Provide adjunct services within the school setting, including individually-appropriate academics, pragmatic language training, alternative communication systems support, social/behavioral training, pre-vocational training, self-care and independent living skills training.
 - d. Develop secondary school programs that include:
 - 1) Strong vocational training that leads towards meaningful paid employment upon exiting the school system (e.g. work experience opportunities, technology training, job clubs, social/behavioral training for the worksite, identification of work skills and then matching those skills with vocational opportunities, utilization of government agencies that promote successful transition toward work such as the Transition Partnership Program, the California Department of Education workability program, and programs offered by the Department of Rehabilitation).
 - 2) Academic-based programming for students that will pursue higher education.
 - e. Bring additional focus to helping students and their families through key transition periods (e.g. transitions from IFSPs to IEPs, changes in classroom or other placements, transition to the work place or higher education, etc.).
 - f. Improve and expand inclusion programs with typically-developing peers so that students with autism have the opportunity to participate in a socially-based curriculum and successfully engage in campus activities.
 - g. Develop and support well-run after-school recreational programs and leisure activities for students with autism that are staffed by individuals who are trained in supporting these students.
4. Staffing/Training:
- a. Recruit and retain highly qualified and appropriately trained professionals and paraprofessionals to deliver services to students.
 - b. Develop guidelines for the appropriate staffing of classrooms based on each individual student's needs in order to provide a stimulating and safe learning environment.
 - c. Provide sustained training and support for special education and general education teachers, paraprofessionals/aides, specialists, principals, administrators and families on evidence-based programs and teaching strategies for students with autism of all ages and abilities.
 - d. The SMCOE should create a strand of demonstration classrooms that would not only serve students with autism and their families, but also support teachers and staff with in-service training. These classrooms would showcase a variety of methodologies and provide a model for developing programs at the district level. The SMCOE also should have specialists follow-up on such trainings with visits to teachers' classrooms to assist them in the design and implementation of these methodologies.

- e. Explore opportunities for local community colleges and other local post secondary education programs (e.g. the Berkeley Extension) to provide appropriate autism training courses for aides and other educators.
- f. Educate general education students about the range of issues that students with autism confront and where possible provide them with strategies to support their classmates with autism. Such education programs should review the strengths as well as the deficits of children with autism, and help general education students understand the disorder from the perspective of the student with autism.
- g. Expand training opportunities for non-English speaking families.
- h. Establish a plan to recognize and reward staff who attend trainings and then implement strategies that they have learned, possibly by awarding an autism competency certification.

D. Future Funding Availability for Autism

1. The Federal and State government, as well as advocacy organizations and foundations, are investing more resources in autism, which in turn will create opportunities for San Mateo County to obtain funding.
2. Federal:
 - a. The US Office of Special Education and Rehabilitative Services will from time to time make funds available for autism focused grants. For example, a \$1.0 million competitive grant was announced in November 2006 to fund the establishment and operation of a professional development center to provide training for autism professionals.
 - b. The Combat Autism Act was passed in 2006 and allocates \$920 million over five years primarily for research.
 - c. The Expanding the Potential of Individuals with Autism Act was introduced in March 2007 and will provide \$350 million primarily for services. This legislation will establish demonstration grant programs for service providers.
3. State:
 - a. The California Legislative Blue Ribbon Commission on Autism will make significant recommendations to the legislature and Governor later this year. Some of these recommendations will likely include new funding.
 - b. The California Department of Education Autism Advisory Commission will report to the Governor in November 2007.
 - c. The California Department of Developmental Services (DDS) will issue a major report by December 2007 on best practices for serving individuals with autism.
4. Advocacy Organizations and Foundations:
 - a. Autism Speaks, a leading national advocacy group, now has an annual budget of over \$50 million which will grow to \$100 million in the next few years. Autism Speaks plans to make grants to local service providers.

- b. Major philanthropic organizations, such as the Silicon Valley Community Foundation, also are promising sources for funding.
- c. The San Mateo County First 5 Commission has initiated a “Special Needs Project” which offers funding, particularly with respect to early diagnosis and early intervention programs.

E. San Mateo County’s Ongoing Role

1. The Task Force believes we must be proactive in addressing what is the number one special education challenge facing San Mateo County today and establish the County as a state leader in serving children with autism.
2. We should build on our existing efforts to help children with autism by:
 - a. Creating and supporting a standing San Mateo County Autism Commission (see Section F below).
 - b. Defining and staffing the following positions (see Sections G and H below):
 - 1) Autism Resource Coordinator
 - 2) Autism Specialist
 - c. Aggressively pursuing public and private funding (see Section I below).
3. The combination of a standing autism commission and two autism specific positions at the county level will demonstrate San Mateo County’s commitment to children with autism and significantly enhance its ability to secure significant funding.

F. Standing San Mateo County Autism Commission

1. A standing San Mateo County Autism Commission should be formed in order to:
 - a. Develop a detailed strategic autism plan for San Mateo County. This plan would expand on the work of the existing Blue Ribbon Autism Commission reflected in this report and would include:
 - 1) A comprehensive survey of existing services and their costs.
 - 2) A description of model programs that exist in San Mateo County today.
 - 3) Specific recommendations for actions that can be taken in San Mateo County to improve services provided to children with autism.
 - b. Monitor the implementation of the strategic autism plan and make adjustments in that plan as best practices evolve over time.
 - c. Provide a forum for:
 - 1) Sharing best practices and discussing emerging issues.
 - 2) Receiving input and ideas from parents, service providers, educators and members of the general public.

2. The membership of the SMC Autism Commission should be expanded beyond the stakeholders currently represented on the Blue Ribbon Autism Task Force. Among others, stakeholders should include:
 - 1) Parents
 - 2) SMCOE/SELPA staff
 - 3) GGRC staff
 - 4) School district special education directors
 - 5) Nonpublic agency staff
 - 6) Physicians/healthcare professionals
 - 7) SMC Mental Health/SMC First Five Commission staff
 - 8) Elected officials
 - 9) Autism scientists/researchers
 - 10) Work force development specialists

G. Autism Resource Coordinator

1. The Autism Resource Coordinator's role would primarily entail strategic planning, program design and implementation, and the facilitation of interagency activities. Specifically, the Autism Resource Coordinator's duties would include such tasks as:
 - a. Providing general staff support for the SMC Autism Commission.
 - b. Overseeing/monitoring the implementation of specific recommendations set out in the strategic autism plan.
 - c. Facilitating regular communications between and among the SMC Autism Commission and stakeholder groups (e.g. the SMCOE, school districts, service providers, parents, etc.)
 - d. Preparing a feasibility study on the possibility of the SMCOE providing high quality, cost effective, intensive, home based programs (e.g. ABA) that would reduce the school districts' dependence on NPAs for such programs.
 - e. In collaboration with the SMCOE's program managers, developing a consistent strand/continuum of County autism classes as described in more detail above, together with supportive services through the SMCOE's Early Childhood Education program, to assist children with moderate to severe autism.
 - f. Developing training programs for aides, resource specialists, school psychologists, and teachers (both general and special education).
 - g. Identifying and promoting best practices/programs that currently exist in school districts throughout the County.
 - h. Promoting interagency collaboration to address autism on a County-wide basis. As recommended by the San Mateo County Grand Jury in its June 2005 report, this would include investigating cost sharing with other public agencies, particularly mental health.
 - i. Overseeing the development and maintenance of an autism website for the SMCOE and the SMC Autism Commission.

2. Hiring a SMCOE “Program Coordinator” was recommended by the San Mateo County Grand Jury in its June 2005 report.

H. Autism Specialist

1. The Autism Specialist would provide direct services and “hands-on” support for classroom and school site staff. Specifically, the Autism Specialist’s duties would include such tasks as:
 - a. Assisting school districts in designing and implementing autism classes and inclusion programs:
 - 1) How to set up the classroom.
 - 2) Components of an effective program.
 - 3) Utilization of alternative curriculum where appropriate.
 - 4) Creating a learning environment that is optimal for students with autism.
 - b. Providing support services as needed to autism classes offered by the SMCOE and by school districts.
 - c. Offering follow-up consultations to teachers after they observe the model classrooms offered by the County described above.
 - d. Working with the Autism Resource Coordinator to implement specific proposals of the SMC Autism Commission.
 - e. Conducting training programs, including organizing “job a like” meetings.

I. Budget

1. To establish and staff the standing autism commission, fill the two autism specific positions described above, and support grant writing and other fund generating activities, the Task Force estimates that an investment of approximately \$250,000 would be required during the 2007 – 08 school year.
2. The Task Force recommends that the SMCOE and the SELPA provide the necessary funding during 2007 – 08.
3. Procuring SELPA funding may require:
 - a. An amendment to the SELPA Agreement approved by 80% of the school districts.
 - b. Authorization by the SELPA Board to draw from a contingency fund of approximately \$240,000.
4. It is preferable that the Autism Specialist not be funded on a contract basis with the school districts, as that would likely lead to half or less of the school districts receiving services and would hinder the Autism Specialist from taking a more proactive approach.

J. Pursuing Public and Private Funding

1. While initial funding is required from the SELPA and the SMCOE to begin the initiatives described above, further funding should be pursued by:
 - a. Immediately seeking grants from the Silicon Valley Community Foundation and other foundations.
 - b. Preparing proposals to seek funding available under Federal and State programs and from advocacy organizations.
 - c. Creating an appropriate mechanism/structure to allow parents and other community members to make tax deductible donations to support the County's autism efforts.
2. It is projected that within two years such fund generating activities will cover the budget described above as well as support a number of new autism programs in the County.

BLUE RIBBON TASK FORCE ON AUTISM LIST OF MEMBERS

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