

Autism Speaks San Francisco Bay Area Chapter Advocacy Group
Formerly Bay Area Autism Advocacy Group
Input for the Legislative Blue Ribbon Commission on Autism Draft Report
September 18, 2007 Meeting
Submitted September 24, 2007
Chair Kristin Jacobson Kjacobson5@yahoo.com 650-759-5737
sfautismaction@aol.com

Overview

- **Congratulations on this achievement** - The opportunity for broad public input to the Commission's recommendations is necessary to achieve buy-in and to build the necessary grass roots support for a successful legislative process. We would like to commend the Commission and the Commission staff for reaching out in countless ways to parents and advocates across California and listening to our concerns, many of which are reflected in this draft report. Particularly with respect to health insurance issues, we have seen the Commission's thinking evolve with the information it has received from the advocacy community.
- **Offer to be a partner and drive grass roots support.** Thank you for your work on our community's behalf thus far - we are ready and willing to join with you to see that the job gets done. We'd like to offer to help develop the legislation and then coordinate a grass roots effort involving many advocacy groups to support this legislation - if you want to be involved please contact us at sfautismaction@aol.com We are already collaborating with other advocacy groups, e.g., we collaborated with CAPCA (California Association for Parent-Child Advocacy) on the development of our dispute resolution input.
- **Need clear and actionable next steps with a timetable**- We'd like to congratulate Senator Steinberg for asking the Commission to make bold recommendations, and it is critical that this report not become like others before it and remain on a dusty shelf. The Commission has rightly stated that the autism crisis in California is growing and that a policy response is urgently needed. We need to develop actionable next steps to implement these recommendations. We request that:
 - Agree with recommendation that policymakers **make ASD a public policy priority** and enact legislation proposed by Commission.
 - **Senator Steinberg personally introduce a few key bills**, including autism-specific insurance legislation, in the next legislative session and identify additional influential colleagues to introduce several others with his endorsement.
 - Senators Steinberg and Perata, together with Assemblyman Nunez **support an Autism Legislation day** in April 2008 and the **re-birth of an active Autism Caucus** in the California legislature.

Conclusions and Next steps

- **Prioritization and implementation** - We would like to see a clearly-defined action plan for introducing necessary legislation. We believe the Commission must set priorities for its recommendations, because the problem is too big and overwhelming if we try to achieve all of the necessary solutions all at once. Without setting clear priorities and a timeline for what we must achieve, we run the risk of achieving nothing at all. The completed Commission report should define a clear process for prioritizing these recommendations and translating them into laws in this and subsequent legislative sessions. Our strong recommendation would be to place **insurance reform** and the **stay put between RCs and LEAs** at the top of the list.

- **Follow-through** -We are pleased that the Commission has been extended for another year and hope we can expect another extension in 2008. Recommendations made by this Commission will require oversight and guidance to ensure they are appropriately implemented and effective legislation is passed, and we believe a two-year extension of the Commission is appropriate.

Areas remain where report should go further or be bolder

- **Funding** - The most obvious omission in the report and summary of findings is adequate discussion of the significant funding gaps that underlie all of the current problems. Addressing the funding short fall is a pre-requisite to most of the proposed recommendations. Without appropriate funding, effective solutions to this crisis can not be provided and the state will find itself paying significantly higher amounts in later years to meet the needs of a less independently-functioning population of adults with ASD. Insurance reform may yield a secondary funding scheme.
- **Best practices** - We urge the Blue Ribbon Commission to discuss more directly the importance of identifying and mandating best practices for educational, social and medical interventions, as well as community support for individuals with autism and their caregivers. The development of such guidelines is briefly discussed in the health insurance section but should also be discussed in its own chapter since best-practice guidelines are necessary for most areas, including but not limited to Early Intervention services and Education services. Further, it should be specifically noted that evidence-based best practices should be developed in a way that ensures the process is not politicized or subject to undue influence by interested parties behind the scenes. The process should be transparent to parents, caregivers and professionals and include opportunities for those on the front lines of caring for individuals with autism to review and provide comment before the guidelines are finalized. Individuals with autism deserve cutting-edge treatment and the best possible support to reach their full potential, regardless of political or fiscal considerations.
- **Highlight gaps front and center** The overall draft report addresses key gaps the Commission identified, and these gaps should be highlighted front and center in the Executive Summary and the Introduction. For example, there is minimal mention of the health insurance gaps in the Introduction, yet there were clearly significant gaps identified since an entire chapter of the report is dedicated to insurance reform. We would encourage that this section include a brief summary of the key gaps identified in each chapter.

Early Intervention

- **Strong identification of Gaps.** The Early identification section does a nice job of describing the significant gaps present in this portion of the care continuum, serious delays frequently missed, best practice guidelines for detection not followed, lack of sufficiently trained early identification specialists, extremely problematic transition at age 3 from RCs to LEAs However the policy recommendations need more elaboration and should be stronger. We would like more specific recommendations in all areas, but especially our two top priority areas: smooth transitions especially between RCs and LEAs and adequate training of medical professionals.
- **Smooth transitions** - Transitions from Regional Centers to school districts must be improved. Age three is perhaps the worst possible time for a gap in services. The Commission's current recommendations call for "seamless system for service delivery . . . from birth to kindergarten" but do not include any specifics about how to achieve that. One party needs to be primarily responsible and any cooperation needs to be required with specific guidelines and clear consequences for defiance of these guidelines. To ensure smooth transitions we recommend:
 - **Regional Centers continue coordinating services until age 5 or 6** when the child enters kindergarten so the transition is not at the critical age of three often just after diagnosis.

- **"Stay put" be guaranteed during the transition between RCs and LEAs**
Services provided by Regional Centers/Early Intervention should be maintained through a "stay- put" law until parents and school districts can agree on an appropriate program for a child transitioning from IDEA Part C to IDEA Part B; This is particularly important now that stay put has been eliminated by AB 1663 – the effect of which will be to make transition from RCs to LEAs, already identified by the commission as a significant problem, much worse by gutting the only protection families had to ensure somewhat of a smooth transition. Before any additional progress can be made in this area, the Commission should make it a priority that this minimal protection for children be restored. This is not a costly mandate but levels the playing field for families facing LEAs with ultimate power.
- **Institute consistent eligibility requirements among Regional Centers and school districts**, particularly when addressing children on the higher-functioning end of the spectrum. All children with a Pervasive Developmental Disorder according to the DSM-IV, including Aspergers' and PDD-NOS, should be eligible for school district and Regional Center services. This should be maintained after age 3.
 - **Regional Centers have been mentioned by the Commission as having a crucial role to play in assisting clients in navigating the services offered by a slew of different state agencies.** But most Regional Centers now exclude individuals with Asperger's or PDD-NOS from receiving services. These individuals and their families are in desperate need of support as well, and should be included as Regional Center clients throughout the state.
- **Ensure consistent service packages across regional centers**, including the portability of services during a transition from one RC to another.
- **Improved screening and diagnosis** – the gap identification is correct but the recommendations need to be stronger and more specific to be effective and widely adopted.
- **Require Continuing Medical Education Training (CME) training for all Pediatric Health Practitioners in screening for Developmental Disabilities including ASD.** Pediatric primary care providers fail to detect developmental delays because they are still using informal milestone checklists, which have been proven ineffective. Accurate screening tools that are designed for a busy primary care practice are available online at www.dbpeds.org The American Academy of Pediatrics' (AAP's) 2006 policy guidelines recommend standardized developmental screening tests be administered regularly at the 9/12 month, 18 month and 24/30 month visits. In addition, the AAP recommends that an autism specific tool should be administered to all children at the 18th month visit. However, providers need training and reimbursement in order for them to be used broadly. The CME in this area should be mandatory for Pediatric Provider's licensure in California. The reimbursement by insurance companies for developmental screening should be mandatory for all coverage for children.
 - **Routine screening by pediatricians should be implemented now.** We strongly agree with Commissioner Tsakopoulos-Kounalakis that the AAP's guidelines (above) can and should be implemented now for little or no cost. The AAP guidelines also indicate there are already CPT codes in place for paraprofessional and MD screening for developmental issues, so reimbursement should not be a hurdle. Simple training could be provided to ensure the screening is done properly. We still encourage the addition of mandatory CMEs in autism to bring the medical profession up to date on this health epidemic it does not adequately understand or address.
- **Lack of Diagnosing Practitioners.** Once a disability is suspected, there is a delay in

diagnosis and onset of therapeutic intervention due to a lack of knowledge of resources by primary care practitioners and a lack of qualified diagnosing practitioners.

- **Require Continuing Medical Education (CME) units in ASD to maintain CA medical licenses.** M.D.s and Nurse Practitioners who currently provide well-baby/child care should be required to complete CME units in the screening and diagnosis of autism spectrum disorders and proper referral of patients requiring further evaluation/intervention. The Commission recommends expanding resources etc for healthcare professionals with no specifics. CMEs are a well established way of providing professional training to the medical community. The establishment of CME requirements in the area of ASD will ensure that training courses are developed by the free market much the same way they have for the area of pain management after CMEs were required for that field.

Insurance

- **Thanks for listening** - The Commission should be commended for listening to the public input on the crisis of health insurance coverage for ASD and dedicating an entire chapter to the issue. The description of the problems is comprehensive and poignant and the policy recommendations are appropriately detailed. However we have a few concerns and suggestions:
- **Mechanism of change is unclear – should be statewide legislation not policy guidelines from Departments of Managed Care and Insurance.** After listening to yesterday’s hearing, our understanding of the Commission’s position is that specific legislation mandating coverage for ASD should be passed at the state level, but we feel this position should be made more explicitly in the written report. The legislation should specify the coverage requirements described under policy recommendation 1, establish the Advisory Council for best-practice guidelines in recommendation 2 and include the enforcement mechanisms discussed in recommendation 3. The role of the Department of Managed Care and Department of Insurance should be to implement and enforce the legislation but not to draft policy guidelines internally to accomplish the recommendations. These policy recommendations need to be subjected to the open and rigorous process of legislative review and be adopted as state law.
- **Autism-specific insurance coverage should be mandated** - New insurance legislation requiring coverage by health insurers of treatment related to ASDs is essential. Even if enforced, AB 88 is inadequate and autism-specific insurance legislation is necessary. The report correctly points out that all the states that have passed autism specific health insurance legislation already had mental health parity laws. The evidence is clear that **mental-health parity laws**, while still necessary, **do not adequately address the unique health issues associated with autism.**
- **Clear classification as a medical condition is imperative** - Autism must be designated by the state of California as a medical or neurological disorder, not a mental illness. The report recommends classifying ASD as a “brain-based disorder” and “provid[ing] the same coverage as afforded to medical conditions” without clearly reclassifying it as a medical condition. This language leaves ASD in the current limbo between medical and mental health and does not address the issue of lack of clear roles and responsibilities identified by the report. We instead recommend changing the wording to state **“that all health plans and insurers classify ASD as a brain-based or neurological medical condition and provide the same coverage as afforded to other medical conditions such as stroke and other neurological disorders”**. Since it is a medical condition, it should be covered through the medical side, not mental health side of health plans. The apparently subtle language change makes a large difference. Widely-accepted treatment methodologies like Applied Behavioral Analysis (ABA), Floortime and social skills training should be covered as a medically-necessary benefit along with traditional medically-based therapies such as speech, occupational and

physical therapy.

- **Specifically define ASD to include full ASD spectrum, including** Autism, Asperger's and Pervasive Developmental Disorder, not otherwise specified
- **ABA and other intensive 1:1 behavioral therapies, PT and social skills should be specifically described as part of the full range of therapies to be covered in item one.** ABA and Floortime treatments should be specifically described since they are unique to ASD, have the most evidence supporting medical necessity, are the cornerstone of early intervention programs, and yet are the most likely to be resisted by insurance providers because of their short-term expense. Further, as your chapter explains, social skills are a core ASD deficit and often very difficult to get covered, therefore they require specific inclusion in the policy recommendations. Including these therapies can be easily accomplished by revising the second bullet under policy recommendation one to read, **"That all health plans and insurers provide a full range of services including but not limited to assessment, behavioral (e.g., ABA, Floortime and other intensive 1:1 behavioral interventions), psychotherapeutic, psychopharmacological, social skills therapy, speech therapy, occupational therapy and physical therapy for ASD"** These need to be explicitly spelled out in the legislation so that everyone is clear on what constitutes medically necessary treatments for ASDs. There is currently way too much wiggle room for insurance companies to issue denials. These therapies need to be mandated
- **Insurance companies and health plans must also provide lists of autism specialists within the full range of specialties,** so that the consumer does not have to waste valuable time and resources trying to determine who on the long list of providers have expertise and experience treating children with ASDs. This, too, should be explicitly spelled out, because it has been a major shortfall within the mental health parity legislation. Failure to provide qualified personnel with availability is justified grounds for seeking outside treatment at the expense of the insurance company.
- **Clarification of specific role of Autism Professional Advisory Council** (named in second recommendation). Given that we're currently awaiting guidelines from both The National Standards Project and the Sonoma State Autism Project, we would like to see specific information on what the actual role of the Autism Professional Advisory Council (named in second recommendation) will be in this process. Perhaps one thing that they can do is weigh in on new or experimental treatments which do not have a solid evidence base, yet show promise, in following the example of New York State. New York's autism legislation does not allow insurance companies to deny treatments based on experimental status and instead refers them to a committee.
 - **Ensure transparent process for developing best-practice guidelines.** The evidence-based best practices mentioned in policy recommendation number two should be developed in a way that incorporates the National Standards Project and the Sonoma State Autism Project and that ensures the process is not politicized or subject to undue influence by interested parties behind the scenes. The process should be transparent to parents, caregivers and professionals and include opportunities for those on the front lines of caring for individuals with autism, including parents, to participate on the committees, review and provide public comment before the guidelines are finalized.
- **Procedures for monitoring, oversight and accountability should be part of state law not developed by Departments of Managed Care and Insurance.** Policy recommendation three correctly calls for enforcement mechanisms. To be effective, these enforcement mechanisms must be included as part of the legislative solution so the court systems are available to families for enforcement. The California Department of Managed Care and Department of Insurance can be responsible for primarily ensuring the laws are followed but not independently developing the enforcement policies. One of the problems with AB 88 is

that it is not enforced. Any new legislation must proactively address enforcement, and institute penalties—over and above being forced to pay disputed claims--for non-compliance. Under the current system, there is almost an incentive for insurance companies to deny claims, since the worst that will happen is that they might eventually be ordered to pay the claim. In the meantime, denying a claim allows the company to delay a payment and discourages at least some policyholders from the hassle of disputing the insurance company's denial. We believe this lack of penalties, in addition to minimal enforcement, is the answer to the question that was raised several times at the Hearing about why current laws are not followed.

- **Still Enforce AB 88** The Insurance Commission should consider having the top 5 or 6 insurance companies testify as to how they apply AB 88. Consistent guidelines should then be issued to the insurers and follow up evaluation made of how they apply the guidelines.
- **Suggested hearing on the Insurance issue:** While we support Commissioner Tsakopoulos-Kounalakis' suggestion for a Commission hearing dedicated to issues around insurance coverage of ASDs, we are concerned that such a hearing at the wrong time might slow the process of writing legislation. We agree with Commissioner Kears that the time has never been better to introduce legislation requiring insurers to cover broader autism treatment, given the national conversation about health care reform. We would, however, support a Commission hearing in order to highlight the issues families are facing and better make the case that this legislation is urgently needed, as long as it is at a time that will not unnecessarily slow down the process of drafting the legislation.

The ASD Public Health Crisis

- **We strongly support all the recommendations in this section including the requiring the state to establish 1) an ASD Public Health Initiative, 2) a statewide system, infrastructure and office of ASD, 3) a statewide volunteer registry, and 4) funding training and assistance to community based resource centers.**
- **ASD Public Health Initiative** – As part of the ASD Public Health Initiative, the Commission should recommend that the State of California consider preparing a state-wide RFP for a public awareness program for Autism in partnership with a non-profit organization. The type of communication activities that could encompass such a campaign include: Public Service Announcements (radio and broadcast), Celebrity support, Billboards, Ongoing Media relations, State-wide material development for use in schools / at pediatrician offices, in pharmacy (places where families are adept to receiving healthcare information) to teach children/families about Autism.

Education

We support the Commission's recommendations in this area but we also share the concerns voiced by several Commissioners that these recommendations could be even stronger. We strongly agree with Commissioner Koegel, who observed that hands-on training with ongoing feedback from an expert mentor is often more effective than classroom-style seminars. We also agree with Commissioner Castruita, who mentioned the importance of training classroom aides because they are often the people actually implementing IEPs. Finally, we strongly agree with Commissioner Martin's request that recommended training be mandatory and available to all school personnel – general education teachers, special education teachers, aides, and therapists – and be designed in such a way that the training encourages the widest possible participation, such as on school sites.

- **Alternative credentialing programs for special education teachers:** We strongly support the Commission's recommendation that the state establish alternative credentialing programs with specialized training on ASDs. One of the major issues facing our children are

educational programs with poorly-trained personnel. An alternative mechanism to bring in new trained teachers faster is essential.

- **Multidisciplinary team training program:** We also strongly support the Commission's recommendation that the CA Department of Education establish an ASD Multidisciplinary Education Team Training program. School districts need resources to help them inform their general and special education teachers about effective teaching practices for the population of students with autism. They also need information about curricula that are effective with students with ASD and other learning differences, as many of these students are capable achievers if presented with information in a way that is accessible to their learning style. We stress that all school personnel who work with our children need access to these resources, including aides, therapists and both general and special education teachers.
 - **ASD Credential with differential pay.** We urge the legislature and the Department of Education to encourage local education agencies to develop an ASD credential as part of this training program and to offer differential pay for it. We want to ensure that these new credentialing programs are made available for current as well as new educators, including teachers, speech therapists, occupational therapists and other specialists.
- **Specialized training for aides and paraprofessionals with improved compensation.** We strongly support the recommendation to establish specialized training for aides and paraprofessionals. These individuals provide a substantial amount of education for children with ASD. Appropriate compensation must be provided along with the training to attract talented workers. We'd like to see this program move quickly from a model program to one that is rolled out statewide.
- **Address funding gaps for special education specifically:** School districts in California cannot address the educational part of the autism crisis adequately if they are not adequately funded. For years the Legislature and the Governor's office have played complex games with California's IDEA funding, effectively reducing our allocation and allowing our most vulnerable students to do without services they are entitled to receive. California should immediately resume funding a full COLA on the Federal and state contributions to IDEA, and the Legislature should study the real cost of providing quality special education programs to students with ASDs, so that it can fund them appropriately in every district.

Dispute Resolution

- **Comprehensive Review of the Dispute Resolution process** We strongly support the recommendation for a comprehensive review of the process for resolving disputes about Regional Center and special education services. The finding presented by Harriet Levy that parents believe that OAH has not been fair and impartial in administering fair hearings in special education disputes, while school districts say they are satisfied is very troubling to us. This disconnect seems to indicate that there are problems with the dispute resolution process strongly favoring school districts, since in a fair process both sides would presumably feel equally satisfied or dissatisfied with outcomes.
 - **We urge a drastic overhaul of the dispute resolutions system not increased funding for Alternative Dispute Resolution.** We share the concern raised at the hearing that more funding provided to SELPAS for alternative dispute resolution may be detrimental to families who already face an inequitable system.
- **More accountability and monitoring is needed ongoing** While a comprehensive review is a good start in gaining insight to where services are breaking down, we also urge better monitoring and accountability of Regional Centers, insurers and school districts.

- **Information should be tracked and made available on an ongoing basis** and not just as part of a one-time review. It should be easily accessible to all.
- **Ombudsman as part of new Office of ASD.** The Education and Professional Development Task Force had initially recommended creating an ombudsperson to investigate and resolve complaints as a disincentive for Regional Centers, school districts and insurers who misapply the law, and we continue to feel that more proactive enforcement by the state is necessary. Such an ombudsperson should be empowered and have the resources to investigate complaints, conduct audits, and order remedies.
- **"Stay put" should be guaranteed during the transition between RCs and LEAs**
Services provided by Regional Centers/Early Intervention should be maintained through a "stay- put" law until parents and school districts can agree on an appropriate program for a child transitioning from IDEA Part C to IDEA Part B; This is particularly important now that stay put has been eliminated by AB 1663 – the effect of which will be to make transition from RCs to LEAs, already identified by the commission as a significant problem, much worse by gutting the only protection families had to ensure somewhat of a smooth transition. Before any additional progress can be made in this area, the Commission should make it a priority that this minimal protection for children be restored. This is not a costly mandate but levels the playing field for families facing LEAs with ultimate power
- **Alternative dispute resolution needs to be supported by legal rights.** The Commission should revive and support AB 1659, a bill sponsored by Protection & Advocacy and CAPCA, which had received unanimous support in the policy committee (Assembly Education) and was intended to correct some of the problems with dispute resolution in California under OAH and CDE. Alternative dispute resolution can only work if there is a credible fall-back system for cases that cannot be resolved informally. Right now, school districts are cutting back on autism services because they think they can, and because fiscal pressures push them to do so if at all possible, regardless of the greater long-term costs resulting from cutbacks in early intervention. Moreover, any alternative dispute resolution system needs to be set up carefully to avoid pushing parents into waiving valid claims for little or nothing in return. Parents can easily be manipulated in meetings which do not feature lawyers, but do pit them against highly experienced professionals in the field who are getting legal advice in the background. ADR has a legitimate role, but is not a panacea and needs to be implemented with due regard for its substantial dangers.
- **Shift burden back to school districts and regional centers.** Will California join New York by requiring school districts to prove they have offered a free and appropriate education? Further will it allow for reimbursement of expert testimony to level the playing field between families and RCs and LEAs, who employ their own experts.

Needs of youth and adults with ASD

- **We support the recommendations regarding expanded employment opportunities and housing.**
- **Physician training in ASD for all specialties is necessary** and missing in the report, especially training for primary care physicians, psychiatrists, and neurologists who treat adults. This expertise is currently lacking.

Law Enforcement and 1st responders

- **We support these recommendations to require training programs** for law enforcement and first responders. Voluntary attendance does not work.

Next Steps

- **Medi-cal** The points about the problems with Medi-cal that the Commission highlights as important but not addressed in this report, including access to specialists with ASD experience and access to mental health services, need to be addressed sooner rather than later and a plan should be put in place to adequately review these issues.
- **Action plan with timelines** is necessary to ensure this does not become another report that just sits on a shelf