



DARRELL STEINBERG
President Pro Tempore, 6th Senate District
Chair, Senate Select Committee on Autism and Related Disorders

January 25, 2010

Dear Senator Steinberg,

We are writing to you to express our most urgent request that you introduce and carry an autism insurance mandate clarification bill this legislative session. Given the fiscal crisis faced by California and the autism epidemic that grows larger with every passing day, our great state can wait no longer to require health plans and insurers to pay their fare share of autism treatment and stop shifting costs to the public sector. The state currently spends hundreds of millions of dollars every year on medically necessary treatment for individuals with autism which legally and morally is already the responsibility of the health insurance industry. And thousands of children and adults with autism go without treatment, which is unconscionable since there are now many evidence-based treatments for autism.

Our organization, Alliance of California Autism Organizations (ACAO), is comprised of more than 40 autism organizations throughout the state, and we are certain that we speak for the autism community about this issue. Insurance reform is our organization's top legislative priority for 2010. We are seeking meaningful health insurance reform that ends discrimination against individuals with autism and provides the health coverage that our families pay for and do not receive.

We applaud your excellent record of leadership in the autism arena – including Chairing the Blue Ribbon Commission on Autism, Forming and Chairing the Senate Select Committee on Autism and the carrying numerous bills over the years that have helped our community. You are the ideal person to take the leadership on this essential bill. There is no way you could do more to help California families struggling with autism.

There are few legislative opportunities that can make such a meaningful impact on the lives of some of the most needy Californians and save the state hundreds of millions of dollars in the process. We believe this issue has the unique opportunity to unite a wide and disparate group of constituents, including the autism community, regional centers, school districts, teachers, health care providers, and taxpayers. Our community is energized about this opportunity and we are committed to delivering the grass roots support needed to pass this important piece of legislation.

Please review the position paper we have prepared as to the innumerable reasons you should introduce this legislation now. Please contact Kristin Jacobson at 650-759-5737 or kjacobson5@yahoo.com with any questions.

Sincerely,

Greg Fletcher
ACAO Representative

ASA–Autism Society of America
ASA-CA / Autism Society of California
ASA-Coachella Valley Chapter
ASA–Greater Long Beach/San Gabriel Valley Chapter
ASA–Inland Empire Chapter
ASA–Los Angeles Chapter
ASA–San Diego County Chapter
ASA–Santa Barbara Chapter
ASA–San Francisco Bay Area Chapter
ASA–Ventura County Chapter
ASD Insurance Help
Autism Action Network
Autism Awareness Assoc–UC Davis
Autism Education Network
Autism Speaks–Bay Area
Autism Speaks–Los Angeles
Autism Speaks–Orange County
Autism Speaks–San Diego
Autism Speaks–Sacramento
Burlingame Mothers for Special Kids
California Autism Foundation
California Parents Association of America
California Disability Community Action Network
FEAT– Los Angeles
FEAT–Sacramento
FEAT–Fresno-Madera Counties
Friends of Children with Special Needs
Friends of The Bay School
Goh Foundation
K.E.N. Project
Kaiser Spectrum Kids
LIA Foundation
NAA–National Autism Association
Parents Helping Parents
Sacramento Asperger Syndrome Info & Support
Sacramento BioMed
Schafer Autism Report
Santa Clarita Autism Asperger Network
Solano FEAT
Special Needs Advocates for Understanding
TACA–Talk About Curing Autism
Unlocking Autism



Position Paper: Why We Should Introduce an Autism Insurance Mandate Clarification Bill in California

The Bottom Line:

**Health Plans are acting in bad faith
Every time they lose an argument they make up another one
They won't stop until we stop them
A strong mandate clarifying AB 88 is the only way to close the loopholes
Families can't wait any longer
The state can't afford to wait any longer
The legislature can and should do this now**

What are we talking about?

A strong mandate in the form of a clarification to AB88, California's existing mental health parity law, that would close the loopholes and allow the original intent of the mandate to be met. (AB 88 = Health & Safety Code 1374.72 and Insurance Code 10144.5)

This is not a new mandate – it is a clarification of an existing mandate

AB 88 *already* mandates medically necessary treatment for autism, which was recently confirmed by a California Superior Court Judge¹ – it is just not enforced

- See Appendix 2 for key excerpts from decision

Can we pass this in the current budget climate?

The state can't afford not to pass this clarification of AB 88. It will save our state millions of dollars every year starting immediately.

- The state currently spends about \$250 million dollars annually on behavioral services through the regional center system, which should be the payer of last resort
 - Instead, they bear the full burden because health plans shift their responsibility to the state
- School districts spend additional hundreds of millions of dollars on autism treatment – some of which may also be the responsibility of health plans
- The potential state budget relief of this bill is not merely a one-time reduction in expenditures
 - California will save year after year after year
 - The savings will increase year after year after year (long term savings of proper treatment for ASD is more than \$3 million per affected individual)
 - The savings start immediately
 - There is NO short term cost
- With the looming budget cuts to schools and regional centers (RC), it is critical that we stop the health plans from shifting expenses from the private to the public sector

All other efforts to fix this problem have failed, and families can't wait

After three years of working on the incremental approach to change:

- Less than 100 Californians have been able to secure the standard of care treatment (ABA) through health insurance, and those are only individuals with the resources to fight
- More than 100,000 Californians have an autism spectrum disorder
- Governor vetoed SB1563 due to redundancy with mental health parity law and DMHC Autism Workgroup
- DMHC Autism workgroup cancelled due to pressure from health plans
- Mental Health Parity Law as currently written is not working for families dealing with autism
- Efforts to work with DMHC for 3 years on enforcement have failed – DMHC has indicated preference for legislative solution
- Litigation and early legal decisions against DMHC ongoing but ineffective in changing DMHC behavior to date
- Litigation against health plans (Kaiser, Blue Cross) ongoing but ineffective to date

Health plans are devoting full resources to avoid responsibility. Their tactics are delay and double talk. They are arguing to the courts that DMHC has jurisdiction, while arguing to DMHC that the courts have jurisdiction. This will extend litigation indefinitely.

What's the urgency?

- Autism is now 1 in 110 (per CDC²) and 1 in 51 boys
- In the past two decades California has had a twelve-fold increase in ASD rates
- Latest research from the MIND Institute confirms the increase is real and cannot be attributed to population growth or changes in diagnostic practices³
- The budget crisis: California is going bankrupt, the entire regional center system is at risk of failing, school budgets are cut to the bone, there those resources are tapped
- DMHC is not acting as a patient advocate but rather has folded to the demands of health plans
 - Despite 100% Independent Medical Review (IMR) overturns for ABA since 2008, DMHC is no longer sending ABA cases to IMR (illegally allowed health plans to change denial reasons)
 - DMHC frequently ignores statutory 30 day review deadline – sits on case for 6 months to a year
 - DMHC refuses to change policies despite Judge Chalfant's finding that DMHC made underground regulations and is illegally allowing health plans to violate AB 88
 - DMHC allows medical necessity denials due to diagnosis of autism alone, as opposed to individual case details
 - DMHC requires licensed providers for ABA despite no CA licensing requirement – by allowing health plans to use “no licensed provider” denial
- DMHC feels AB 88 is unclear and has asked for legislative clarification
- Every year of delayed treatment is missed opportunity for a child that can NEVER be gotten back
- Every year of delayed treatment costs 10 fold over the life time
- California is falling behind – more than 15 states have strong autism mandates

Why health plans?

- Health plans are already legally required to be doing this and they are not
- Health plans are acting in bad faith and will never do it voluntarily (see Appendix 1)
- Health plans have been pocketing the premiums and shifting their costs from the private sector to the state of California (regional centers and school districts) for decades

There is a consensus on the medically necessary standard of care for autism

Medical necessity of standard autism treatments is well researched and established. There is consensus on the standard of care in the medical community.

- Nearly unanimous independent medical review (IMR) decisions. (January 2008 - March 2009)
 - 100% overturn of denials for Applied Behavior Analysis (ABA) (18/18)
 - 85% overturn of denials for Speech Therapy (ST) (22/26)
 - 86% overturn of denials for Occupational Therapy (OT) (18/21)
- American Academy of Pediatrics states standard of care for autism is clear and includes ABA, ST, OT, PT, among other 2007⁴
- Surgeon General agrees standard of care for autism includes ABA, ST, OT, PT
- National Standard Project concludes there are now 11 Established Treatments for Autism spectrum disorders, including ABA, and a further 22 Emerging treatments⁵
- Health plans are the ONLY ones promulgating the MYTH of lack of consensus to further their financial interests

Lots of people and organizations will support the bill

- Autism Parent organizations
 - Guaranteed support from at least 40 autism parent organizations, unanimous support anticipated
 - This is the top legislative priority of autism groups and families in the state of California
- Regional Centers
 - Sent a letter to DMHC asking them to force insurance companies to pay for ST, OT, PT and ABA (copy available)
- Healthcare providers (ST, OT, ABA, physicians, psychologists, etc.).
 - Anticipated unanimous support (hundreds/thousands of providers)
- School Board Members and Superintendents
 - Early polling (from this fall) suggests broad support
- Teachers unions and PTAs
- General taxpayers – who do not want their taxpayer dollars padding the pocket of insurance companies
- Autism insurance mandates in other states have passed with bipartisan, even unanimous support from the legislature

The autism community is not looking for a handout

- We pay our insurance premiums and receive no benefit
- We are energized to fight for what we deserve
- We are looking for the legislature to partner with us
- We are only asking that discrimination against people with autism spectrum disorders be stopped

It's a good business decision to cover medically necessary treatment for autism spectrum disorders

Self-Insured companies who have analyzed the cost benefit of providing autism insurance coverage have concluded the benefits (e.g., increased employee productivity, retention and morale) far outweigh the costs. It is also the right thing to do.

- California Employers with comprehensive autism coverage are increasing and include:
 - Microsoft
 - Home Depot
 - NetApp
 - Cisco Systems (added 2007)
 - Oracle (added 2008)
 - Yahoo (Added 2009)

How a Gubernatorial veto can be avoided

- It is Governor Schwarzenegger's last term – he could give the autism community a parting gift
- Bob Wright, a grandparent with Autism Speaks, is a convincing advocate with Governors and Politicians
- Senator Steinberg can appeal directly to the Governor
- With education from the autism community, Maria Shriver could be swayed to champion this cause
- There is high likelihood that Autism Speaks Public Relations and grass roots advocacy resources will be brought to bear – www.autismvotes.org and e-mail lists
- Issue passes most states with bipartisan – often unanimous support from the legislature
- Governor has no choice in this economic climate – it might be the alternative to eliminating Healthy Families/CALWORKS/IHSS or letting hundreds of thousands of prisoners back out on the street

Why we shouldn't wait for federal reform

- Obama's bill, even if passed, won't become effective until 2013-2018 – we can't afford to wait, families can't afford to wait
- Obama's bill currently includes behavioral health services, but is not strong enough to address the issues of accessing healthcare faced by families with autism

Why this won't bankrupt health plans, small business, or the general worker

- Premiums will not be meaningfully impacted
 - Every independent economic analysis has shown the premium impact will be minimal – (The Pennsylvania legislature's independent cost study showed a premium impact of less than \$1 per member per month
 - Only the health plans want to convince everyone that it's too costly
- When core autism deficits are properly treated, utilization of other healthcare services decreases
- This is not a tax increase, it's a tax reduction.
 - California taxpayers are already paying this bill through school districts and regional centers
 - If anything, this bill could reduce taxes

We are not shifting the entire cost to health plans

- Regional centers pay today
- Schools pay today
- Health plans pay nothing today – we're asking them to pay their fair share.

It is worth doing even if the Governor vetoes it – (which we believe we can avoid)

- The author will be the hero of autism community
- The author will be the hero of California taxpayers
 - The money saved can be used to preserve another important taxpayer priority (e.g., schools, prisons)
- It will make the bill easier to pass the next time
 - It will build grass roots
 - It will build support in the legislature
 - It will build awareness of autism

Prepared for DARRELL STEINBERG, President Pro Tempore, 6th Senate District, and Chair, Senate Select Committee on Autism and Related Disorders, at the request of Lou Vismara, January 25, 2010

Prepared by Kristin Jacobson
Alliance of California Autism Organizations – Steering Committee Member
Autism Deserves Equal Coverage – Co-Founder
Autism Speaks – Statewide Advocacy Chair
kjacobson5@yahoo.com
650-759-5737

Appendix 1
DOUBLE TALK - The ever changing tide of health plans arguments

When health plans were winning IMRs they wanted all disputes to go to IMR and be decided individually.

Now that health plans are losing IMRs, health plans are putting intense pressure on the DMHC not to send disputes to IMR and calling it a coverage issue (which violates AB 88).

And yet they still argue to the California courts that courts do not have jurisdiction to rule on the pending litigation because these disputes are individual and should be handled through IMR.

Health plan argument/tactic	The truth	The problem
ABA is experimental	Health plans lost - it is proven effective	
ABA is not medically necessary	Health plans lost - IMRs cite strong medical research and call ABA the standard of care	
ABA is educational	Health plans lost - IMRs find ABA is medically necessary	
ABA is custodial	Health plans lost - IMRs find ABA is medically necessary and improves outcomes	
Refusal to implement IMR – Regional Center is providing	Health plans lost - IMRs are binding	
Delay Implementing IMRs – looking for provider	Health plans lost – health plans have 5 days to implement IMR decisions	
Delaying IMRs – requesting reevaluations after appeals finalized and IMRs are filed	Health plans lost – health plans only have 30 days to respond to appeals	
ABA is not a healthcare service	Health plans will lose this too - autism is a medical condition and ABA is the most effective evidence-based treatment	DMHC politicians have taken over and are letting health plans get away with this illegal action
ABA is not a covered benefit	Health plans will lose – AB 88 requires coverage of medically necessary treatment. ABA is medically necessary and therefore cannot be excluded from coverage	DMHC politicians have taken over and are letting health plans get away with this illegal action
ABA requires a license	Health plans will lose – Knox keen Act requires no license for ABA	DMHC politicians have taken over and are letting health plans get away with this illegal action

Bottom line:
Health Plans are acting in bad faith
Every time they lose an argument they make up another one
They won't stop until we stop them
A strong mandate clarifying AB 88 is the only way to close the loopholes
Families can't wait any longer
The state can't afford to wait any longer
The legislature can and should do this now

Appendix 2
Excerpts from Consumer Watchdog Decision

Case of Consumer Watchdog *et al* vs California Department of Managed Health Care *et al*, Los Angeles County Superior Court, Presiding Judge James C. Chalfant, Case number BS121397

"In any event, the purpose of the MHPA is to require plans to provide services for mental health, including ABA for autism, on an equal footing with services for physical conditions."

"It is true that the court should defer to an agency's interpretation of its own regulations. Yet, the Department cannot adopt a regulation which exceeds its statutory authorization, and a court does not defer to an agency interpretation when deciding whether a regulation lies within that scope of authority . . . There is no licensing requirement for provision of ABA services."

"In sum the MHPA requires that a plan offer mental health services on the same conditions as services for physical conditions. The Knox Keene Act does not require that health care providers be licensed or certified unless the law so requires. ABA services are provided by professionals who are not licensed or certified in California but are certified by a private organization. Therefore plans must offer such services unless they have licensed providers who will provide the same services."

"The Department's interpretation of section 1300.74.72(b) is consistent with the MHPA's purpose of parity in the provisions of services for mental health problems. By interpreting section 1300.74.72(b) to permit a plan to deny referral of ABA treatment to non-licensed providers, the Department is permitting plans to avoid provision of ABA at all. This interpretation is not consistent with the MHPA purpose of preventing private plans from inadequately covering mental health illness and shifting the costs of mental health treatment to the state."

"Petitioners have submitted a viable claim that section 1300.74.72 (b) must be interpreted to permit provision of ABA through a professional certified by a private agency and the department has a ministerial duty to adjudicate enrollee grievances to permit it."

"Since there are clearly different possible interpretations of section 1300.74.72, the Department's interpretation is not the only legally tenable one. Indeed, it is not the correct one. The Petition states a viable cause of action that the Memo constitutes an underground regulation. The demurrer is overruled in its entirety."

¹ Judge James C. Chalfant of Los Angeles County Superior Court in the case of Consumer Watchdog *et al* vs California Department of Managed Health Care *et al*, Case number BS121397

² <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>

³ <http://www.ucdmc.ucdavis.edu/newsroom/newsdetail.html?key=1861&svr=http://www.ucdmc.ucdavis.edu&table=published>

⁴ www.pediatrics.org/cgi/content/full/peds.2007-2362v1

⁵ http://www.nationalautismcenter.org/pdf/NSP%20report%20overview_9-09.pdf