

# Autism's Rapidly Changing Landscape: The Promise & The Challenge



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Senate Select Committee on Autism & Related Disorders

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**The 2nd Annual Autism Community Symposium – Sonoma  
May 17, 2011**

# The Momentum for Change

- **Greater Awareness & Public Engagement**
- **Advances in Basic and Applied Research & Evidence Based Best Practices**
- **Intensified Advocacy**
- **Proactive Public Policy Reform**



## The California Legislative Blue Ribbon Commission on Autism

- Legislation sponsored by The Help Group and enacted in 2005
- SCR- 51 (Sen. Perata) receives unanimous & bipartisan support
- Established 16 Member Commission

**Senator Darrell Steinberg - Chair**

**Barbara Firestone, PhD - Vice Chair**

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**Louis Vismara, MD - Policy Consultant to the  
Sen. President pro Tem**

# The California Legislative Blue Ribbon Commission on Autism

- **Autism Commission Goals ~ Identify & Close Gaps:**
  - Early identification & intervention
  - Education & continuous treatment
  - The “aging out” of children
- **Commission’s Three Task Forces**
  - Identify existing problems & gaps
  - Review potential strategies
  - Provide specific recommendations
- **Task Forces Reports (March 1, 2007)**
- **Statewide Townhall Meetings**
- **Final Report to Governor & Legislature (September 2007)**
- **Commission Sunset in Nov. 2008**

**Web site:** <http://senweb03.senate.ca.gov/autism>



Barbara Firestone, PhD, Vice Chair and Senator Darrell Steinberg, Chair at public hearing

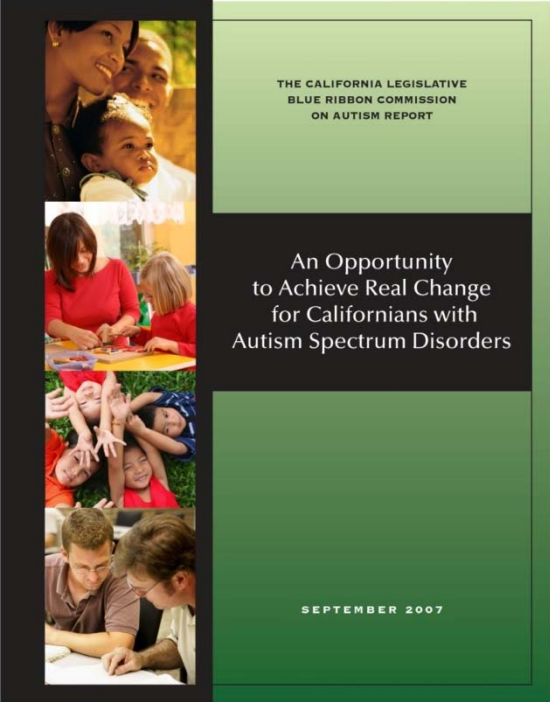


Commission Members at public hearing in Sacramento



## Factors & Considerations

- **Consumers, parents & families as well as individuals working in the field must be involved**
- **The state should have a clear role and a responsibility to address these issues**
- **The solutions should be clearly identified**
- **The solutions should be reasonable & feasible to implement**
- **The solutions should have outcomes that can be monitored & measured**
- **The solutions should have the potential to effect broad “systems change”**



THE CALIFORNIA LEGISLATIVE  
BLUE RIBBON COMMISSION  
ON AUTISM REPORT

An Opportunity  
to Achieve Real Change  
for Californians with  
Autism Spectrum Disorders

SEPTEMBER 2007

# The Blue Ribbon Commission's Report to the Governor & Legislature:

<http://senweb03.senate.ca.gov/autism/index.html>

## Overview of Policy Recommendations

1. **Building Models of Integrated, Comprehensive Services for Early Identification & Intervention**
2. **Ensuring Appropriate and Equitable Coverage for ASD by Private Health Plans & Insurers**
3. **The ASD Public Health Crisis: Improving Access to Services & Navigating Complex Systems of Care**
4. **Preparing Teachers & Other School-Based Personnel to Educate Children with ASD**
5. **Resolving Service Disputes Effectively & Equitably**
6. **Designing New Employment & Housing Strategies for Individuals with ASD**
7. **Increasing Awareness and Knowledge of ASD among Law Enforcement Officers & Other First Responders**
8. **Conclusions & Next Steps**

# April 2, 2008 Press Conference in Sacramento Announcing the Autism Legislative Package

**Dr. Barbara Firestone, Sen. Tom Torlakson, Sen. Don Perata,  
Sen. Darrell Steinberg, Dr. Louis Vismara**



# The California Autism Legislative Package:

## Signed into Law:

**SB 1175** (Sen. Darrell Steinberg) to expand the housing and independent living opportunities for adults with ASD

**SB 1531** (Sen. Lou Correa) to improve the training and knowledge of ASD among law enforcement officers

**AB 131** (Asm. Jim Beall) to expand the credentials that would qualify teachers to educate preschool students with ASD

**AB 2303** (Assembly Speaker Karen Bass) to expand the credentials of qualified teachers who are able to instruct K-12 students with ASD

## Passed by the Legislature but Vetoed by the Governor:

**SB 527** (Sen. Darrell Steinberg) to improve the early identification and intervention for young children with ASD

**SB 1475** (Sen. Tom Torlakson) to improve the coordination of ASD services and programs between regional centers and school districts for children from birth to five years of age

**SB 1563** (Sen. Don Perata) to provide appropriate and equitable coverage for ASD by private health plans and insurers

**AB 1872** (Asm. Joe Coto) to establish a state clearinghouse for the education of students with ASD.

## Set Aside During Committee Hearings:

**SB 1364** (Sen. Gil Cedillo) to improve community awareness and outreach efforts on ASD by the California Department of Public Health. Set aside due to lack of funding.

<http://senweb03.senate.ca.gov/autism/index.html>

# The California Senate Select Committee on **AUTISM & RELATED DISORDERS**



*“Partnering with Families and Communities for a Brighter Future”*

For more information about the Senate Select Committee please visit:

[www.senate.ca.gov/autism](http://www.senate.ca.gov/autism)

# Championing Change in California Senate Select Committee on Autism & Related Disorders is Established

April 28, 2009



**(L-R) Feda Almaliti, Rick Rollens, Asm. Tom Torlakson, Dr. Barbara Firestone, Senate President pro Tem, Darrell Steinberg, Sen. Majority Leader, Dean Florez, Sen. Elaine Alquist, Sen. Lou Correa, Sen. Carol Liu, and Sen. Roy Ashburn**

# Autism's Rapidly Changing Landscape: The Promise & The Challenge *(budget cuts, budget cuts, budget cuts!!!)*

## Goals & Objectives of Presentation

*(“always put a bad crisis to good use”)*

- Proposed Budget Reductions
- Senate Select Committee on Autism & Related Disorders
- Current Legislation
- Future Possibilities

# The 2011 Budget Challenge:

(“the elephant; 500 lb. gorilla; & all other bad metaphors”)

## THE CURRENT FISCAL DEFICIT:

Current fiscal year (2010-11):

**\$6.1 billion.**

Budget year (2011-12—starts on July 1, 2011):

**\$19.2 billion.**

**Legislature and Governor will need to close a \$25 billion gap by June 30, 2011.**

***Problem could be higher***, given potential federal actions on estate tax (will reduce our state revenues by another \$2.7 billion).



# Dept. of Developmental Services Proposed Budget Reductions (March 2011)

**Proposed Budget in March 2011: Reduction of \$576.9 million in state general; (combined with the loss of federal funding ~ total reduction of nearly one billion).**

- Expanded Federal Funding Waiver (\$132.5 M)
  - General standards for Regional Centers ( \$50.6 M)
  - Suspension or Restriction of Regional Center Services (\$36.4 M)
  - Behavioral Service Standards & Group Parent Training (\$33.8 M)
  - Developmental Centers (\$17.2 M)
  - Transportation Reform (\$36.6 M)
  - Neighborhood Preschools (\$ 17.8 M)
  - Altered Living Supports (\$27.8)
  - Changes in Early Start Programs (\$54.5)
  - Changes in Respite Services (\$8.2 M)
- TOTAL OF \$402.9 Million

DEFICIT OF \$174 Million to be resolved by “Purchase of Service Standards”

# **DDS Proposal for Purchase of Service Standards**

*(\$174 M General Fund Budget Reductions)*

1. Reduced expenditures (\$55.6 M)
2. Additional federal Waiver (\$22.5 M)
3. Reduce DDS contracts (\$1.7 M)
4. Reduce RC staffing & overhead (\$14.1 M)
5. Reduce Community Placement Plan (\$6.9 M)
6. Change rate setting for some RC services (\$3.4 M)
7. Increase fees to families (\$3.6 M)
8. Reduce in-home services (\$1.3 M)
9. Increase school-based funds (\$10.2 M)
10. Share Supported Living Services (\$5.4 M)
11. Changes in “day-services” program (\$9.6 M)
12. Changes in behavioral services (\$3.8M)
13. Change Prevention Program  
to Family Resource Centers (\$7.5 M)
14. Increase public transportation (\$1 M)

# Senate Select Committee on Autism & Related Disorders (Adopted: March 4, 2009)

*“partnering with families & communities to plan for a brighter future”*

## LEGISLATIVE INTENT

To provide a legislative forum to promote policies and legislation to better assist individuals with ASD and their families

To advance the work of the California Legislative Blue Ribbon Commission on Autism & ASD Leg. Package (2007-08)

To deal with the fiscal challenges that confront the State



Senate Autism Committee Web Site:

[www.senate.ca.gov/autism](http://www.senate.ca.gov/autism)

# Senate Select Committee on Autism & Related Disorders

## Issues & Areas to be Addressed

- *Early ID & Rx.*
- *Health Insurance Coverage*
- *Training & Employment*
- *Housing*

## **Task Forces & Working Groups:**

- Network of advocates
- Exchange information
- Promote community outreach
- Provide recommendations

## Autism Regional Task Forces

- Sacramento (Steinberg)
- Marin/SF (Leno )
- East Bay/Oakland (DeSaulnier)
- Peninsula/Santa Clara (Alquist)
- North Bay (Wolk)
- Central Valley:
  - Fresno (Florez; Asburn)
  - Bakersfield (Florez; Asburn)
- Los Angeles:
  - North LA (Liu, Padilla, Pavley)
  - South LA (Price)
- Orange County (Correa)
- San Diego (Hollingsworth)

# Senate Autism Regional Taskforces: Statewide Strategies & Recommendations

## Early Identification & Treatment

- *Coordination between school districts & regional centers*
- *Promote early diagnosis and treatment of ASD*
- *Technology: application and expansion*

## Health Insurance Coverage

- *Mandate behavioral intervention therapy*
- *Knox-Keene Certification of behavioral therapists*
- *Healthcare coverage under policy of parents or conservator*

## Vocational Training & Employment

- *I.T.P. starting in middle school*
- *Social skills curriculum as part of I.T.P.*
- *Integrated employment pilot project*

## Appropriate & Affordable Housing

- *Permanent funding source*
- *Federal “Achieving a Better Life Experience (ABLE) Act*
- *Extend the Senate Autism Committee and Regional Taskforces*

State Regulated AB 88 – Mental Health Parity Law  
(H&S Code 1374.72) states:

- *Every health care service plan contract...*
- *shall provide coverage for the diagnosis and medically necessary treatment of severe mental illnesses of a person of any age, . . .*
- *“severe mental illnesses” shall include: . . .  
Pervasive Developmental Disorder or Autism. . .*

## **Current Senate Bill 166 (Steinberg) in 2011**

*To provide coverage for behavioral intervention therapy for ASD*

**Sponsor:** Alliance of California Autism Organizations

- Behavioral intervention therapy (BIT): ~ effective medical treatment for ASD (Am. Academy of Pediatrics; NIMH; U.S. Surgeon General)
- Many private health plans deny BIT as educational & not a covered benefit
- Coverage issues: Not reviewed by physicians or other medical providers
- SB 166 requires coverage for BIT services that meet defined standards
- SB 166 closes a dangerous loophole in the existing mental health parity law
- Ensures that healthcare decisions for ASD are provided only by medical professionals

# **Current Assembly Bill 171 (Beall) in 2011**

*To Provide Comprehensive Health Insurance Coverage for ASD*

**Sponsor:** Alliance of California Autism Organizations

## **Coverage for treatments deemed medically necessary & prescribed by a licensed provider**

- All diagnostic evaluations
- Specific treatments: behavioral health treatments; pharmacy care; psychiatric care; speech; occupational; physical therapy
- Any medically necessary care for ASD based on “practices or evidence-based research”
- Health plans must have an adequate network of qualified providers
- Prohibits termination or modification of coverage due to ASD
- Prohibits any cap on age, visits or annual benefit dollar limit
- Must comply with existing mental health parity requirements
- Applies to Medi-Cal patients

## Autism Legislative Package: 2010-2011 Session

- **SB 166** (Steinberg) – medical insurance mandate to require coverage for behavioral intervention therapy
- **SB 764** (Steinberg) – Autism Tele-Health Program to enhance Regional Center services for ASD
- **SB 453** (Correa) – Anti-bullying bill
- **SB 472** (Correa) – a statewide system of services to enhance the development of children who have disabilities

## LEGISLATIVE PACKAGE CONT' D

- **AB 171** (Beall) — medical insurance mandate to require specific coverage and treatment for autism spectrum disorders
- **AB 254** (Beall) Employment First Policy
- **AB 1205** (B. Berryhill) – ABA licensing bill
- **AB 1244** (Chesbro) Individual choice budgets for regional center consumers
- **AB 1375** (Huber) Statewide standardized guidelines, best practices and innovative approaches for ASD

# Technology & the Future of ASD



**EMR**



**Multimedia Medical Record**

- Currently most EMRs are limited:
  - ✓ Serve as databases
  - ✓ Lack multimedia files
  - ✓ Limited content related to ASD
- Computers can help kids interact
- Technology ~ supplement to “live” interactions
- “There’s an app for that”

**Change is going to come**

# The Pyramid for Change

*“Every accomplishment must start with all of us”*



# Lou's "3 Bs" for Change

*Gandhi: "Be the change you want to see"*

- Be Involved
- Be Knowledgeable
- Be Connected

# Autism's Rapidly Changing Landscape: The Promise & The Challenge



*“Never doubt that a small group of committed people can change the world. Indeed, it is the only thing that ever has!”*

~ Margaret Mead

# Contact Information

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