NEW DIRECTIONS IN AUTISM PUBLIC POLICY

"Some succeed because they are destined to; most succeed because they are determined to"

- Anatole France

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Chair, Statewide Coordinating Council of Autism Taskforces of the Calif. Senate Select Committee on Autism & Related Disorders

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Prevalence of Autism Spectrum Disorders

CDC Report March 2012

Autism and Developmental Disabilities Monitoring (ADDM) Network

About **1 IN 88 CHILDREN** has been identified with an ASD

ASD **5 TIMES MORE COMMON AMONG BOYS** (1 in 54) than among girls (1 in 252)

ASD occur in all racial, ethnic, and socioeconomic groups

The largest increases were among Hispanic and black children

More children are being diagnosed at earlier ages — (18% by age 3)

Most children are not diagnosed until after they reach age 4

Parents of children with ASD notice a developmental problem before 1st year of age

The co-occurrence of non-ASD developmental diagnoses is 83%

The co-occurrence of one or more psychiatric diagnoses is 10%

The majority (62%) of children with ASD did not have an intellectual disability

The Impact of ASD on the Nation, State & Communities

National Statistics on ASD

There are over 24,000 new cases diagnosed annually.

ASD is more prevalent than juvenile diabetes, childhood cancer & pediatric AIDS combined.

ASD is the fastest growing serious developmental disability.

The economic impact of autism is over $137 billion annually.

Medical expenditures for ASD were 4.1–6.2 times greater than for those without an ASD.

Behavioral therapies for ASDs cost $40,000 to $60,000/child/yr.

California Regional Centers

Caseload ↑ 634% from 1987 to 2002.

There are over 60,000 consumers.

ASD now represents 2/3 of new cases.

RC serve only 20% of all ASD cases.

84% of ASD consumers < 22 yrs/age.

School Districts

>60,000 students with ASD/Special Ed.

Districts ~ 2X ↑ ASD students/4 yrs.

ASD students in special education have increased > 400% in past 9 years.

>1000% increase in ASD students K-12 during past 12 years.

The California Legislative Blue Ribbon Commission on Autism

"supporting individuals with autism & their families: forging new directions for real change"

Dr. Barbara Firestone
Sen. Darrell Steinberg
Dr. Lou Vismara

Senate Concurrent Resolution #51 (Sen. Perata)

Enacted 2005; unanimous, bipartisan support.

Autism Commission's Goals ~ identify & close gaps:

Early identification & intervention of ASD.
Education & continuous treatment of children, adolescents, transitional youth & adults with ASD.
The "aging out" of children.

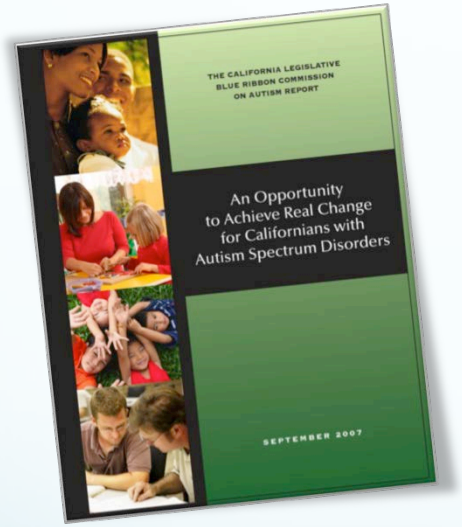
Autism Commission's Guiding Concepts:

Involvement of consumers, parents, families & providers.
The state must have responsibility.
The solutions should be clearly identified.
The solutions should be feasible.
Measurable outcomes.
Effect broad "systems change."

The California Legislative Blue Ribbon Commission on Autism

Report to the Governor & Legislature

(September 2007)



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

Integrated, Comprehensive Services for Early Identification & Intervention.

Appropriate and Equitable Coverage for ASD by Health Plans and Insurers.

Improving Access to Services & Navigating Complex Systems of Care.

Preparing Teachers to Educate Children with ASD.

Designing New Employment & Housing Strategies.

Law Enforcement Officers & Other First Responders.

REPORT: *senweb03.senate.ca.gov/autism*

The California Senate Select Committee on
AUTISM & RELATED DISORDERS

"Partnering with Families and Communities for a Brighter Future"

The Senate Select Committee is a bipartisan body comprising 20 Senators who share a deep commitment to individuals with autism and their families.

For more information about the Senate Select Committee please visit:

http://autism.senate.ca.gov/

Senate Select Committee on Autism & Related Disorders

Established by Senate Rules Committee in 2009

Issues & Areas Addressed

- To provide a legislative forum.
- To promote policies and legislation.
- To better assist individuals & families.
- To deal with the State's fiscal challenges.

Task Forces & Working Groups:

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

Autism Regional Task Forces

Sacramento (Steinberg, Gaines)

Marin/SF (Leno)

East Bay (DeSaulnier, Corbett)

Peninsula/Santa Clara (Alquist)

North Bay (Wolk)

North Coast (Evans)

Central Valley:

- **Fresno** (Berryhill)
- **Bakersfield** (Fuller)

Los Angeles:

- **North LA** (Liu, Padilla, Pavley)
- **South LA** (Price, DeLeon, Hernandez)

Inland Empire (Dutton, Emmerson)

Orange County (Correa)

San Diego (Vargas)

Website: www.autism.senate.ca.gov/

Senate Select Committee on Autism & Related Disorders and the North Los Angeles Autism Regional Taskforce

2012 Excellence in Employment Awards Reception

The California Senate Select Committee On
Autism & Related Disorders
and the
North Los Angeles Autism Regional Taskforce

EXCELLENCE IN EMPLOYMENT AWARDS RECEPTION

APRIL 20, 2012

Opening Remarks

BARBARA FIRESTONE, PHD
Chair, Statewide Coordinating Council of Autism Taskforces
Chair, North Los Angeles Autism Regional Taskforce

Special Remarks & Awards Presentation

SENATOR CAROL LIU
California State Senate, 21st District
Member, Senate Select Committee on Autism & Related Disorders

AWARD RECIPIENTS

LINDA BELL BLUE
DAN HENRY
ENTERTAINMENT TONIGHT
THE INSIDER

AARON KAPLAN
KAPITAL ENTERTAINMENT

DAVID FEINBERG, MD, MBA
MARK SPEARE
ROBIN EPSTEIN LUDEWIG
ROBIN CLAYTON
PAUL WATKINS
UCLA HEALTH SYSTEM

JENNIFER NASSRAWAY
LISSETTE CARRILLO
PETCO

SUSAN BERMAN, PHD
DEBBY WEBB, MSW
THE HELP GROUP
SILVERLINING

CECIL KOST
PRECISION DYNAMICS CORPORATION

ELVA DIAZ
VASANTI SHAH
NATASHA VOLKOVA
TJ MAXX

AL SANTILLO
RALPHS STUDIO PLAZA

Recent Autism Legislation

Passed by Legislature but Vetoed by Governor

- **SB 764 – Voluntary use of telehealth by regional centers** (Sen. Steinberg)
- **SB 1050 – ASD demonstration project using telehealth** (Sen. Alquist)
- **SB 527 – Early Identification of ASD** (Sen. Steinberg)
- **SB 1475 – Pilot on Transitional Services for Early ASD Treatment** (Sen. Torlakson)
- **AB 1872 – State Clearinghouse for the Education of Students with ASD** (Asm. Coto)

Enacted into Law

- **SB 1175 – Expansion of Housing for ASD** (Sen. Steinberg)
- **SB 1531 – Police Officer Training on ASD** (Sen. Correa)
- **AB 2302 – Expanding Credentials to Educate Students with ASD** (Asm. Bass)
- **AB 131 – Teacher Credentialing for Preschool Age Children with ASD** (Asm. Beall)
- **SB 812 – Housing Element Information on Individuals with Disabilities** (Sen. Asburn)
- **SB 946 – Autism Insurance Mandate for Behavioral Health Treatment** (Sen. Steinberg)

California Dept. of Developmental Services:

STATE BUDGET

FY 2009-10: GF reduced $334 M + 3% ↓ provider payment

FY 2010-11: GF reduced $200 M + 4.25% ↓ provider payment

FY 2011-12: GF reduced $576.9 M

FY 2012-13 Budget ($4.661 Billion) Reductions/Savings Achieved By:

- Technology & Other Measures ($5.2 M)
- Community First Choice Option ($7 M)
- Supported Living Services ($7.6M)
- Redesign Services for Individuals with Challenging Needs ($20.4M)
- Rate Reduction ($45.5M)
- Home & Community-Based Waiver ($61M)
- Autism Insurance Mandate – SB 946 ($79.8M)

SB 946 (Steinberg): Autism Insurance Mandate

Issues & Problems Addressed by Legislation

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. Lou Vismara

Coverage of health care, behavioral and psychotherapeutic services is limited, inconsistent or excluded altogether.

The roles and responsibilities of health plans and insurers for ASD services are not well defined.

Frequently there is lack of consensus about the "medical necessity."

When health plans and insurers contract ("carve out") behavioral health services, there is often fragmentation and/or denial of services.

Health plans and insurers frequently lack access to professionals with adequate training and expertise in ASD.

Overview of Health Insurance Coverage in California

Source of Insurance Coverage:

Employer~49%; (9% are self-insured)

Medi-Cal~17%; (8% in managed care)

Medicare~9%; (3% in managed care)

Individual~6%

Uninsured~19%

Regulation: Dept. of Managed Health Care & Calif. Dept. of Insurance

AGENCY	DMHC	CDI
# OF CARRIERS	49	285
REVENUE	**$83.5 Billion**	**$17.3 Billion**
TOTAL ENROLLEES	21.6 Million (59%)	2.4 Million (7%)
MARKET SHARE	**91%**	**9%**
PRODUCTS	HMO; 2 PPO; vision, dental	Most PPO; Part D; Medicare supp; Dental; Stop-loss

SB 946 (Steinberg)
Actions & Requirements of the Autism Insurance Mandate

Every health care service plan contract that provides hospital, medical, or surgical coverage shall also provide coverage for behavioral health treatment for pervasive developmental disorder or autism no later than July 1, 2012.

Does not require any benefits to be provided that exceed the essential health benefits required by the federal Patient Protection and Affordable Care Act of 2010.

Not affect or reduce any obligation of any IEP or IPP.

Maintain an adequate network of qualified autism service providers.

SB 946 (Steinberg)
Actions & Requirements of the Autism Insurance Mandate

Behavioral Health Treatment: Professional services, including applied behavior analysis and evidence-based behavior interventions, that develop or restore, to the maximum extent practicable, the functioning of an individual ASD/PDD that meet all of the following criteria:

1) The treatment is prescribed by a licensed physician or psychologist.

2) The treatment is provided under a treatment plan prescribed by a qualified autism service provider and is administered by:

   A qualified autism service provider (licensed or certified); or

   A qualified autism service professional (provides BHT & RC vendorized) supervised and employed by the qualified autism service provider; or

   A qualified autism service paraprofessional (unlicensed/non-certified) supervised and employed by a qualified autism service provider.

SB 946 (Steinberg)
Actions & Requirements of the Autism Insurance Mandate

The treatment plan has measurable goals over a specific timeline that is developed and approved by the qualified autism service provider for the specific patient being treated.

The treatment plan shall be reviewed no less than once every six months by the qualified autism service provider and modified whenever appropriate, and shall consist of the following:

> Describes the patient's behavioral health impairments to be treated.
>
> Designs an intervention plan (service type, objectives, duration).
>
> Utilize evidence-based practices.
>
> Discontinuation criteria.

Autism Regulatory Actions by CDI & DMHC

California Department of Insurance (CDI)

(Blue Shield, Anthem/Blue Cross, Health Net, Cigna)

- **Provide ABA therapy as a covered service**
- **Provide for the medical necessity of ABA therapy**
- **Avoid unnecessary IMR**
- **Maintain an adequate provider network**
- **Customer service units or support teams for ABA therapy**

California Department of Managed Health Care (DMHC):

- **ABA therapy consistent with California's Mental Health Parity Act.**
- **Autism coverage was required before SB 946.**
- **Healthy Families & CalPERS must provide Behavioral Health Treatment.**
- **Plans ~ SB 946 must demonstrate adequate network of providers.**
- **Kaiser to stop denying physical, occupational & speech therapy to patients with developmental delays.**

SB 946 (Steinberg)
Actions & Requirements of the Autism Insurance Mandate

The DMHC shall convene an Autism Advisory Task Force:

- Patient selection, monitoring and duration of therapy.
- Qualifications, training and supervision of providers.
- Adequate networks of providers.
- Requirements that unlicensed providers must meet in order to obtain licensure from the state.
- Scientifically validated interventions & treatments.

The DMHC reports Task Force findings to Gov. & Legislature

by December 31, 2012.
Web Site: www.dmhc.ca.gov ~ (Autism Taskforce "tab")

SB 946 "sunsets" on July 1, 2014

SB 946 does not alter California's Mental Health Parity Law

SB 946 (Steinberg)
Preliminary Findings & Recommendations of the DMHC Autism Insurance Taskforce

Multiple Functions in the Care of ASD/PDD:

- Monitoring, Evaluation & Coordination of Care.
- Screening, Diagnosis & Prescribing.
- Treatment plan development & Treatment provision.
- Individuals with Autism & their families.

Licensed Behavioral Health Practitioner:

- Certification: BACB or other national entity ~ NCCA.
- Master or Doctoral degree; supervised experience; examination; recommendations.
- Interim Commission until permanent Licensing Board.
- Ethical standards, complaint processes, disciplinary actions.

Senate Select Committee on Autism & Related Disorders

Informational Hearing on April 30, 2012

Ensuring Fair & Equal Regional Center ASD Services:

DDS average spending on children with ASD: $11,723/White; $11,063/Asians; $7,634/Latinos; and $6,593/Blacks.

Regional Center (RC) services for ASD averaged $9,751 statewide. Range from $1,991/South Los Angeles to $18,356/ Orange County).

At 14 of the 21 RCs, the spending on White children > both Blacks and Latinos.

Lanterman RC for ASD children: $12,794/White; $9449/Asians; $5,094/Blacks, and $4,652/Latinos.

Informed parents obtain better services. Minorities & underserved face formidable barriers in accessing appropriate ASD programs.

http://autism.senate.ca.gov/informationalhearings

Taskforce on Equity & Diversity for Regional Center Autism Services:

Overview & Guidelines

Existing statutes, regulations, oversight & compliance procedures.

Regional Center (RC) information to consumers & families that is understandable & culturally/linguistically appropriate.

Demographic analysis of service expenditures by RCs.

Performance measures & indicators to evaluate RC on issues of equity/ diversity.

To identify the best practices & implementation strategies.

Autism Public Policy: Future Legislative Actions

- Renewal of Autism Insurance Mandate Bill (SB 946)
- Behavioral Health Treatment Licensure
- Equity & Diversity Services for ASD Regional Center Services
- Programs & Supports for Transitional Youths
- Housing & Supported Employment Programs
- Telehealth & Technology Expansion

NEW DIRECTIONS IN AUTISM PUBLIC POLICY

"You can't rely on your eyes, if your imagination is out of focus"

Mark Twain

"To accomplish great things, we must not only act but also dream, not only plan but also believe."

Anatole France

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