

**Cultural Competence & Mental Health  
Northern Region Summit  
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Modesto, CA**

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***“Implications of Integrated Care  
for Workforce Development,  
Policy & Legislation”***

**Louis Vismara, M.D.  
Policy Consultant to Senator Darrell Steinberg  
President California Senate  
Ph. 916 651-4189  
Fax. 916 327-8867  
[Louis.Vismara@sen.ca.gov](mailto:Louis.Vismara@sen.ca.gov)**

# Integrated Care for Workforce Development, Policy & Legislation

## *Goals & Objectives of Presentation*

- *Share my personal story*
- *Overview of autism spectrum disorders (ASD)*
- *Behavioral & physical health co-morbidities ~ ASD*
- *The UC Davis MIND Institute: Science & a workforce for the 21<sup>st</sup> century*
- *Challenges of equity & diversity related to ASD services*
- *Public policy & legislation to improve linguistic & cultural competency*
- *“Lessons learned”: Promoting culture into integrated healthcare*

## Lou's Background & Perspectives:

- Immigrant from Italy; (1950)
- Interventional Cardiologist. (1972-1999)
- Co-founder of The MIND Institute (1999)
- First 5 Ca State (Prop 10) Commission (1999-2007)
- Policy Consultant to CA. Senate Pro Tem: (2000-Present)

Sen. John Burton

Sen. Don Perata

Sen. Darrell Steinberg

- Parent of 4 children:  
Mark ~ DSM V Autism.



# THE 10 TOP THINGS THEY DON'T TEACH IN MEDICAL SCHOOL

10. *Having a child with disability or special needs is really tough*
9. *Having a child with a disability strains ALL relationships*
8. *How to care for a disabled child while spending the entire day either filling out forms and/or being placed on hold*
7. *How to keep your child with autism from killing the cat, smashing furniture, and/or putting his head through the plate-glass window while you're on hold and/or filling out forms*
6. *How to maintain your sanity when, after finishing the correct form and speaking to a real, live person, you're informed that there's a waiting list of >6 months for the program's enrollment.*

# THE 10 TOP THINGS THEY DON'T TEACH IN MEDICAL SCHOOL

*(continued)*

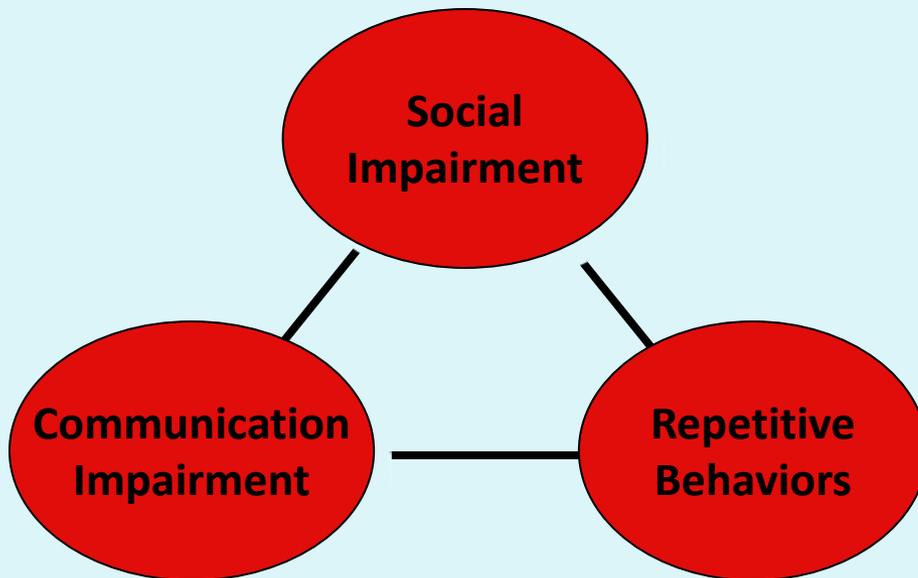
5. *How to know whether your child is being denied enrollment in the program because of “eligibility” or because of “functional assessments”*
4. *How to deal with “systems” that appear to be:*
  - *Not knowledgeable*
  - *Not Listening*
  - *Not Caring*
3. *How to get information transferred from one program to another*
2. *That systems responsive to Autism Spectrum Disorders will better serve a wide array of developmental and learning disabilities*
1. *Information about Autism!!!*

## *BUT- WHAT I HAVE LEARNED:*

*There are an incredible number of dedicated, loving, and wonderful people who are committed to improving the lives of children, and their families, who have disabilities and special needs*

# ***Manifestations of Autism Spectrum Disorders (ASD)***

## **Autism: The Triad**



**Autism ~ all economic levels**

**Autism ~ races, ethnicities, religions**

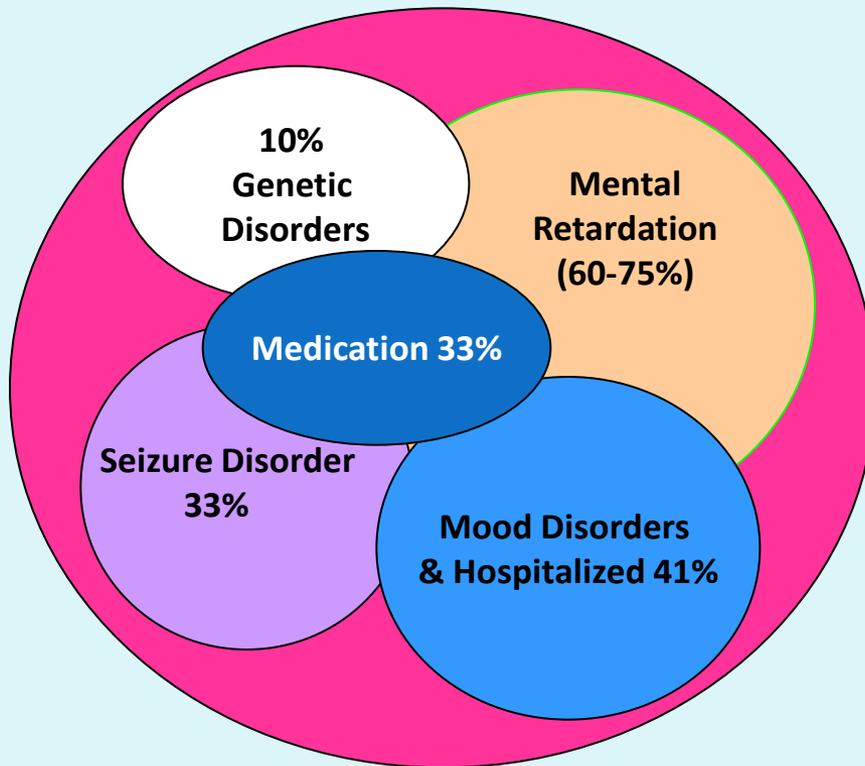
**Pediatricians ~ ignore family concerns**

**Autism NOT caused by parenting.**

### **Advances in ASD**

- Multiple forms of ASD
- Factors Associated with ASD
- Brain changes
- Diagnostic tests
- Animal models of ASD
- Early identification of ASD
- Specific treatment for ASD

# Conditions Associated with Autism Spectrum Disorders



## Other Medical Problems ~ ASD

- *Genetic Abnormalities*
- *Autoimmune disorders*
- *Asthma*
- *Skin allergy or eczema*
- *Food allergy*
- *Sleep problems*
- *Headaches or migraines*
- *Diarrhea, colitis & other GI problems*
- *Ear infections*
- *Infections (PANDAS)*
- *Toxic & environmental factors*
- *Anxiety*
- *Behavioral & mental health disorders*

# Mental Health Co-Morbidities in Individuals with Autism

- 75% of ASD individuals ~ criteria for at least one other mental health disorder
- Multiple mental health disorders common ~ with ASD
  - 17% of ASD ~ two additional mental health disorders;
  - 24% exhibited three or more mental health disorders
- ADHD ~ 30% – 50% of individuals with ASD
- Anxiety disorder ~ 40% of individuals with ASD
- OCD ~ 10% – 33% of individuals with ASD
- Major Depression ~ 30% – 37% of individuals with ASD
- Suicide ideation ~ 14% of individuals with ASD

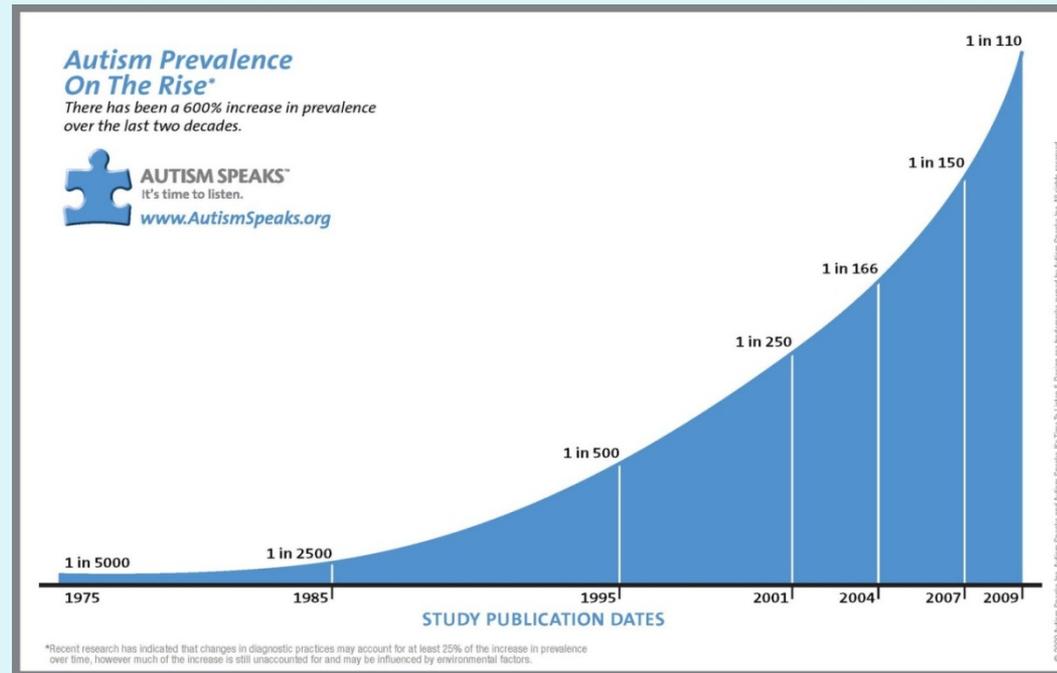
***MENTAL HEALTH PROBLEMS USUALLY NOT DIAGNOSED ~ WITH ASD***

# THE AUTISM EPIDEMIC – A PUBLIC HEALTH CRISIS

- 1970 ~ 1 in every 10,000 births
- 1993 ~ 1 in every 1,000 births
- 1995 ~ 1 in every 750 births
- 1998 ~ 1 in every 500 births
- 2008 ~ 1 in every 150 births (1 in 94 males)
- 2010 ~ 1 in every 88 births (1 in 54 males)

## PRESENTLY

- One in 50 births
- One in 31 males; one in 143 females



Increase In Autism in California from 1987-2012

# The Autism Tsunami: A Public Health Crisis

## National Statistics on ASD

- ASD now affects 1 in 50 children
- There are over 24,000 new cases diagnosed annually
- ASD is more prevalent than juvenile diabetes, childhood cancer & pediatric AIDS combined.
- ASD is fastest growing serious developmental disability
- The economic impact of autism is over \$137 billion annually

## California Statistics on ASD

### Regional Centers

- Caseload increased 634% from 1987 to 2002
- There are over 60,000 consumers with ASD
- ASD now represents two-thirds of all new cases
- Regional Centers probably serve only about 20% of ASD
- 84% are under the age of 22 years

### School Districts

- >60,000 students with ASD in special education
- Districts ~ doubled ASD students in past 4 yrs.
- ASD in special education has increased >400% in past 9 years
- There has been >1000% increase in ASD students K-12 during past 12 years

***“Is this a real increase in autism or an artifact of changing diagnostic criteria & better awareness?” . . .***



# The Changing Landscape of Autism

## A New Era of Help and Hope

### Propelling Systemic Change Through:

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- Increasing **Awareness**
- Expanding basic and applied **Research**
- The greater focus on the development and use of evidence-based **Best Practices**
- Intensified **Advocacy**
- Accelerated **Public Policy Reform** efforts

# The Origins of the MIND Institute

## Medical Investigation of Neurodevelopmental Disorders

### ***“DEVELOPMENT” APPROACH***

- (1997) 5 Families & UCD**
- (1998) \$3.5 M private endowment**
- (1998) \$3.7 M State appropriation**
- (1998) MIND established**
- (2000) Legislature \$34 M**
- (2003) MIND complex completed**
- (2005) MIND > \$70 M State funding**
- (2006) MIND complex includes  
academic offices, clinics,  
research labs**

### ***“LEGISLATIVE” APPROACH:***

- **Problem clearly defined: “autism epidemic.”**
- **The MIND Institute : “one of a kind.”**
- **The MIND Institute would provide “answers.”**
- **Backing by key legislators and staff.**
- **Economic savings to state.**
- **Resources available  
(state budget \$ surplus.)**



# The UC Davis MIND Institute

Mission Statement: “A parent-founded & inspired research institute dedicated to finding the cause(s), better treatments and ultimately a cure(s) for autism spectrum and other neurodevelopmental disorders”

## Current Status of the MIND Institute

52 Senior Researchers & Faculty

95 Research Fellows

54 Major Research Projects

288 Employees

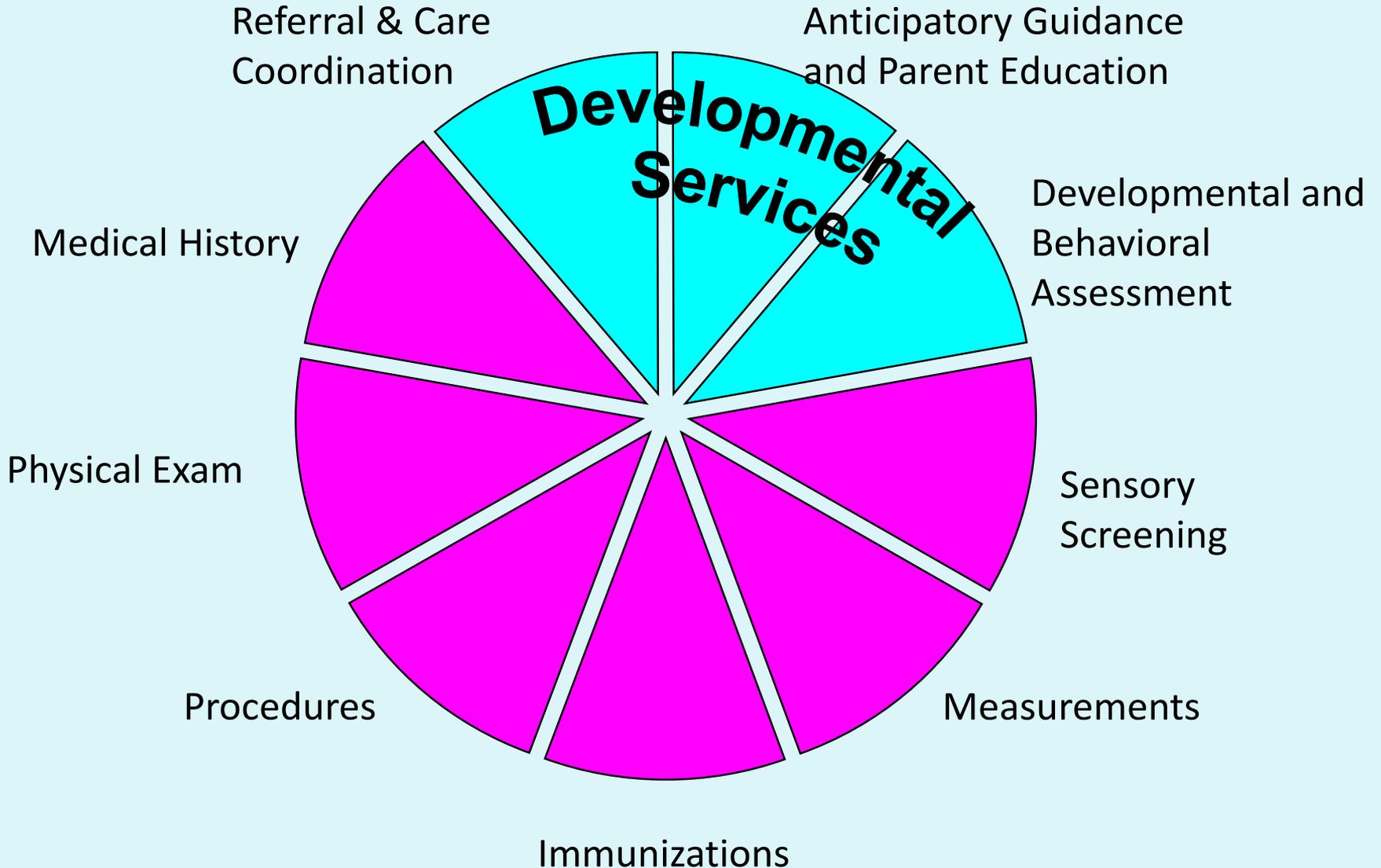
>200 Volunteers

Annual research budget >\$30 M

Ongoing State Funding



# ***Evaluation of Children by Primary Care Physicians***



# Barriers to the Evaluation of Children by Primary Care Physicians

- *Insufficient Time (80%)*
- *Unable to unbundle from “well-child” visit (56%)*
- *Inadequate reimbursement (55%)*
- *Lack of non-MD staff (51%)*
- *Unfamiliar with codes (46%)*
- *Lack of Dx & Rx Services (34%)*
- *Lack of training (28%)*
- *Unfamiliar with screening procedures (24%)*
- *Lack of referral resources (19%)*

# Barriers to Early Detection of Childhood Mental Health Problems in Primary Care

- Brevity of pediatrician-family interactions
- Insufficient pediatrician training
- Infrequent use of practical screening tools
- Under-referral of mental health problems
- Reluctance to discuss behavioral/emotional concerns
- Limited perception of mental health services needed
- Few links to community resources
- Limited insurance coverage
- Stigma associated with mental health issues

# Barriers to the Evaluation of Children with Autism Spectrum Disorders

- ASD often identified late in childhood or missed altogether.
- Lack of timely & appropriate intensive interventions.
- Children ~ underserved communities often diagnosed later & less likely to access early interventions.
- Existing community systems of care often do not collaborate.
- Medical system is overwhelmed, under-funded, and ill-prepared.
- Crisis during transitions ~ services for ASD (3 yrs. of age & 22 yrs. of age).

# The California Legislative Blue Ribbon Commission on Autism

Legislation (Sen. Perata) in 2005;  
Unanimous & bipartisan support

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 & Townhall Meetings

**Final Report to Governor & Legislature  
(September 2007)**

***Web site:* [senweb03.senate.ca.gov](http://senweb03.senate.ca.gov)**

**Google: “Calif. Autism Blue Ribbon Commission”**



# Barriers to Medically Necessary Services for ASD

- 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

# Senate Select Committee on Autism & Related Disorders ( 2009)

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

## Series of Informational Hearings:

*The Science and Treatment of ASD*

*Regulatory Framework Private ASD Insurance*

*Challenges Faced by Consumers*

*Technology & Telehealth Services for ASD*

### Focus of Committee 2012:

Issues of Equity & Diversity for ASD Services

*Video & Transcripts of the Hearings: <http://autism.senate.ca.gov/>*



## **SB 946 (Steinberg): Autism Insurance Mandate** *Legislation Implemented in 2012*

- Every health care plan that provides hospital, medical, or surgical coverage shall also provide **coverage for behavioral health treatment** for pervasive developmental disorder or autism.
- This section shall not affect or reduce any obligation of any **IEP or IPP**
- Every health care plan shall maintain an **adequate network** of qualified autism service providers
- Does not require any benefits to be provided that exceed the essential health benefits required the **federal Patient Protection and Affordable Care Act of 2010**



# L.A. Times Series on Inequities in Regional Center (RC) Services

(Dec. 11, 2011 by Alan Zarembo)

Wide variation in RC spending for ASD: \$1,991(South LA) to \$18,356 (OC)

One RC av. spending per ASD child: white \$12,794; Asian \$9,449  
black \$5,094; Latino \$4,652

14 of 21 RCs spending for ASD white children > black or Latino

DDS expenditures for all ASD children (3-6 yrs./age) averaged **\$9,751**

White \$11,723; Asian \$11,063; Latino \$7,634; Black \$6,593

Schools: ASD in OC is 3 times > than in Fresno

White ASD ~ school aide 10 times > Latino ASD students

Aggressive & informed parents more likely to obtain services

Minorities & underserved communities ~ challenges/barriers RC services

# Senate Autism Hearing on Equity & Diversity

April 30, 2012

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



# Senate Taskforce on Equity & Diversity

20 Taskforce members: consumers, families, advocates, experts, providers, RC staff, community-based organizations

Co-Chairs: Dr. Sergio Aguilar-Gaxiola & Ms. Areva Martin

Taskforce ~ five “Workgroups” to focus on the following:

- 1) *Existing statutes, regulations, & compliance requirements.*
- 2) *Regional center methods ~ linguistic/culturally information*
- 3) *Assessment on RC purchase of service expenditures*
- 4) *Performance & outcome measures ~ equity/diversity*
- 5) *Best practices ~ linguistic/culturally competency*

Each “Workgroup” ~ 4 Taskforce members and 6 other representatives

THE SENATE SELECT COMMITTEE ON AUTISM & RELATED DISORDERS

Chair, President pro Tempore  
Darrell Steinberg

**“A Report by the Taskforce on Equity  
and Diversity for Regional Center  
Autism Services”**

Submitted by Taskforce Staff:

Lou Vismara, MD  
Bob Giovati  
Concepción Tadeo

2013-2014 Legislative Session



# Recommendations of the Equity & Diversity Report for ASD Services

## Role of Dept. of the Regional Centers (RCs)

- *RCs ~ information in a culturally/linguistically competent manner*
- *The individual program plan (IPP) ~ culturally/linguistically competent*
- *Culturally/linguistically competent services ~ flexibility & creativity*
- *RCs ~ strategic plans to achieve equity & cultural/linguistic competency*
- *Cultural/linguistic competency ~ community partnerships*
- *RCs ~ appropriate funding & resources*

# Recommendations of the Equity & Diversity Report for ASD Services

## Role of Dept. of Developmental Services (DDS)

- *Standards on equity & cultural/linguistic competency*
- *Provide standards, guidelines, and outcome measures*
- *Uniform data collection, analysis, evaluation, transparency, & oversight*
- *Establish a culture that promotes equity, fairness, & diversity*
- *Performance measures and indicators*
- *Utilize specific examples of effective regional center programs*

# 2013-2014 Legislative Package on Equity & Diversity

**SB 158 (Correa)** *Establishes a coordinating center to establish best practices to improve services to underserved communities in a linguistically & culturally competent manner; promote screening & treatment, reduce stigma.*

**SB 555 (Correa)** *Regional centers must make every reasonable effort to communicate in the “native language” of the consumer/family during the IPP/IFSP process.*

**SB 208 (Lara)** *Request of Proposals (RFPs) from regional centers must include evaluation of provider’s ability to provide culturally and linguistically competent services and supports.*

**SB 367 (Block)** *Regional center board members to receive necessary training & support to include issues related to linguistic & cultural competency.*

**AB 1231 (V.M. Perez)** *DDS to provide information on the use of telehealth & teledentistry and makes other changes to promote the use of these services in the regional center system.*

**AB 1232 (V.M. Perez)** *Linguistic/cultural competency must be included as outcome measures as part of the DDS quality assurance instrument.*

## **“Lessons Learned”: Factors & Considerations in Legislative Initiatives**

- 1. Consumers, parents, families, & workers must be involved*
- 2. The solutions should be clearly identified*
- 3. The solutions should be reasonable & feasible to implement.*
- 4. The solutions should have outcomes (monitored & measured)*
- 5. Potential to effect broad “systems change”*
- 6. The state should have a clear role & responsibility*

# ***Public Policy & Advocacy ~ “Getting it done!”***

## **Rules of the Road:**

- 1. Know your subject*
- 2. Focus & brevity*
- 3. Frame the issue and make it relevant*
- 4. Offer a tangible solution.*
- 5. The first meeting is never the end*
- 6. Pick your battles*
- 7. Know your opposition; organize & be assertive*
- 8. Alliances*
- 9. Advocacy is for the long haul*
- 10. Relationships, Relationships, & RELATIONSHIPS*

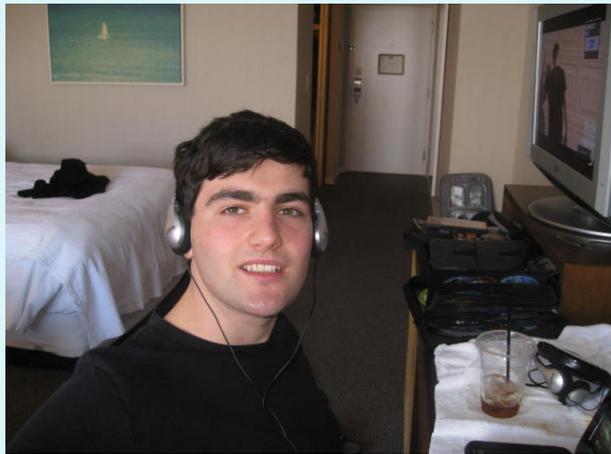
## FINAL CONCEPTS



***“Dignity, Hope, Opportunity, & Love  
are the birthrights of all Individuals”***

**“We all need a Job, a Home, & a Friend”**

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



**“Never miss a good chance to shut up!!”**  
~ Will Rogers

**The End**

