

**Cultural Competence & Mental Health
Northern Region Summit
October 2, 2013
Modesto, CA**

***“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**

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 21st 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:

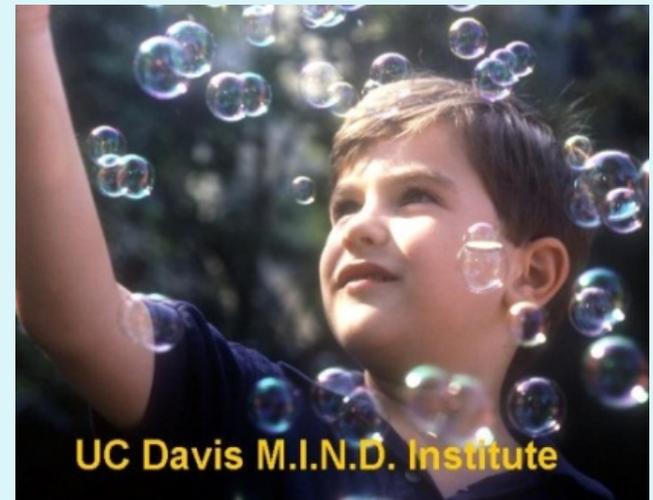
- Immigrant from Italy; (1950)
- Interventional Cardiologist. (1972-1999)
- Co-founder of The MIND Institute (1999)
- First 5 Ca State (Prop 10) Commission (1999-2007)
- Policy Consultant to CA. Senate Pro Tem: (2000-Present)

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)

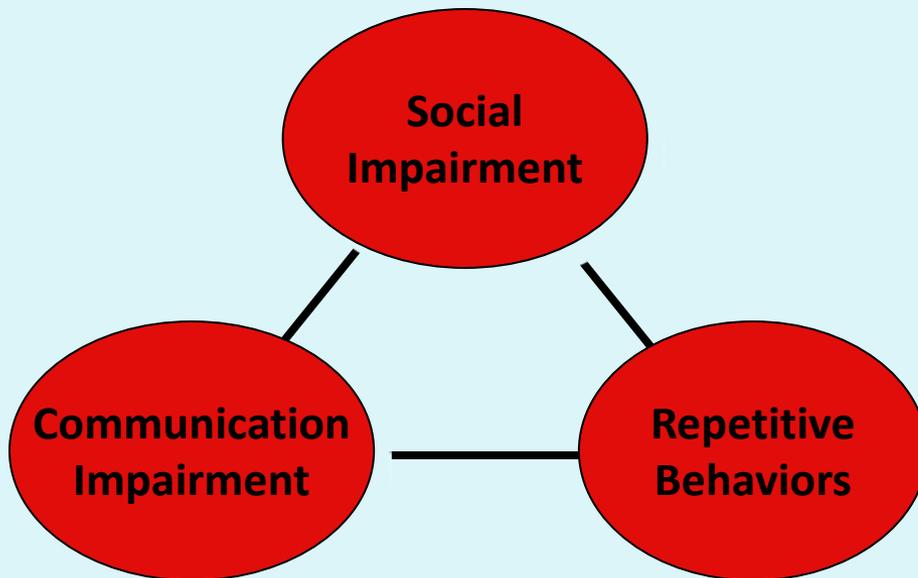
5. *How to know whether your child is being denied enrollment in the program because of “eligibility” or because of “functional assessments”*
4. *How to deal with “systems” that appear to be:*
 - *Not knowledgeable*
 - *Not Listening*
 - *Not Caring*
3. *How to get information transferred from one program 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

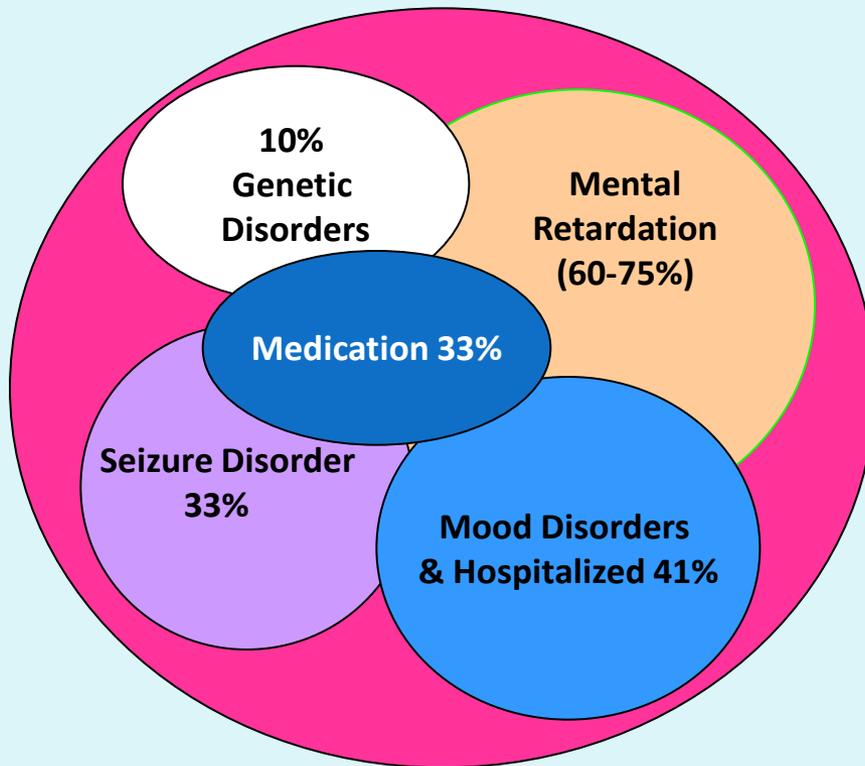
Pediatricians ~ ignore family concerns

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

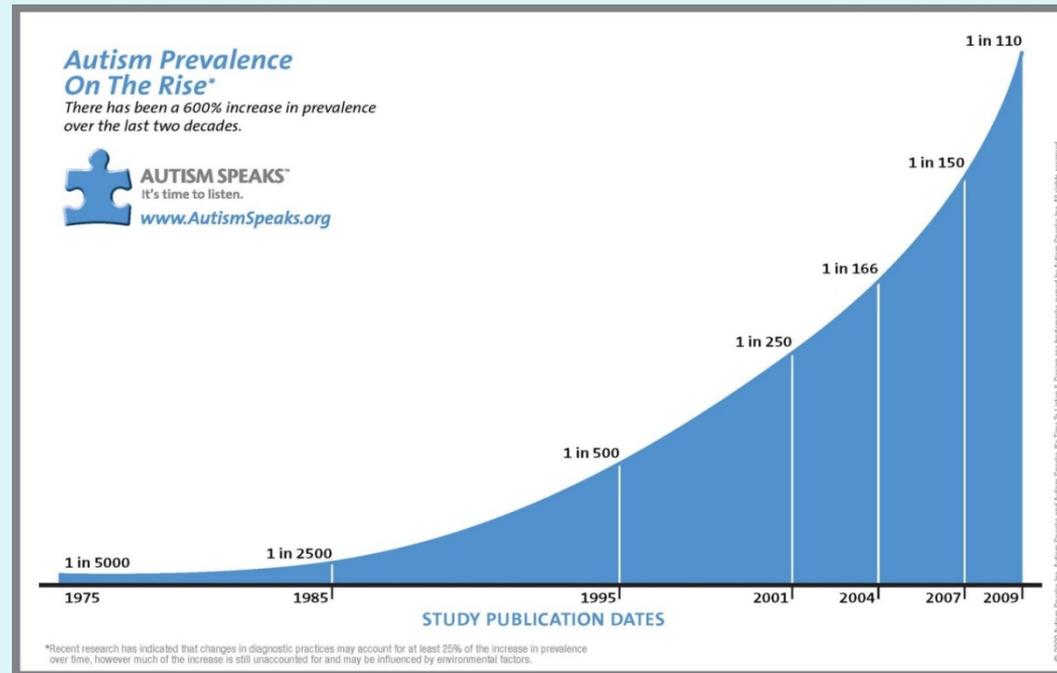
MENTAL HEALTH PROBLEMS USUALLY NOT DIAGNOSED ~ WITH ASD

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:

- 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

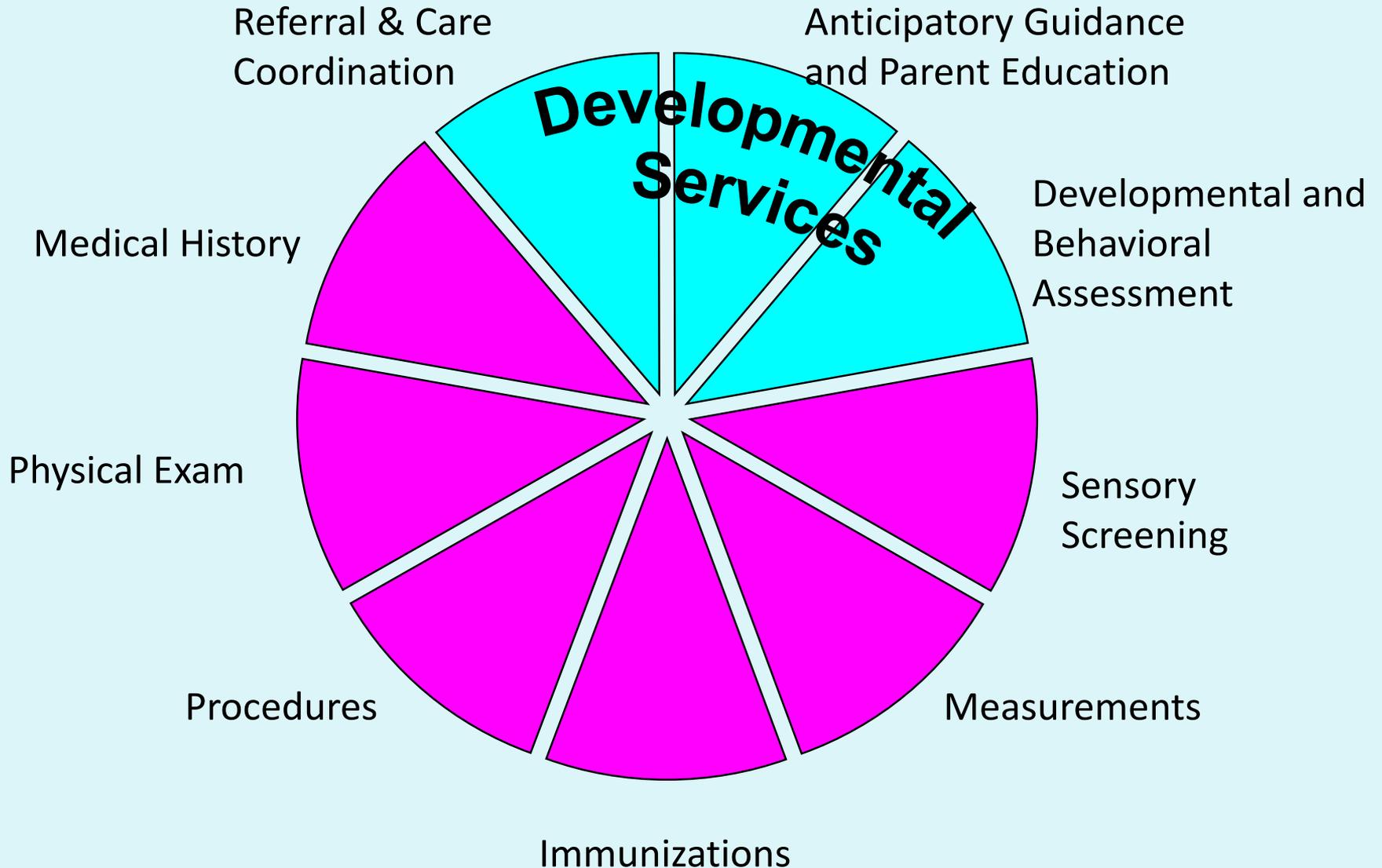
>200 Volunteers

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

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*

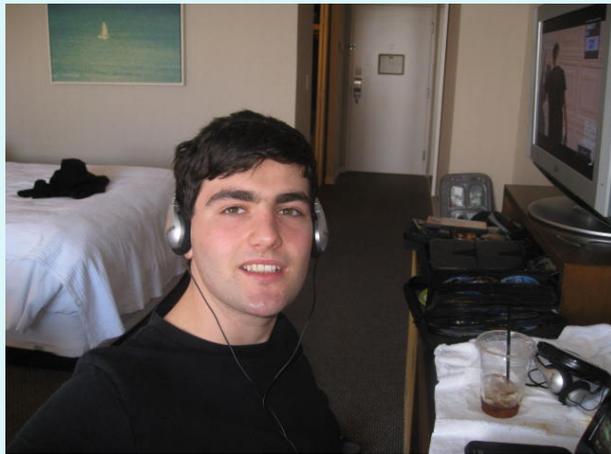
FINAL CONCEPTS



***“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

