

# *“From Passion to Action: A Journey in Advocacy & Public Policy”*

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**Indian Health Services 2016 California Providers'  
Best Practices Conference**



# Indian Health Services 2016 Best Practices Conference

## Health Concerns Among American Indians

- ↑ incidence of heart disease, cancer, accidents; diabetes, & stroke.
- ↑ prevalence/risk of mental health, substance abuse, & suicide.
- ↑ of sudden infant death syndrome (SIDS), & teenage pregnancy.
- ↑ liver disease, and hepatitis.
- ↑ Tb. rate 8 times greater than Caucasians.
- ↑ Cultural barriers; isolation; socioeconomic barriers.
- U.S. Dept. Health & Human Services  
[Office of Minority Health](#)

### Lessons from Autism: The Importance of Hope

*Those who say it can't be done are usually interrupted by others doing it. – J. Baldwin*

*We are all faced with a series of great opportunities brilliantly disguised as unsolvable problems. – J. Gardner*

*The best way to predict the future is to create it. – Alan Kay*



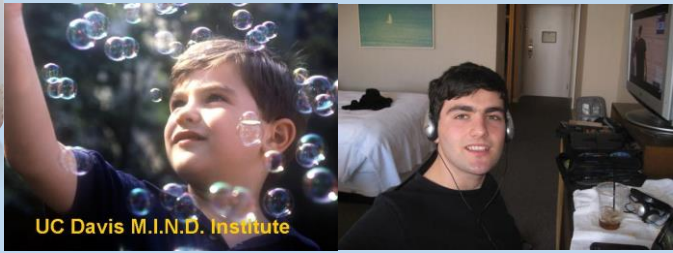
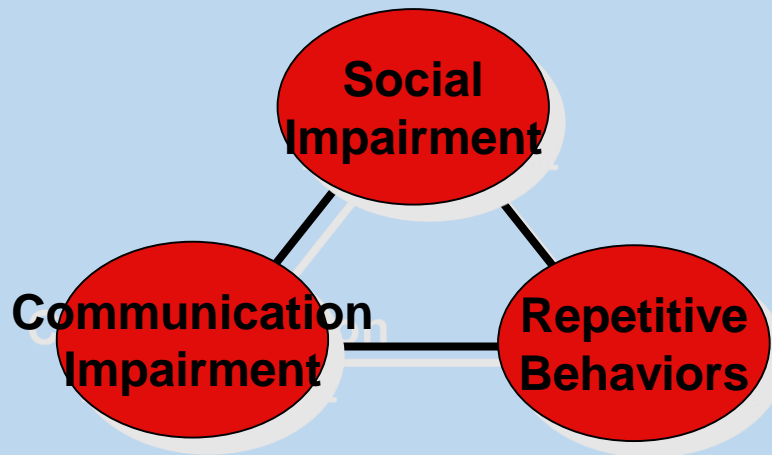
# Today I would like to share the following:

- Our family's story in overcoming Autism.
- My perspective as a physician/consumer.
  - Cardiologist 1975-1999.
  - UCD MIND Institute (1999-2000)
  - CA. Senate Health Policy Consultant (2000-2015)
  - Exec. Director, Univ. Development Foundation (20015-Present)
- Opportunities for changes in public policy.
- Potential strategies for effective advocacy.

*“Some succeed because they are destined to; most succeed because they are determined to” — Anatole France*



# The Many Faces of Autism Spectrum Disorders



Autism ~all economic levels & races.

Parent's concerns often ignored.

Autism NOT caused by parenting.

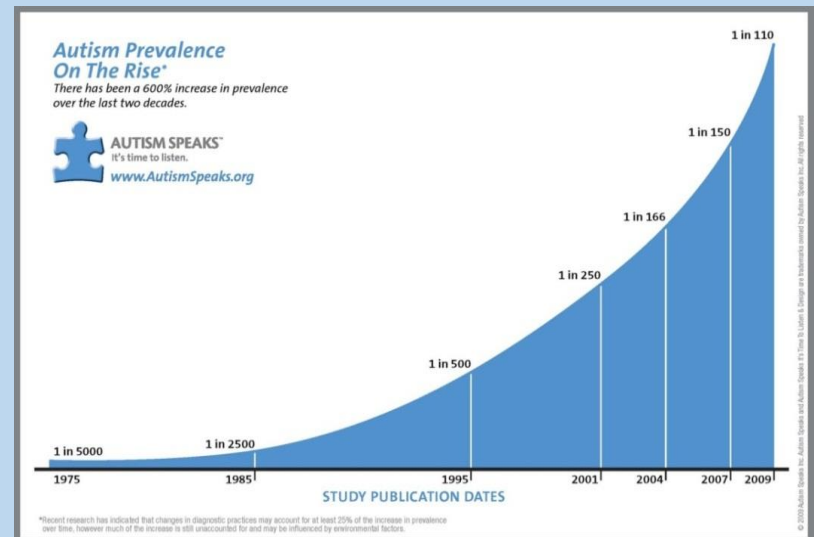
Conditions ~ ASD:

Mental Retardation (40%).

Behavioral Disorders (>80%).

Seizure Disorders (31%).

Autism Epidemic since 1990s



“Life is either a daring adventure or nothing at all” — Helen Keller

# What They Don't Teach In Medical School

## My "Top Ten List"

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 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 person, you're informed that there's a 6 month waiting list for the program.*



# What They Don't Teach In Medical School:

5. Whether your child qualifies for *program because of "eligibility" or "functional assessments."*
4. *How to deal with "systems" that are: Not knowledgeable &/or Not Listening.*
3. *How to get information transferred from one program to another.*
2. *That systems responsive to Autism will better all children ("Canary in the coal mine").*
1. *The number of dedicated & amazing individuals.*

*"No problem can be solved from the same level of consciousness that created" it."*

*"Education is what remains after you've forgotten everything you learned in school."*



*“A vision without action is merely a dream. Action without a vision is a nightmare.” – Japanese proverb*

## Lessons Learned from Autism

- *Identify & clarify a specific problem.*
- *Focus & simplicity.*
- *Provide solutions.*
- *Positive approach.*

Challenge (1998): *Lack of Autism Research & Scientific Studies*





# The UC Davis MIND Institute

(Medical Investigation of Neurodevelopmental Disorders)

## *Key Factors*



Spearheaded by families (1996-1998)

- Private-Public partnership.
- Support by California Legislators.

Compelling narrative

- Unique (“one of a kind”)
- Would provide “answers.”
- Economic savings to state.
- Leverage additional resources.



Current status of MIND Institute.

[www.ucdmc.ucdavis.edu/mindinstitute/](http://www.ucdmc.ucdavis.edu/mindinstitute/)

*“Amazing results occur if you don’t care who gets the credit.”*  
*“The best sign of success is when other take credit for your idea.”*



## Lessons Learned: Senior Policy Consultant— CA Senate President pro Tem (2000-2015)

*Consumers, parents, & families must be involved.*

*The state should have a clear role & responsibility.*

*Solutions should be clearly identified; reasonable & feasible.*

*Outcomes: monitored & measured.*

*Effect broad “systems change.”*

*Identify Implementation opportunities & strategies.*



# Challenge: *Autism Excluded from Child Care/Education*

California Proposition 10 Initiative <http://www.ccfc.ca.gov/>

Statewide Ballot Initiative in 1998 (Rob Reiner)



50 cents tax on cigarettes. (\$800 M/Year)

Goals & Objectives:

- \*School Readiness.
- \*Parental Education.
- \*Universal Preschool.

Lou's Focus on State Commission (1999-2008)

- Disabilities & special needs.
- Seamless & Integrated approach.
- Improve Early Identification & Service Delivery.

*"Think big; start small."*

*The Willie Sutton Rule: go where there's the money"*



# Challenge: *Autism Public Policy Agenda in California*

## The Legislative Blue Ribbon Commission on Autism

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

Commission established by Legislation (2005):

Goals — Identify & close gaps:

- Early identification & intervention.
- Education & treatment of children.
- Youths & adults with ASD.

Task Forces Reports & Townhall Meetings:

Report to Gov. & Legislature by Sept. 30, 2007

<http://senweb03.sen.ca.gov/autism>

*“If you want to go fast go alone; If you want to go far with others.”* – African Proverb



# Challenge: *California Autism Legislation*

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

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

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

### Goals & Objectives:

- Legislative forum to promote policies.
- Advance the work of the California Legislative Blue Ribbon Commission.
- Address the fiscal challenges that confront the State.

### Implementation Strategies:

- Informational hearings.
- Regional Taskforces.
- Autism legislative agenda (yearly).



*“Leaders are those who empower others.”* - Bill Gates.

*“Always drink upstream from the herd.”* – Will Rogers.

# Challenge: *Diplomacy & Politics*

## Autism & Developmental Disabilities Legislation

YEAR	MEASURES INTRODUCED	PASSED	VETOED	LAW
2014	8 in Senate & 1 regulatory change	5	0	5
2013	10 in Senate 2 in Assembly	9	3	6
2012	4 in Senate	4	2	2
2011	4 in Senate 2 in Assembly	2	0	2
2010	5 in Senate	3	1	2
2009	4 in Senate	1	0	1
2008	8 in Senate 3 in Assembly	8	3	5
<b>TOTAL</b>	<b>51</b> 43 in Senate; 7 in Assembly; 1 Regulation.	<b>33</b>	<b>9</b>	<b>23</b>

*Process is complicated.*

*Relationships are key.*

*Learn to compromise.*

*Seek bipartisan support.*

*Staff are crucial.*

*Never “love” with your bill.*

*Seek “low-hanging fruit.”*

*Compelling personal stories.*

***Advocacy is key!***

*“Diplomacy is building a fire under people without making their blood boil”- F.P. Jones*

# Advocacy in Action: SB 946 (Steinberg)

## *California Autism Insurance Mandate (2011)*



**Problem:** *Refusal of health plans to provide behavioral.*

**SB 946:** Every health care plan that provides hospital, medical, or surgical coverage shall also provide coverage for behavioral health treatment for Autism Spectrum Disorders.

Results & Outcomes from SB 946 (March 2014):

- Eligible: 42,000 children (3-21 years of age).
- \$80 Million annual savings to DDS.
- \$200 Million annual savings to schools & taxpayers.
- Affordable Care Act.
- Medi-Cal coverage.

*“If it fails, admit it frankly and try another.  
But above all else, try something” F.D.R.*

# Public Policy & Advocacy: “Rules of the Road”

*Know your subject.*

*Focus & brevity.*

*Frame the issue & make it relevant.*

*Tangible solutions.*

*The first meeting is never the end.*

*Pick your battles.*

*Know your opposition; organize & be assertive.*

*Alliances.*

*Advocacy is for the long haul.*

*Relationships, Relationships, & RELATIONSHIPS.*

*“Be the change you want to see” — Gandhi.*

*Be Involved; Be Knowledgeable; Be Connected*





# What Makes Effective Advocacy?

- Focus on the issue, provide clear recommendations and goals
- Identify your target audience
- Use policy research and data effectively to frame issue and support position
- Build strong coalitions
- Craft clear and concise messages
- Identify credible spokespeople
- Link to legislation and action





## The Art of Advocacy in the 21<sup>st</sup> Century

- Engagement of Youth.
- Quickly reach large number of people:
  - Dissemination of information.
  - Event organization.
- Availability.
- Immediate, real-time communication.
- Compelling visuals.
- Unlimited time & space.
- Generate & focus resources.

*“Those who initiate change will have a better opportunity to manage the change that is inevitable.” William Pollard*

## Final Thoughts & Comments

*“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*

