

The Transformational Power of Early Intervention: *A Personal Perspective*

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A California Summit to Advance Early Intervention
for All Young Children

*“to galvanize a statewide movement that recognizes
early development...as a public health priority..for lifelong success.”*

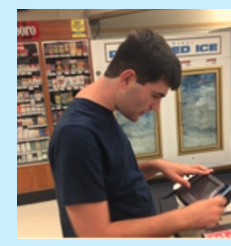
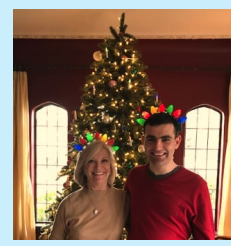
Dr. Deborah Swain, Ed.D., CCC-SLP, BCS-CL

Event Website: www.csus.edu/hhs/ei-summit



Observations & Lessons Learned from Autism

- *Those who say it can't be done are usually interrupted by others doing it.* — James Baldwin
- *We are all faced with a series of great opportunities brilliantly disguised as unsolvable problems.* — John W. Gardner
- *The best way to predict the future is to create it.* — Alan Kay
- *A vision without action is a dream; action without a vision is a nightmare* — Japanese proverb



The Power Of Early Intervention (E.I.)

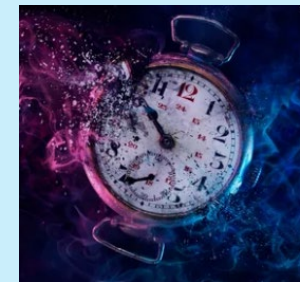
- **WHY** is E.I. Important



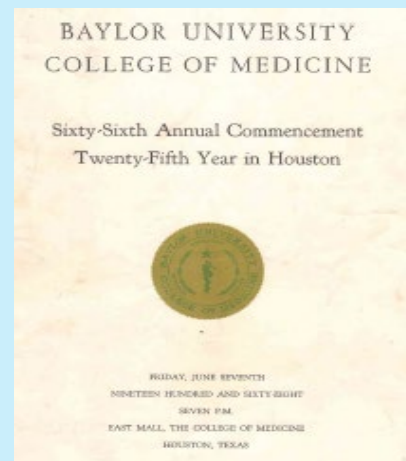
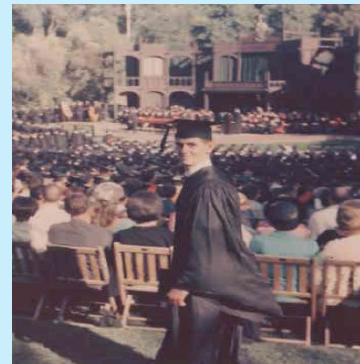
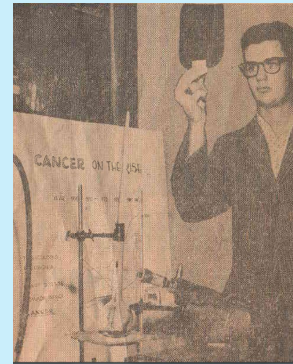
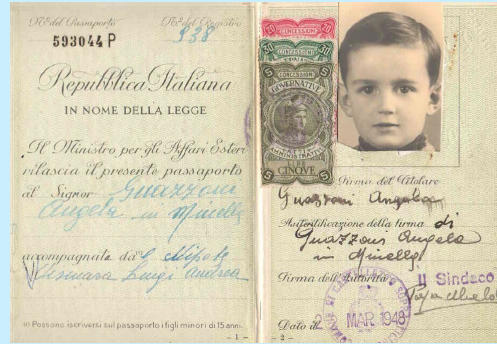
- **How** is E.I. Important



- **When** is E.I. Important



Lou's Early Years & Education



Life is Not Predictable

Mark Walker Vismara



Born April 19, 1993.

Uncomplicated pregnancy, delivery, 1st year.

Dx with DSM IV Autism @ 18 mos.

Interventions & Treatments

ABA (50 hours per week_

Speech & Language: Dr. Lynn Koegel (PRT)

Diet & supplements

Extensive Medical evaluations:

Medications; MRI

Video-monitoring EEG

PT & OT

What They Don't Teach In Medical School

10. *Having a child with disability or special needs is tough.*
9. *Having a child with a disability strains ALL relationships.*
8. *How to care for a disabled child while 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 person, you're told there's a > 6 month waiting.*

What They Don't Teach In Medical School

- 5. Knowing whether your child is being enrolled in the program because of “eligibility” or because of “functional assessments.”*
- 4. Dealing with “systems” that appear to be:
Not knowledgeable; Not Listening; &/or Not Caring.*
- 3. Getting information transferred/communicated 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. There are an incredible number of dedicated & amazing individuals who are committed to children, and their families, with disabilities & special needs.*

Vismara Household 1995-1997



"The definition of insanity is -- doing the same thing over and over and expecting a different result." **Albert Einstein**

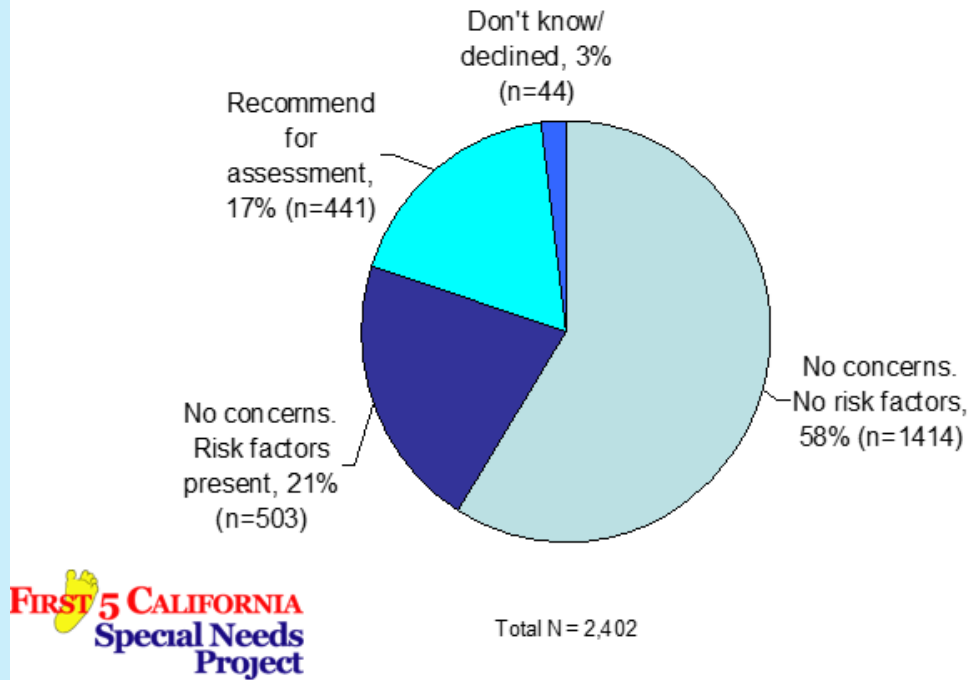


The California Proposition 10 Initiative

First 5 California State Commissioner (1999-2007)



Year 1 Screening Results



Barriers to Evaluation

Insufficient Time (80%)

Inadequate reimbursement (55%)

Lack of non-MD staff (51%)

Unfamiliar with codes (46%)

Lack of Dx & Rx Services (34%)



The UC Davis MIND Institute: *Key Factors*

Medical Investigation of Neurodevelopmental Disorders



Spearheaded by families (1997-1998)

- Initial private endowment
- Private-Public partnership .
- Support by California Legislators

Compelling narrative:

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

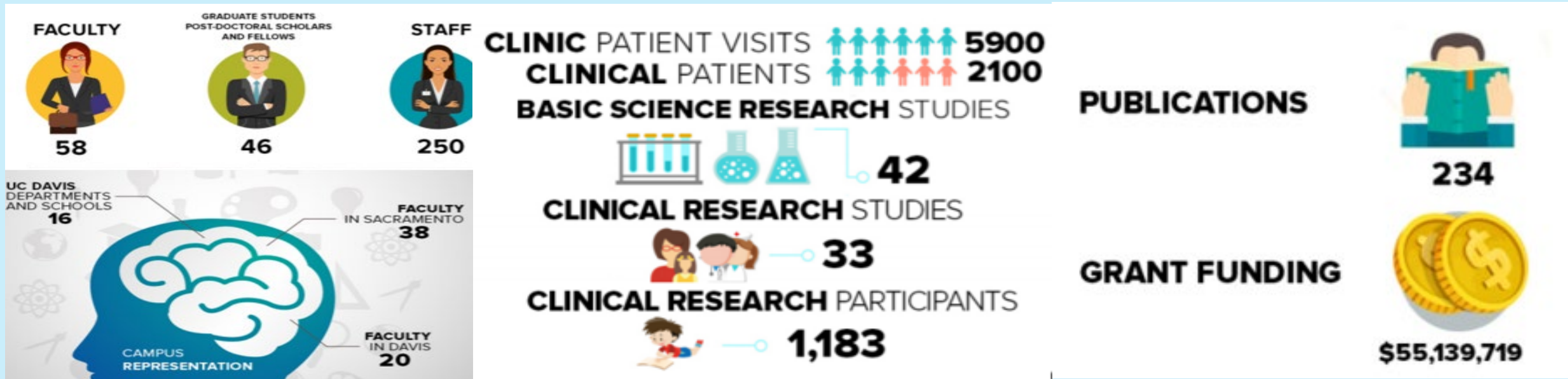
***“To accomplish great things, we must not only act
but also dream, not only plan but also believe.”***

Anatole France



Current Status of the U.C. Davis MIND Institute

<https://health.ucdavis.edu/mind-institute/>



“Amazing results occur if you don’t care who gets the credit.”

“The best sign of success is when others take credit for the idea.”



Lou's 2nd Career — 15 Years in Public Policy Senior Advisor ~ Calif. Senate President



The California Legislative Blue Ribbon Commission on Autism

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

Commission's Goals ~ Identify & Close Gaps:

- Early identification & intervention
- Education & continuous treatment
- The “aging out” of children

Commission Members

- Consumers and their families
- Advocates & stakeholders
- Autism experts
- Public policy & Education leaders
- Business & community development



Task Force Established for Each Goal:

- a. Identify existing problems & gaps
- b. Review potential strategies
- c. Provide specific recommendations

Each Task Force:

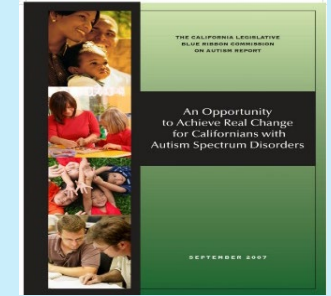
- Community Outreach.
- Workgroups & Townhall meetings

Report/Recommendations to Commission

Final Report to Governor & Legislature
(September 2007)



Blue Ribbon Commission on Autism: Final Report



Factors and Considerations:

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

Policy Recommendations:

- Integrated, Comprehensive Services for Early Identification & Intervention.
- Appropriate & Equitable Insurance Coverage.
- Public Health Crisis: Complex Systems of Care.
- Education of Children with ASD.
- Resolving Disputes Effectively & Equitably.
- Employment & Housing Strategies.
- Law Enforcement & First Responders.



Select Committee on Autism & Related Disorders (2008-2015)



Goals & Objectives:

- *A legislative forum.*
- *Continue work of the Blue Ribbon Commission.*
- *Autism Legislation.*

Series of Informational Hearings:

- *The Science and Treatment of ASD*
- *Regulatory Framework Private ASD Insurance*
- *Equity & Diversity*
- *Technology & Telehealth Services*
- *Private-Public Partnerships*
- *Employment & Vocational Opportunities*
- *SB 946-Autism Insurance Mandate Legislation*

Autism & Developmental Disabilities Legislation from 2008-2014: ANNUAL SUMMARY

YEAR	NUMBER OF MEASURES INTRODUCED	PASSED BY LEGISLATURE	VETOED	SIGNED INTO LAW
2014	8 in Senate & 1 regulatory change	6; (1 held by author)	0; (3 await Gov's action)	2; (3 await Gov's action)
2013	10 in Senate 2 in Assembly	9	2	6
2012	4 in Senate (included 2 Reso.)	4	2	2
2011	4 in Senate (included 2 Reso.) 2 in Assembly	2	0	2
2010	5 in Senate (included 1 Reso.)	3	1	2
2009	4 in Senate (included 1 Reso.)	1	0	1
2008	8 in Senate (included 1 Reso.) 3 in Assembly	8	3	5
TOTAL	43 in Senate; (included 7 Reso.) 7 in Assembly 1 regulatory change	33	8	25 (2 Laws~ Regulations)

California Autism Insurance Mandate: SB 946 by Sen. Steinberg (2012)

Mandated **Behavioral Health Treatment (BHT) coverage** for Autism &/or Pervasive Developmental Disorders the life span.

Defined Behavioral Health Treatment: Evidence –based professional services, that develop or restore, to the maximum extent practicable, the functioning of an individual ASD/PDD that are:

Prescribed by a licensed physician or psychologist.

Treatment plan prescribed by a qualified autism service provider (QASP).

Implemented or supervised by a Licensed or Certified QASP.

Results & Outcomes SB 946 (Jan. 2012-March 2014):

Eligible: 42,000 children (3-21 years of age).

1,600 Regional Center consumers.

\$80 Million annual savings to DDS.

\$200 Million annual savings to schools & taxpayers.

Affordable Care Act & Medi-Cal includes **BHT** for ASD.

SB 946: model for other States

As of 2019 all States provide some form of insurance coverage.



Lessons Learned in the Calif. Legislature



Advocacy: Rules of the Road.

- *Know your subject.*
- *Focus & brevity.*
- *Make it relevant.*
- *Tangible solutions.*
- *Pick your battles*
- *Know your opposition.*
- *Advocacy is long- the 1st meeting is never the last.*
- *Alliances.*
- *Relationships, Relationships,
& RELATIONSHIPS*

Public Policy & Legislation:

- ☐ Involve consumers, families, & providers.
- ☐ Solutions: clearly identified.
- ☐ Solutions: reasonable & feasible.
- ☐ Solutions: outcomes.
- ☐ Potential for "systems change".
- ☐ Clear role & responsibility.

Gandhi: “*Be the change you want to see*”

Be Involved.

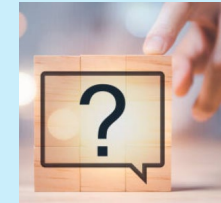
Be Knowledgeable.

Be Connected.

The Power Of Early Intervention: *A Very Personal Perspective*

Why is Early Intervention Important:

- ❖ *Changed and improved lives of our son, Mark.*
- ❖ *Changed and improved our family dynamics.*
- ❖ *Provided hope for the future.*



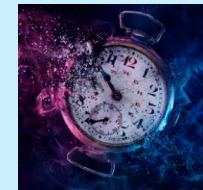
How is Early Intervention Important:

- *Neurobiological basis.*
- *Stress reduction & Improved socialization.*
- *Systems change.*



When is Early Intervention Important:

- ☐ *For all ages.*
- ☐ *For all demographics.*
- ☐ *ACROSS THE LIFESPAN.*



Older Adults & Developmentally Disabled: *Challenges & Potential Synergy*

- “Stressors” on families and caregivers.
- A compelling need for community-based services.
- Access to safe, effective and affordable housing.
- Social; lifestyle; and fiscal challenges.
- Serious & chronic healthcare issues
- Paradigm shift in healthcare delivery systems.
- Transportation & Safety.
- Innovative use of technology.



Community for Health & Independence: AKT & UC Davis—CSUS Concept

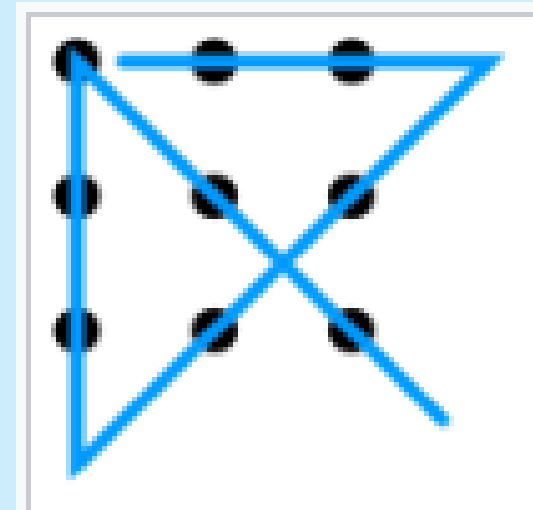
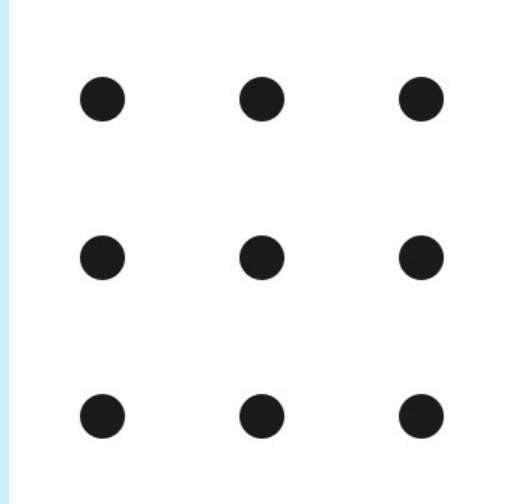
- *To establish an integrated, planned community with a culture, resources, amenities, services/supports, & infrastructure that improves the lives of vulnerable individuals.*
- *2,800 acres in El Dorado & Sacramento counties.*
- *Over next 20 years: 10,000 homes; multigenerational; market-rate & significant affordable housing.*
- *Significant academic & research component integrated within the Project.*



Not just a mission, a movement.

“We envision a world where all people are empowered with the fundamental human right to engage and connect.”

THINK OUTSIDE THE BOX

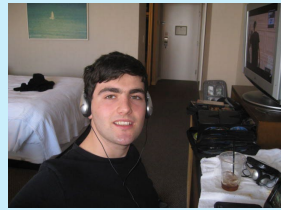


**Connect all dots; only 4 lines;
Can't retrace or lift pencil**

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**



The End