

THE BROOKINGS INSTITUTION & THE HELP GROUP:
AUTISM & HOPE CONFERENCE
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*Autism Public Policy in California:
Is it a Catalyst for National Change?*

By

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

“A vision without action is merely a dream. Action without vision is a nightmare.” (Japanese proverb)

Lou's Background & Perspectives:

- Immigrant from Italy; 7 years old.
- Interventional Cardiologist.
- Co-founder of The MIND Institute.
- First 5 Ca State (Prop 10) Commission
- Policy Consultant to CA. Senate Pro Tem:
 Sen. John Burton
 Sen. Don Perata
- Parent of 4 children:
 Mark, 12 years old ~ DSM IV Autism.



THE CA. PROP 10 INITIATIVE-1998:

- 50 cents tax on cigarettes.
- > \$3 Billion ~ early childhood development.
- State Commission's Focus:
 - ~ School Readiness (\$206.5 M)
 - ~ Universal Preschool (\$100 M)

THE SPECIAL NEEDS PROJECT: GOALS & OBJECTIVES:

- To promote strategies that improve practice in early identification and intervention for children from diverse backgrounds with disabilities, behavioral/mental health concerns, and other special needs.
- To promote school readiness for children with special needs and their families.
- To produce evaluation results for evidence-based practices that will serve as a foundation for future advocacy efforts.



AUTISM LEGISLATION IN CALIFORNIA:

- AB 3854 (Burton, 1974) – *“Public Education of Autistic Students.”*
- AB 430 (Cardenas, 2001) - *“Autism Spectrum Disorders - Best Practice Guidelines for Screening, Diagnosis & Assessment.”*
(www.ddhealthinfo.org)
- AB 2943 (Pavley, 2004) - *“Mercury Free Vaccine Bill.”*
- SB 749 (Speier, 2005-06-Pending): *“Health Plan Autism Diagnosis Bill.”*

THE LANTERMAN ACT OF 1969:

- Entitlements ~ Mental Retardation, Epilepsy, Cerebral Palsy, & Autism.
- Established DDS & Regional Center System.

DEPT. of DEVELOPMENTAL DISABILITIES (DDS):

- ✓ Statewide leadership & policy.
- ✓ Regional Center contracts & oversight.

THE REGIONAL CENTER SYSTEM:

RESPONSIBILITIES:

- ✓ Outreach & Advocacy
- ✓ Coordination & Integration
- ✓ Assessment & Evaluation
- ✓ Prevention
- ✓ Services (IPP)

CONSTRAINTS:

- ✓ Budget & Fiscal.
- ✓ Service Providers.
- ✓ Parental

The Medical Investigation of Neurodevelopmental Disorders

THE MIND INSTITUTE:

1997, \$3.5 M private endowment

1998 SB 2223 Established MIND

2003, MIND complex completed



MIND complex includes:

academic offices, clinics,
research labs & ? future school

UC Davis M.I.N.D. Institute

2825 50th Street

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[http:// www.mindststitute.org](http://www.mindststitute.org)



THE MIND INSTITUTE: SCIENCE & RESEARCH

Bio-Marker Study:

- Neonatal blood from children with autism, mental retardation, cerebral palsy, & controls
- High levels of four proteins (vasoactive intestinal peptide, calcitonin-related gene peptide, brain deprived neurotropic factor, and neurotrophin 4) were found to
- Relate to brain development in newborns later diagnosed with autism or mental retardation.

Bio-Behavioral Studies:

- Infants at Risk of Autism: A Longitudinal Study aka the Infant Sibling Study
- Regression and Imitation in Early Autism
- Sleep in Young Children
- Psychophysiology of Emotion in Neurodevelopmental Disorders
- Neuropsychology of Children with Hyperactivity and Autism

Treatment Studies:

- Two Methods of Teaching Speech to Nonverbal Children with Autism
- Video and Behavioral Modeling
- Parent-Child Interaction Therapy (PCIT) for Autistic Spectrum Disorders
- Double-blind, injectible methyl B 12
- Dietary Restriction of Gluten
- Pharmacogenomics of Risperdal in ASD
- Social Skills Training for Children with ASD



The M.I.N.D. Institute Autism Phenome Project

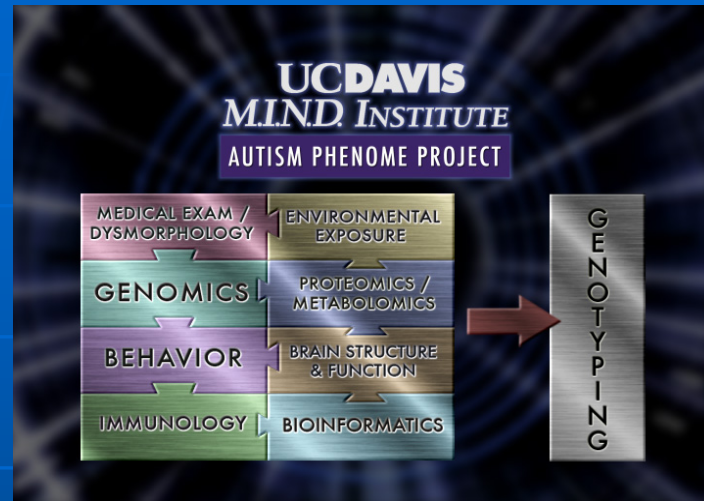
The Problems

Autism is an enormously heterogeneous disorder. It is likely to have a variety of etiologies and ultimately to be considered distinct variants or phenotypes of the same disorder (Autism type A, Autism type B etc.)

AutismS not Autism

To date, research on autism has been too fragmentary to allow determination of the biomedical and behavioral characteristics that define different phenotypes of autism spectrum disorder.

The Brookings & Help Group Conference: Autism Public Policy in California



PHENOME PROJECT: GOALS & OBJECTIVES:

- To establish a database of biomedical, experiential, developmental and neuropsychological features of autism spectrum disorder.
- To apply an integrative bioinformatics approach to define distinct phenotypes of autism spectrum disorder.
- To provide the foundation to pursue hypothesis driven research on each identified etiology of autism.
- To develop new approaches for the prevention, treatment and cures of autism spectrum disorders.

CHILDHOOD AUTISM RISKS from GENETICS & ENVIRONMENT (MIND C.H.A.R.G.E STUDY)



Environmental Factors in the etiology of Autism
and Other Neurodevelopmental Disorders

Blood

analysis of 22 metals in blood
PCBs and PBDEs
fipronil (frontline)
pyrethroids
lipid profile
oxylipid metabolites
eicosanoids



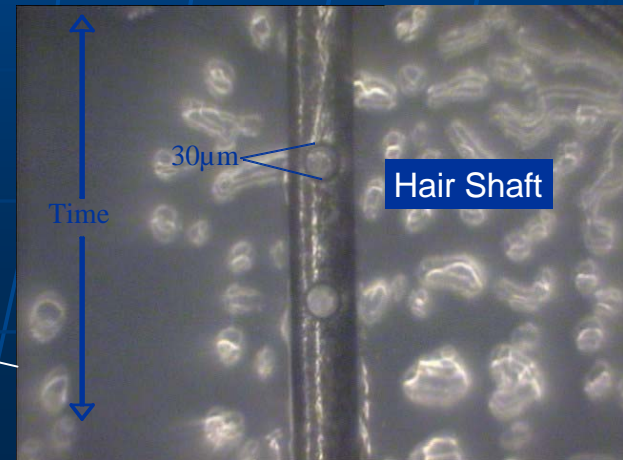
Urine

opioid peptides
tryptophan metabolites



Hair

mercury



CLOSING CONCEPTS & FUTURE CONSIDERTIONS:

- **clarify & identify problems**
 - **focus & simplicity**
 - **provide solutions**
 - **positive approach**
-
- *“the reward of a thing well done, is to have done it” - Ralph Waldo Emerson*
 - *“We cannot discover new oceans unless we have the courage to lose sight of the shore”-Andre Gide*
 - *“On matters of style, swim with the current; on matters of principle, stand like a rock” - Thomas Jefferson*
 - *“If it fails, admit it frankly and try another. But above all else, try something” F.D.R.*