

The Help Group Summit 2009

"A Job, A Home, & A Friend"
Providing Hope and Opportunity for Young Adults with Autism

Panel of Presenters

- **Lou Vismara, Moderator**
Parent of 16 year old son with autism
Staff, Senator Darrell Steinberg
- **Michael Danneker**
Executive Director, Westside Regional Center
- **Geri Fuchigami**
Transition Youth Coordinator, LAUSD
- **Jeff Ross**
Director Student Support Services;
Taft Community College
- **Rachel Spooner**
Jobs Supervisor for Best Buddies Jobs California

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AUTISM : A Public Health Crisis

National Statistics on ASD

- ASD now affects 1 in 150 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 \$90 billion annually

California Statistics on ASD

Regional Centers

- Caseload increased 634% from 1987 to 2002
- There are almost 40,000 consumers with ASD
- 84% are under the age of 22 years
- ASD now represents two-thirds of all new cases
- Regional Centers probably serve only about 20% of ASD

School Districts

- Almost 35,000 students with ASD in special education
- Most districts have doubled ASD students in just the past 4 years
- Proportion of students with 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

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AUTISM: A Personal Perspective

Born April 19, 1993.

Uncomplicated pregnancy, delivery, & first year.

Diagnosed with DSM IV Autism @ 18 mos.

INTERVENTIONS

- ABA in-home program 50 hours per week
- Educational Interventions & Programs
- Dietary interventions and nutritional supplements.
- Physical and Occupational Therapy.
- Extensive Medical evaluations:
- Consultations by specialists
- Developmental and neuro-psychiatric evaluations.
- Medications
- MRI
- Video-monitoring EEG
- Dental hygiene and treatments.

Mark Walker Vismara




UC Davis M.I.N.D. Institute

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THE U.C.D. MIND INSTITUTE
 Medical Investigation of Neurodevelopmental Disorders
 Current Status of The MIND Institute:

- 32 Senior Research Scientists
- Research & Treatment complex (> 125,000 square feet)
- Over 100 Research Scholars &
- Over 100 Support Staff
- Over 80 Separate Research Projects
- Annual Research Budget > \$20 Million
- Established world-class leader in Autism Research & Treatment



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The Tsunami of Young Adults with Autism

Currently 6,000 adults with ASD are Regional Center (RC) consumers

This number will almost double in the next 5 years

By 2018, there will be more than 19,000 adults with ASD in the RC system

Most Regional Centers will see more than a 300% increase in the numbers of adults with ASD during the next decade

Purchase of Services: Costs related to age & diagnosis

▪ children without ASD:	\$3,447
▪ children with ASD:	\$6,993
▪ adults without ASD:	\$15,935
▪ adults with ASD:	\$36,704

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Employment Challenges for Individuals with ASD in California

California ranks 34th in disability employment

Regional Center (RC) consumers ~ unemployment of 84.2%
 Unemployment among individuals with Autism >90%

Only 9,297 participants in supported employment programs

Only 17,623 RC consumers have an earned income
 Annual average: \$4,824

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The Tsunami of Young Adults with Autism

Univ. of Miami Survey of Transition/Adults with ASD in Florida (2008)

- 67% families no knowledge of transition programs
- 78% no knowledge of job development agencies or professionals
- 74% wanted to work but were unemployed
- Of those employed, 74% worked < 20 hours per week
- 85% lived with parents or family members

The Easter Seals' *Living with Autism Study (2008)*

Causes Of Poor Outcomes For Transitional Youths:

- Poorly implemented transition services from school to adult life
- Lack of coordination between educational behavioral, mental health, & vocational rehabilitation services
- Lack of understanding about employment potential
- Lack of adequate and appropriate supports
- Absence of qualified staff

Housing Challenges for Individuals with ASD in California

The Place of Residence for Regional Center Consumers with Autism

- **Living at Home**
53% in 1987
89% in June 2007 (30,673 individuals)
- **Living in Licensed Community Facilities**
31% in 1987
7% in June 2007 (2,205 individuals)
- **Living in Developmental Centers**
11% in 1987
1% in June 2007
- **Living Independently or Supported Living**
June 2007: 754 individuals

Housing Challenges for Individuals with ASD in California

Complex Array of Residential Models:

- Community Care Facilities
- Intermediate Care Facilities
- "962 Homes" (Agnews Model)
- Private Non- Profit Organizations
(<http://www.camphill.org/>)
- Independent Living Services
- Supported Living Services
- Cooperative Living Style Model
- Family Teaching Model
- Community Integrated Housing

The California Legislative Blue Ribbon Commission on Autism

Origins of the Commission

- Established by Legislation enacted in 2005
- Authored by Senator Don Perata;
- Unanimous & Bipartisan Support
- Chaired by Sen. Steinberg;
- Vice-Chair Dr. Firestone



Goals of the Commission

- Identify Existing Problems & Gaps
- Review Potential Strategies
- Provide Specific Recommendations

- Commission Forms Three Task Forces
- Final Report to Governor & Legislature, Sept. 2007
www.senweb03.senate.ca.gov/autism

- Report led to the 2008 Autism Legislative Package



Policy Recommendations on Housing & Employment from the California Legislative Blue Ribbon Commission on Autism

1. Direct the California Community Colleges to expand programs for career training of people with ASD.
2. Direct the Calif. Dept. of Education to establish demonstration projects that will serve as a career technical educational pathway for students with ASD who require intensive supports & assistance.
3. Endorse the efforts of the State Council on Developmental Disabilities in implementing the recommendations of Senate Bill 1270 (Chesbro; 2006) by promoting innovative career training programs for persons with ASD
4. Enact a state housing financing program to add financial support & assistance to local housing initiatives for the development of specialized housing for the ASD population
5. Create a model for housing and support for persons with ASD that treats the individual with respect and dignity, and provides a range of opportunities for employment & leisure activities

**Senate Select Committee on Autism & Related Disorders
Goals & Objectives**

To provide a legislative forum for research, analysis, deliberations, and outreach in order to promote policies and legislation to better assist individuals with ASD and their families

To advance the work of the California Legislative Blue Ribbon Commission on Autism

To address the issues that were identified within the California Autism Legislative Package of 2007-2008

To deal with the fiscal challenges that confront the State in providing the necessary and crucial services for individuals with ASD

To focus on the following issues: Early Identification & Intervention; Insurance Coverage; Training & Employment; Housing

The Subcommittee shall submit its report to the Senate no later than November 30, 2010,

(Adopted: March 4, 2009)

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The Members of the Senate Select Committee on Autism

Senate President Darrell Steinberg –Committee Chair
(Democrat – Sacramento, 6th District)

Senate Republican Leader Dennis Hollingsworth
(Republican – Murrieta, 36th District)

Sen. Elaine Alquist Democrat – Santa (Clara, 13th District), chair, Health Committee

Sen. Roy Ashburn (Republican – Bakersfield, 18th District)

Sen. Lou Correa (Democrat – Santa Ana, 34th District)

Sen. Mark DeSaulnier (Democrat – Contra Costa, 7th District)

Sen. Dean Florez (Democrat – Shafter, 16th District)

Sen. Mark Leno (Democrat – San Francisco, 3rd District)

Sen. Carol Liu (Democrat – Pasadena, 21st District), chair, Human Services)

Sen. Alex Padilla (Democrat – Pacoima, 20th District)

Sen. Fran Pavley (Democrat – Agoura Hills, 23rd District)

Sen. Curren D. Price, Jr. (Democrat – Los Angeles, 26th District)

Sen. Lois Wolk (Democrat – Davis, 5th District)

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Senate Select Committee on Autism & Related Disorders

"This select committee signals California's ongoing bipartisan commitment to individuals with autism and their families. It will provide a legislative forum for research, analysis, deliberations, and outreach on the most pressing issues and concerns facing families who are dealing with autism spectrum disorders."

– Senator Darrell Steinberg;
President Pro Tem, California Senate

Press conference by Sen. Steinberg & SSCA (April 28, 2009):
<http://www.youtube.com/watch?v=dzi8a1jvMg>

Senate Select Committee Web Site Pending
<http://www.senate.ca.gov/~newsen/committees/Select.HTP>
– Select Committees –
Autism (ASD) & Related Disorders

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An Integrated & Planned Community for All Abilities and Across the Lifespan

Vision: To create an integrated, sustainable community where people of all different abilities and ages can work together to pursue productive and mutually beneficial lives. To establish a model that can be replicated throughout the State and Nation.

Project Site: A 577-acre property in the City of Sacramento within 5 miles of the Capitol

Development Concepts:

- 20% of the housing units for individuals/families autism, disabilities & other special needs
- Employment opportunities will be created for people with various disabilities through farming and community gardens, other employment opportunities
- Availability of light rail will facilitate travel to other job opportunities.
- Educational and therapeutic opportunities will be created within the community for people with disabilities, as well as opportunities to socialize.
- An additional percentage of the housing units will be made available to senior citizens.
- Seniors, as well as all other community residents, will be actively offered a variety of opportunities to engage as volunteers within the community.
- <http://www.sacbee.com/opinion/story/2191089.html>

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"Never doubt that a small group of committed people can change the world. Indeed, it is the only thing that ever has!"

~ Margaret Mead

"DIGNITY, HOPE, OPPORTUNITY AND LOVE ARE THE BIRTHRIGHTS OF ALL INDIVIDUALS"

~ Dr. David Firestone
