



The Center for Health Practice, Policy & Research

*Innovative Solutions to Improve Quality of Life
for Individuals with Developmental and
Intellectual Disabilities & Their Families*

*“My Journey with Autism:
Lessons Learned & Hopes for the Future”*

By

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Lou's Background



Medical Career: (Interventional Cardiologist)
Baylor College of Medicine (1964-1968)
Internal Medicine Methodist Hospital (1968-1970)
Cardiology U.C. Davis Med. Center (1971-1974).
UCD Medical School Faculty (1975-1980).
Private Practice Mercy Hospital (1980-1999).

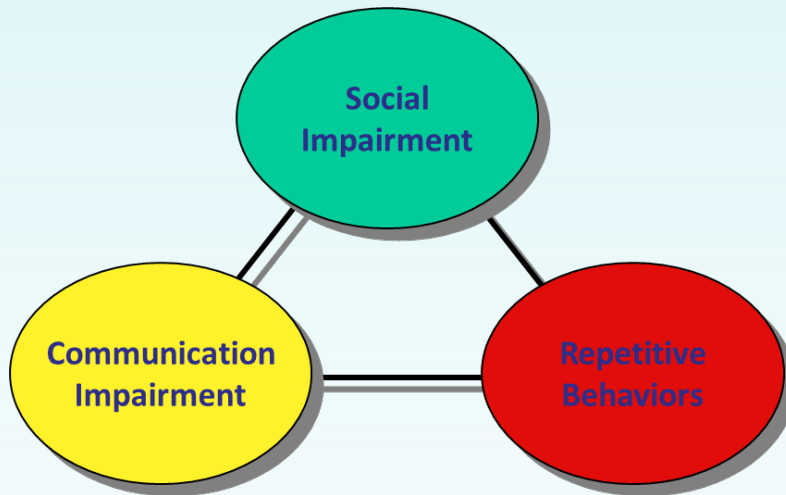


“Life is not predictable”



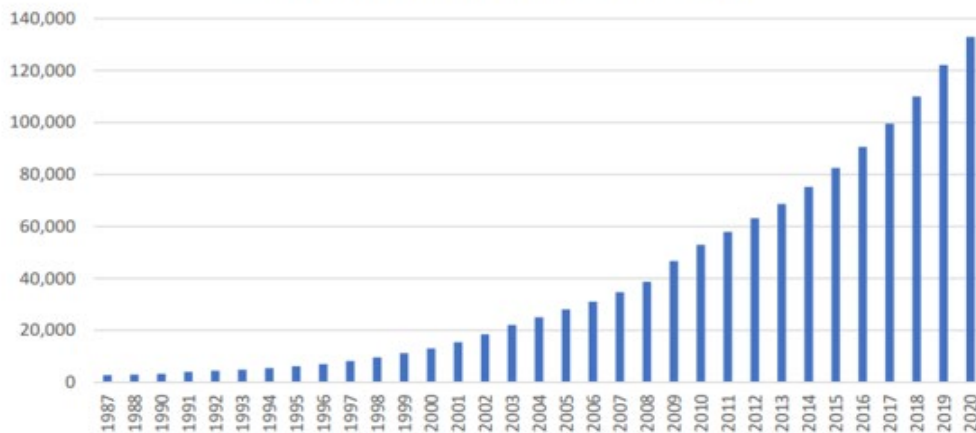
UC Davis M.I.N.D. Institute

Autism: A Triad of Characteristics



California's Autism Explosion

DDS Autism Caseload 1987 - 2020



Increasing numbers of cases every year

Source: DDS

- Affects 1 in 44 children.
- >24,000 new cases annually.
- More prevalent than juvenile diabetes, childhood cancer & pediatric AIDS combined.
- Fastest growing serious developmental disability.
- Economic impact >\$137 B/yr.
- Regional Centers > 100,000 consumers with ASD.
- >900% increase in ASD students K-12 during past 12 years

What 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 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 list.

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.

The UC Davis MIND Institute (1999-2000) *(Medical Investigation of Neurodevelopmental Disorders)* Background & Origins

(1995-1998):



Key Factors

- Spearheaded by families.
- 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.

Current Status of the MIND Institute

<https://health.ucdavis.edu/mindinstitute/>

69 Senior Faculty & 95 Research Fellows

5 UCD Schools/Colleges

14 UCD academic departments.

74 Major Research Projects

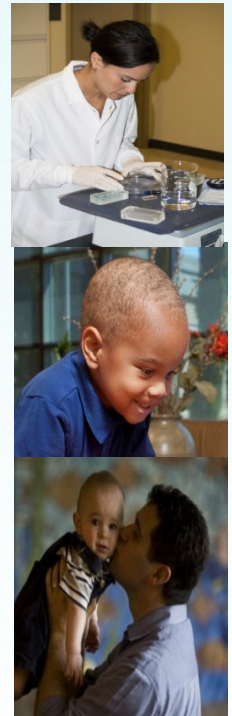
288 Employees

>200 Volunteers

Annual research budget >\$59 M

State funding: \$3.6 M annually

Philanthropy ~ \$3.2 M annually



Lou's 2nd Career — 15 Years in Public Policy

Senior Advisor ~ Calif. Senate President (2000-2015)

Blue Ribbon Commission on Autism

[\(www.senweb.senate.ca.gov.\)](http://www.senweb.senate.ca.gov/)



Senate Committee on Autism

[\(www/autism.senate.ca.gov/\)](http://www/autism.senate.ca.gov/)



California Autism Insurance Mandate [\(SB 946\)](#)

Every health plan providing hospital/medical/surgical care shall also provide coverage for behavioral health treatment for ASD or PDD.

Results & Outcomes (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 (schools & taxpayers)
- Coverage also applied to Affordable Care Act & Medi-Cal

Lessons Learned in the Legislature

- ❑ Involve consumers, families, & providers.
- ❑ The solutions should be clearly identified.
- ❑ Solutions should be reasonable & feasible.
- ❑ The solutions should have outcomes.
- ❑ Potential for "systems change."
- ❑ Define: clear role & responsibility.



Gandhi: “Be the change you want to see”

Be Involved

Be Knowledgeable

Be Connected

Lessons Learned in the Calif. Legislature: Advocacy — “Rules of the Road”

- Know your subject.
- Focus & brevity.
- Make it relevant.
- Tangible solutions.
- Know your opposition.
- Pick your battles.
- Learn to listen.
- Advocacy is a for the long haul.
- Your first meeting is never your last.
- Alliances, Relationships, & RELATIONSHIPS!



“Dr. Vismara, Do you know what we all need in life”
(An Advocate’s question 20 years ago when working in the Legislature)



A Job....



A Home....



And A Friend!!



AKT Investments, Consultant (2016-Present)

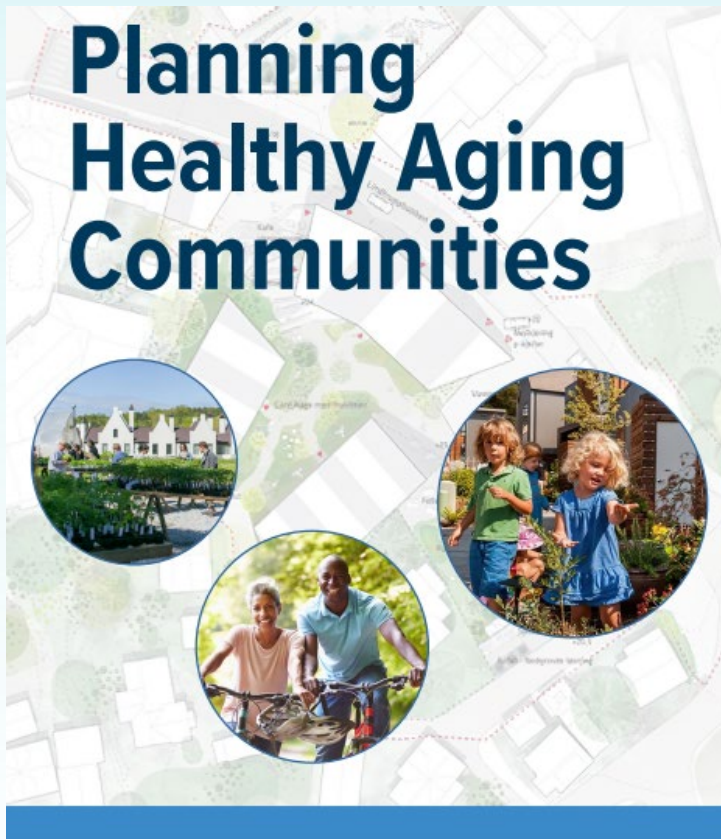
Integrated Community Development

The Vision & Plan

To establish an integrated, planned community with a culture, resources, amenities, services/supports, & infrastructure that improves the lives of vulnerable individuals.



Integrated Community Development: Goals & Objectives



[Link to Report](#)

Beautiful; quality; universal design.
“Market-rate” & affordable housing.
“Aging in place” supports.

- *Information & “Life-long” learning.*
- *Fun & socialization.*
- *Health & wellness.*
- *Effective transportation.*

Community setting & culture.

- *Community parks; Common gardens.*
- *Commercial & retail.*

State-of-the-art technology

Top Five Trends in Senior Care Technology Due to COVID-19



ARTIFICIAL INTELLIGENCE / MACHINE LEARNING

Integrated Community Development: *The Silver Tsunami*

“Baby Boomers”: 76 Million Americans born 1946-1964.

Today there are 40 million Americans over the age of 65.

10,000 Americans turn 65 each day.

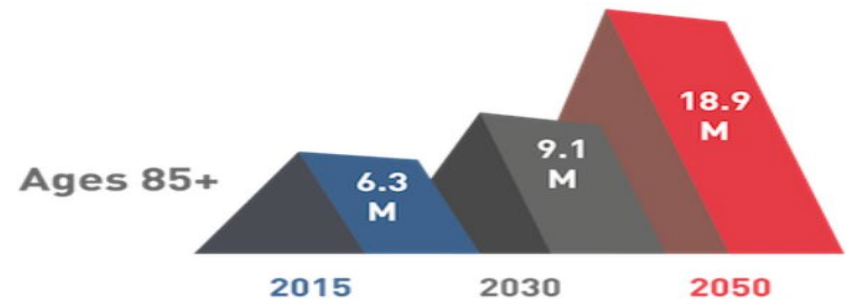
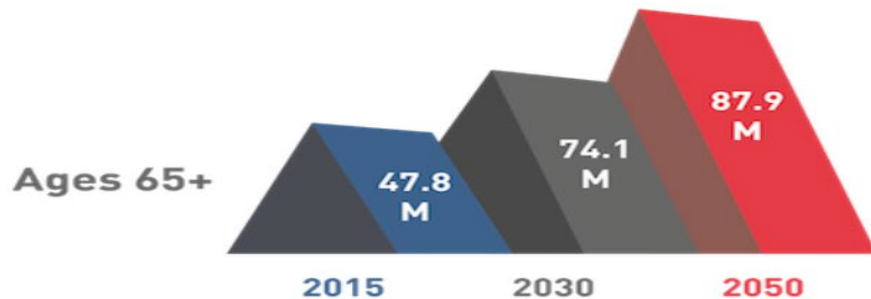
By 2030 the U.S. senior population: 91 million.

Calif. senior population: 11 million

> 1 million need living skills assistance.

“Oldest Old” (85 yrs. & older): fastest growing demographic

6 Million now → 19 Million in 2050.



The Aging & Developmentally Disabled: Areas of Common Challenges & Potential Synergy

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



Services for Older Adults: *The Potential for Future Employment*



Autism Employment: Current Status

Lack of transition services from school to adult life:

67% families no knowledge of transition programs.

78% lacked any assistance for job training.

Lack of understanding about employment potential:

74% wanted to work but were unemployed.

Of those employed, 74% worked < 20 hours per week.

Lack of adequate & appropriate supports:

Absence of qualified staff.

Lack of coordination with behavioral/social services.

Social isolation: 85% live with parents/family.

Mark Vismara: *A Personal Perspective on Autism Employment*

- Works at a High School athletic Program.

- Vending machines.

- Dog-walking service.

- Pride Industries.

- Volunteers at church.

- Before Covid:

- Goodwill Industries.

- Eskaton Assisted Living Pilot Project :

- Learned New Skills: *94% extremely/6% very favorable.*
- Doing a good job: *90% extremely/10% very favorable.*
- Helped Eskaton staff: *94% extremely/6% very favorable.*
- Interacted with residents: *82% extremely/18% very favorable.*

[Video](#): “Adults with Autism: Living in a Neurotypical World.”



Ten Steps to Independence for Mark Vismara

1. Early Intervention approaches are often NOT effective.
2. Individualized.
3. Structured & Consistent.
4. Limit “stressors” & demands.
5. Communication.
6. Desensitization.
7. Back-chaining.
8. Motivation.
9. Persistence.
10. Monitoring.



THE AUTISM FULL EMPLOYMENT ACT

The Next Stage of Jobs for Adults
with Autism, ADHD, and Other
Learning and Mental
Health Differences

Michael Bernick
and Louis A. Vismara, MD

“Top Ten lessons I learned working with Mark”

by

Sac State student (**Bryce J**) who supported Mark for over 2 years.

1. Treat Mark Like Family: *“I started taking more pride in my work.”*
2. The Power of Motivation: *“Mark can do anything with motivation.”*
3. Be Confident: *“This relieves Mark’s anxiety.”*
4. Stay Active: *“Enables Mark to focus and get things done.”*
5. Stay Organized: *“Prevents bad habits...Mark completes tasks more easily.”*
6. Stick to the Schedule: *“This helps the staff be organized and reduces Mark’s anxiety.”*
7. Don’t Panic: *“Remaining calm reduces Mark’s anxiety and promotes his skill sets.”*
8. Change is Possible & Good: *Mark is fine with change as long as he gets something out of it.”*
9. Don’t Underestimate: *“Mark needs an example & guidance.”*
10. YOU WILL BE BETTER: *“I am grateful to Mark because he pushed me to be a more patient leader!”*



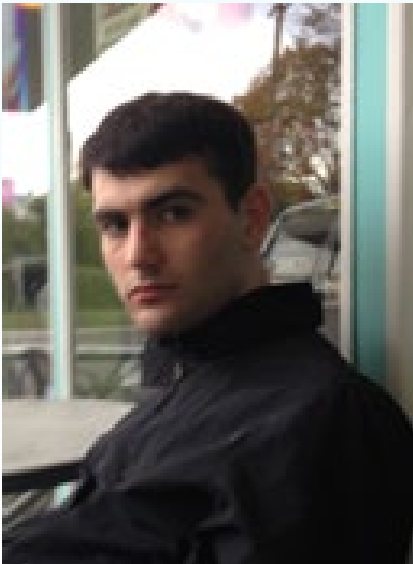
Final Comments: Lessons Learned from Autism



*“Those who say it can't be done
are usually interrupted by
others doing it. — James Baldwin*

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

*“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