

Presentation to the
Board of Directors
Orange County Regional Center

**Thompson Policy Institute on
Disability and Autism**

September 1, 2016

Presentation by
Dr. Don Cardinal and
Dr. Amy-Jane Griffiths

Our Central Topics

- Four stages of TPI purpose
 - An example using the community action plan
- Our research on autism prevalence
- Why community partnerships are important



TPI's Purpose

1. Assess Need

- What is important to everyone in our community?

2. Gather Information and meaningfully analyze it

- Gather & interpret data that already exists
- Do our own research when information is not available

3. Share this information with all relevant stakeholders

- In an accessible way

4. Facilitate and support action

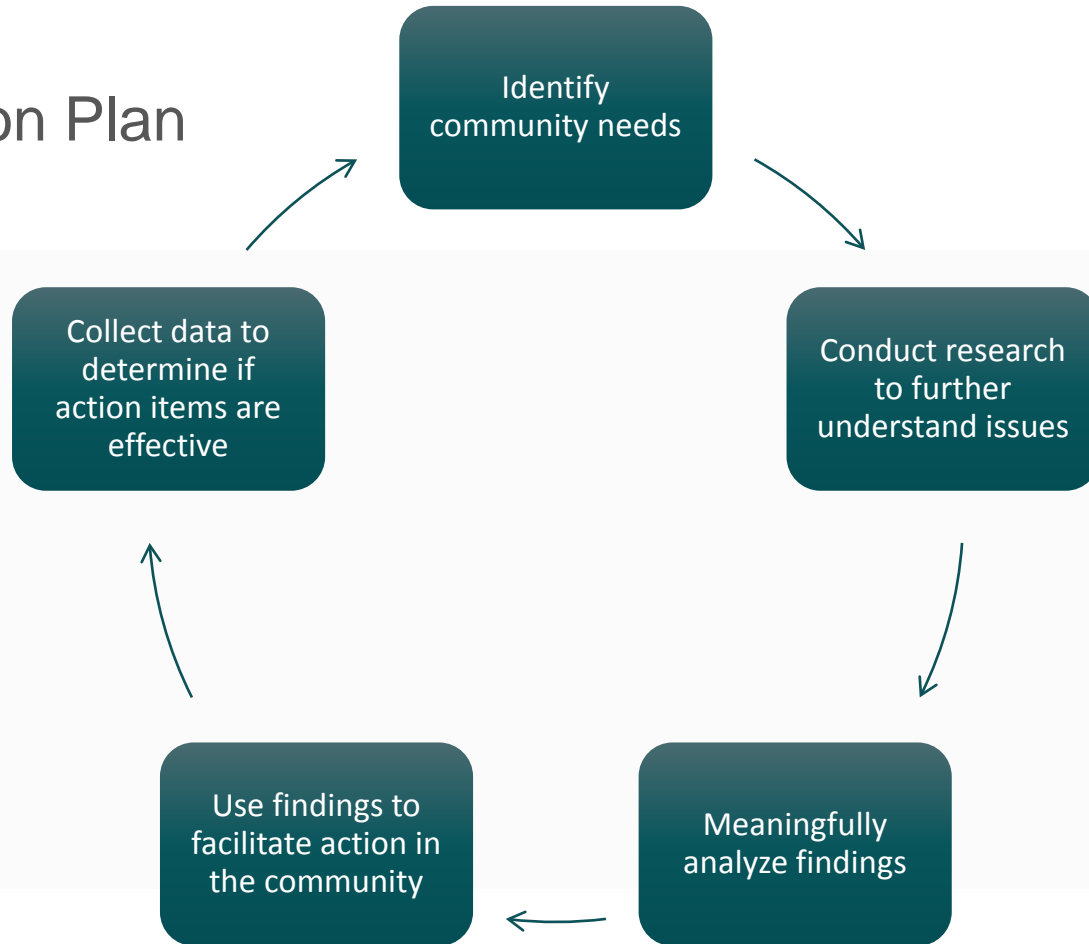
- Convene community leaders to drive action on specific areas of need
- Provide an environment designed for these leaders to **collaborate, connect and implement** actionable goals



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TPI's Community Action Plan

TPI Community Action Plan



A large, stylized, light gray palm tree graphic is centered in the background, spanning across the top and bottom of the slide. The palm fronds are long and thin, radiating from a central point. The trunk is a simple vertical line. The overall style is minimalist and modern.

The Orange County Transition Initiative

Sample TPI Action Project

Identified Community Needs

■ Initial needs assessment:

- Issues related to transition of youth with disabilities
 - Employment of young adults with disabilities
 - Post-secondary education
 - Independent living issues

■ Further research identified specific concerns



Specific Community Needs

(based on survey and focus group data)

Job development

-  Employee and employer support to develop jobs and maintain employment


Training improvements

-  Preparation starting early
-  Work-based learning- learn in setting

Accessible information for parents





Collaboration and Integration

-  Track outcomes across services

-  Share data and expertise across agencies

-  Shared programming

Better understanding/research:

-  Career pathways and trajectories
-  How we prevent disconnection?
-  Impact of co-occurring dx
-  Safety issues- understand the risks

Facilitating Action: OCTI Leadership Group

TPI, with our community partners, facilitate a group to develop hands-on solutions

- Includes all relevant stakeholders
- Working to mobilize community partnerships and establish better support
- Developing forum to provide information and access to already available services
- Early Progress—developed sub-committees in:
 - Employment
 - Training and education



Determining our Impact: OCTI Leadership Group

- Collecting data on the process of developing a community action model
- Tracking outcomes of our efforts
- Using data to inform next steps
AND lead the community and nation in addressing these needs

Why is autism prevalence important?

Let's take a look!

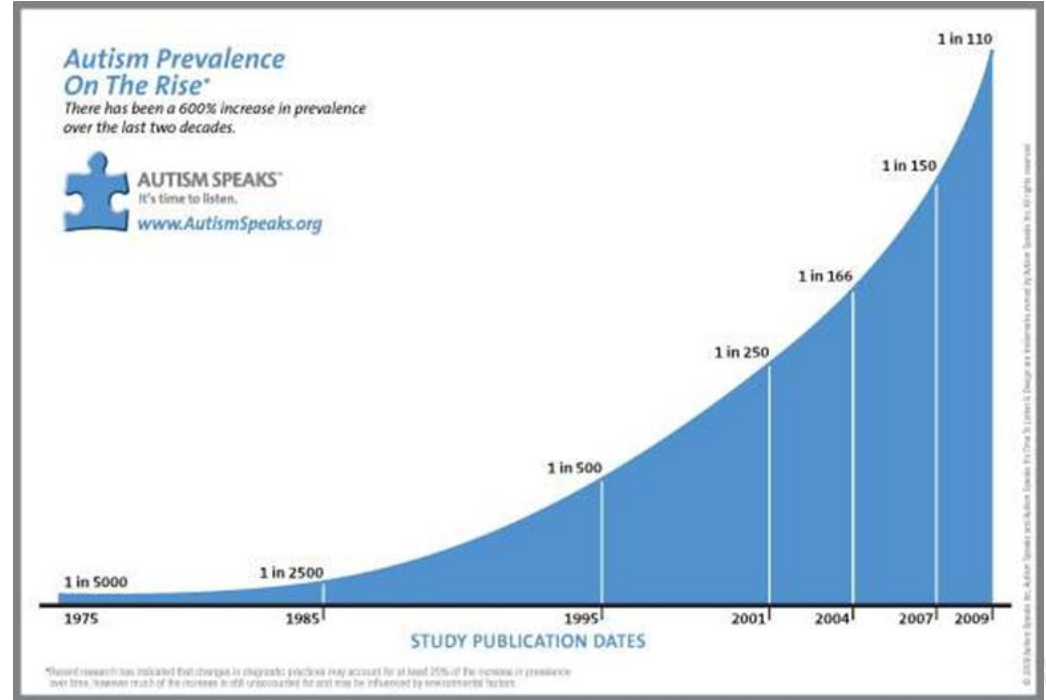


**“What's behind the dramatic rise
in autism cases?”**



with SCOTT PELLEY

"Autism prevalence as reported in the scientific literature has increased by more than 600%."



Autism Cases on the Rise; Reason for Increase a Mystery

Scientists are scouring genetic and environmental data to find a cause for the rise in autism.





With Current Rise in
Autism Rates “Should
All Babies Be Screened
for Autism?”



CHAPMAN
UNIVERSITY

THOMPSON POLICY INSTITUTE





STATE LEGISLATURES

The national magazine of policy and politics

- Thirty-six states established a task force or commission on autism.
- Twenty-seven states have an active legislative standing committee to address autism needs and policies.
- Thirteen states created a bureau or agency to administer or coordinate autism services.
- Some states have developed registries to track diagnoses and treatment.
- **Hundreds of millions of dollars are being spent to understand the autism increase.**

A stylized sunburst or starburst graphic in a light gray color, centered behind a teal horizontal band. The rays of the sunburst extend across the entire width of the image.

Let's learn the facts.

Is there really an alarming increase in autism?

Identified Prevalence of Autism Spectrum Disorder

ADDM Network 2000 – 2012


Combing Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5–9.9)	1 in 150
2002	1994	14	6.6 (3.3–10.6)	1 in 150
2004	1996	8	8.0 (4.6–9.8)	1 in 125
2006	1998	11	9.0 (4.2–12.1)	1 in 110
2008	2000	14	11.3 (4.8–21.2)	1 in 88
2010	2002	11	14.7 (5.7–21.9)	1 in 68
2012	2004	11	14.6 (8.2–24.6)	1 in 68

2000: 1 in 150

2010: 1 in 68

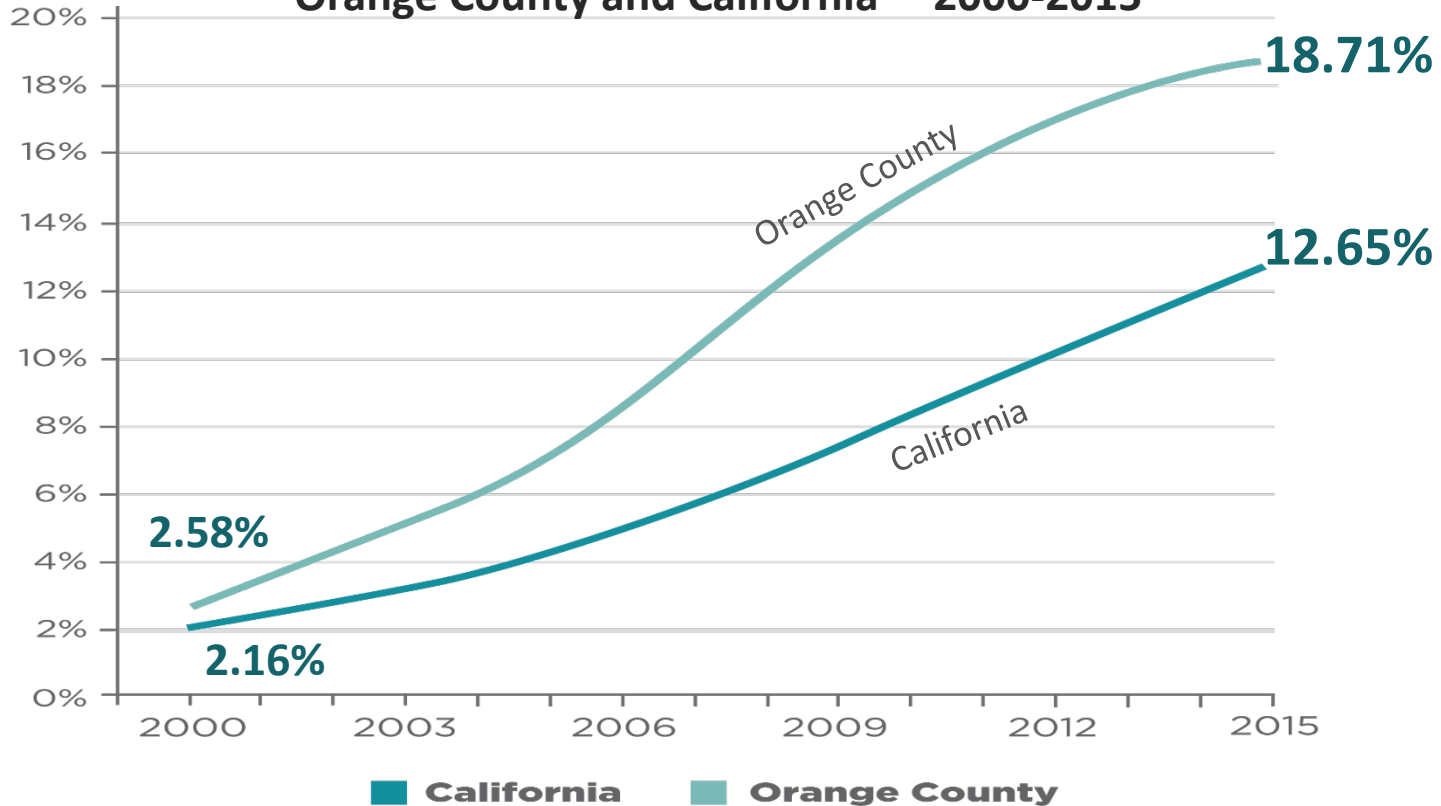


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What about...

California and Orange County

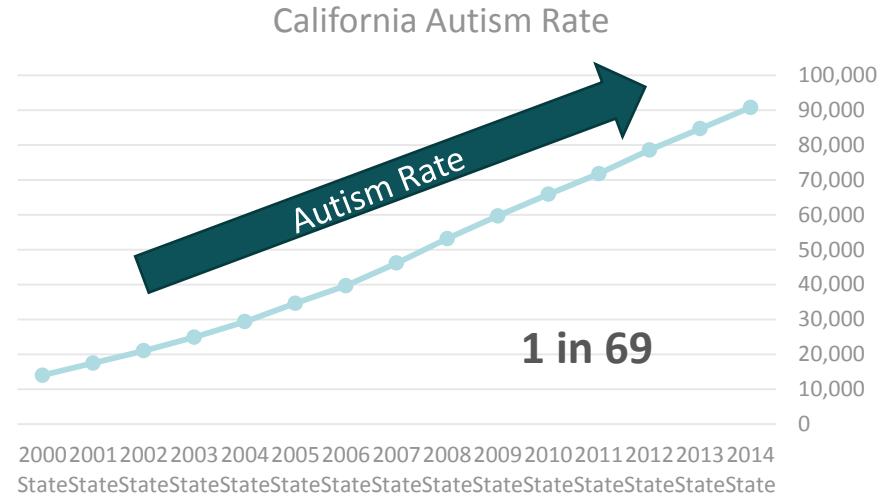
Percent Autism in Special Education Orange County and California 2000-2015



Autism as a total of special education enrollment 2000 - 2015

In 15 years, Autism has increased
from 2.16% of all special education
in California to 12.65%. (+76,755)

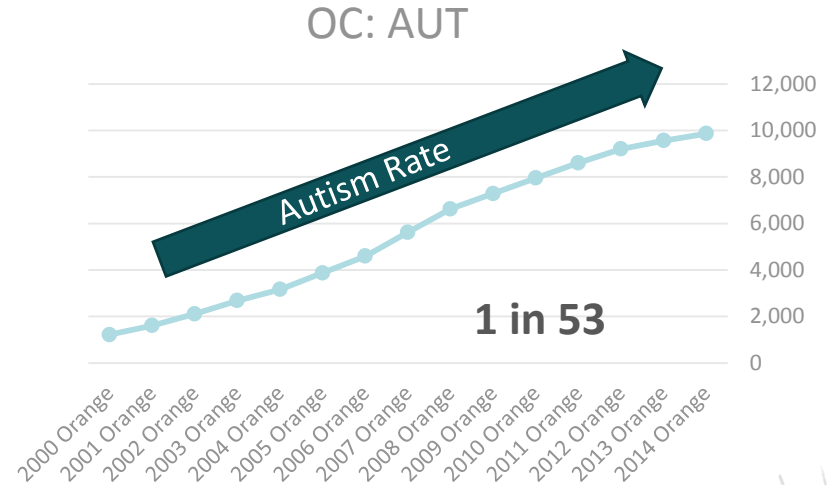
584% over 2000 rate!



Autism as a total of special education enrollment

In 15 years in the OC, Autism has increased from 2.58% of all special education to 18.71%. (+8,653)

812% over 2000 rate!



What's going on?

- The environment?
- Childhood vaccinations?
- An epidemic?
- An awakening of perceptions by the public? (it has been there, we just didn't see it)
- Diagnostic definition changes
- Parental age?
- Connected to ethnicity? Bias? Genetic drift?



A stylized, light gray sunburst or starburst pattern is centered in the upper half of the image. It consists of numerous thin, radiating lines of varying lengths, creating a sense of depth and movement. The background is a solid light gray.

Assessing the autism landscape

The initial ADDAP's Model

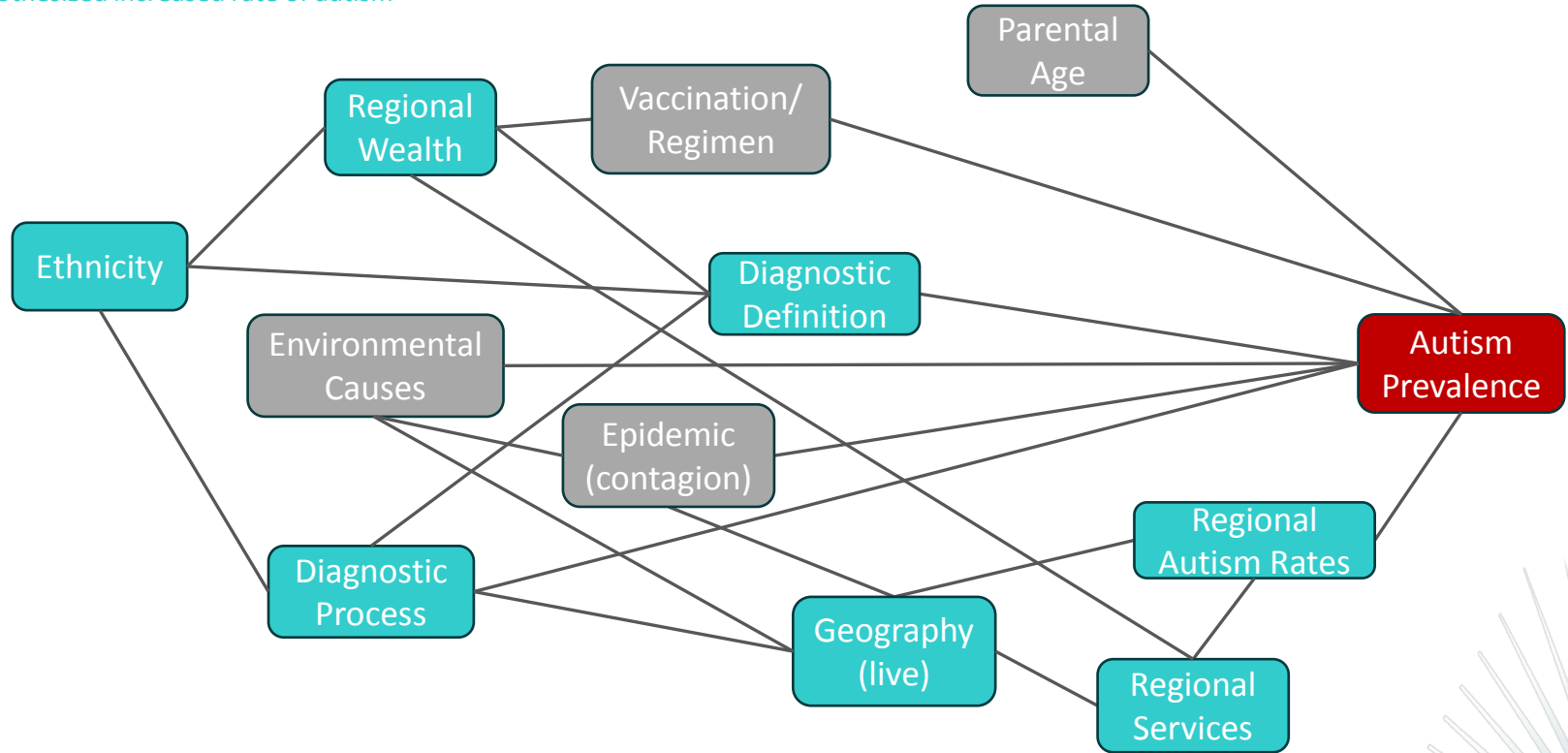
Model of Hypothesized Contributing Factors



Hypothesized to cause of autism



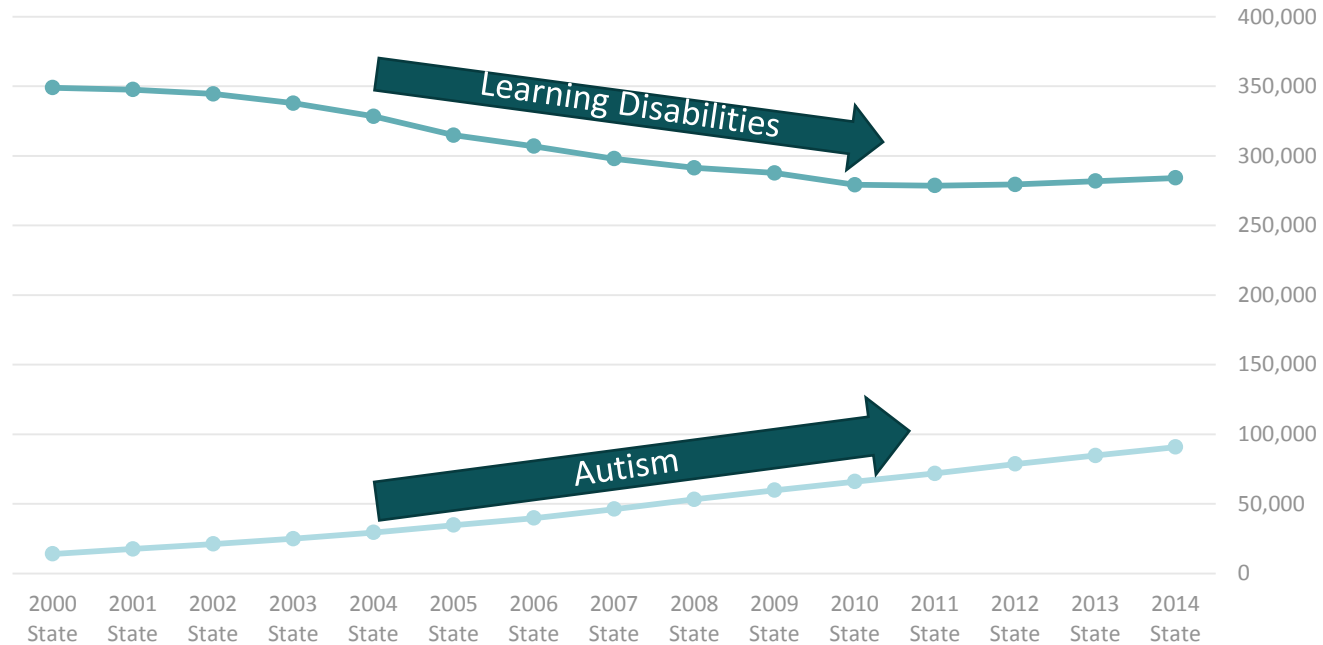
Hypothesized increased rate of autism



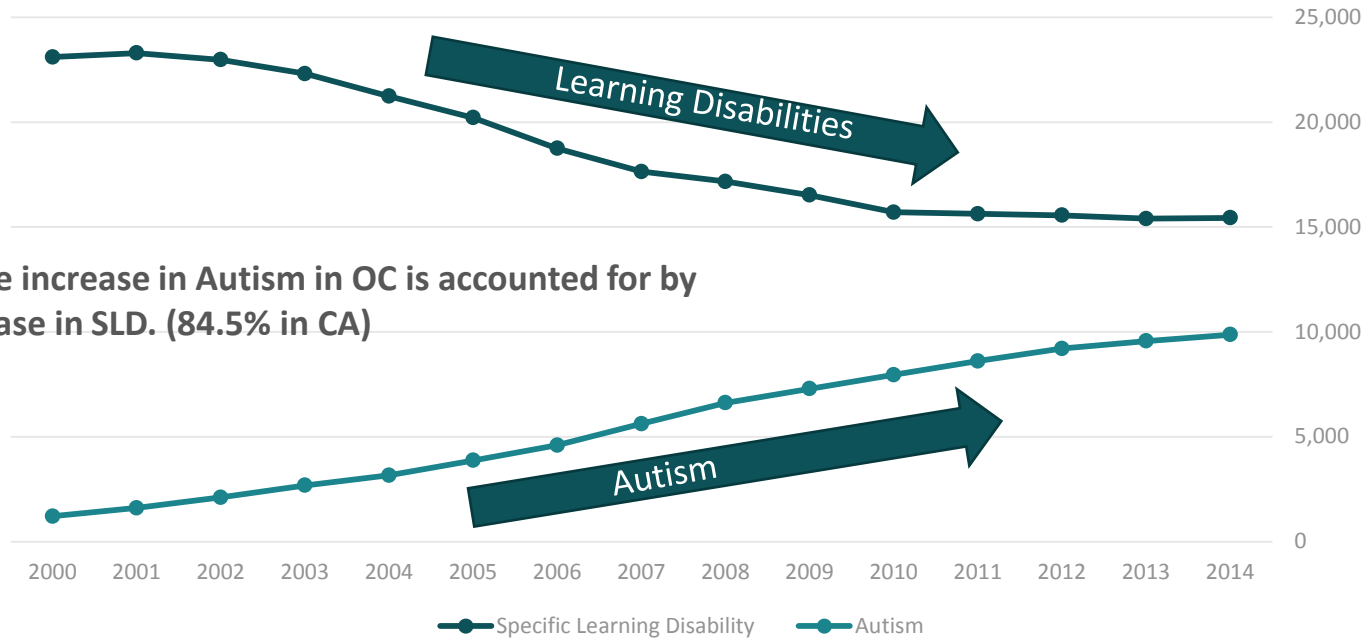
Our findings identify a process variable,
Diagnostic Migration, as a strong explanation
of the increase of autism rates.



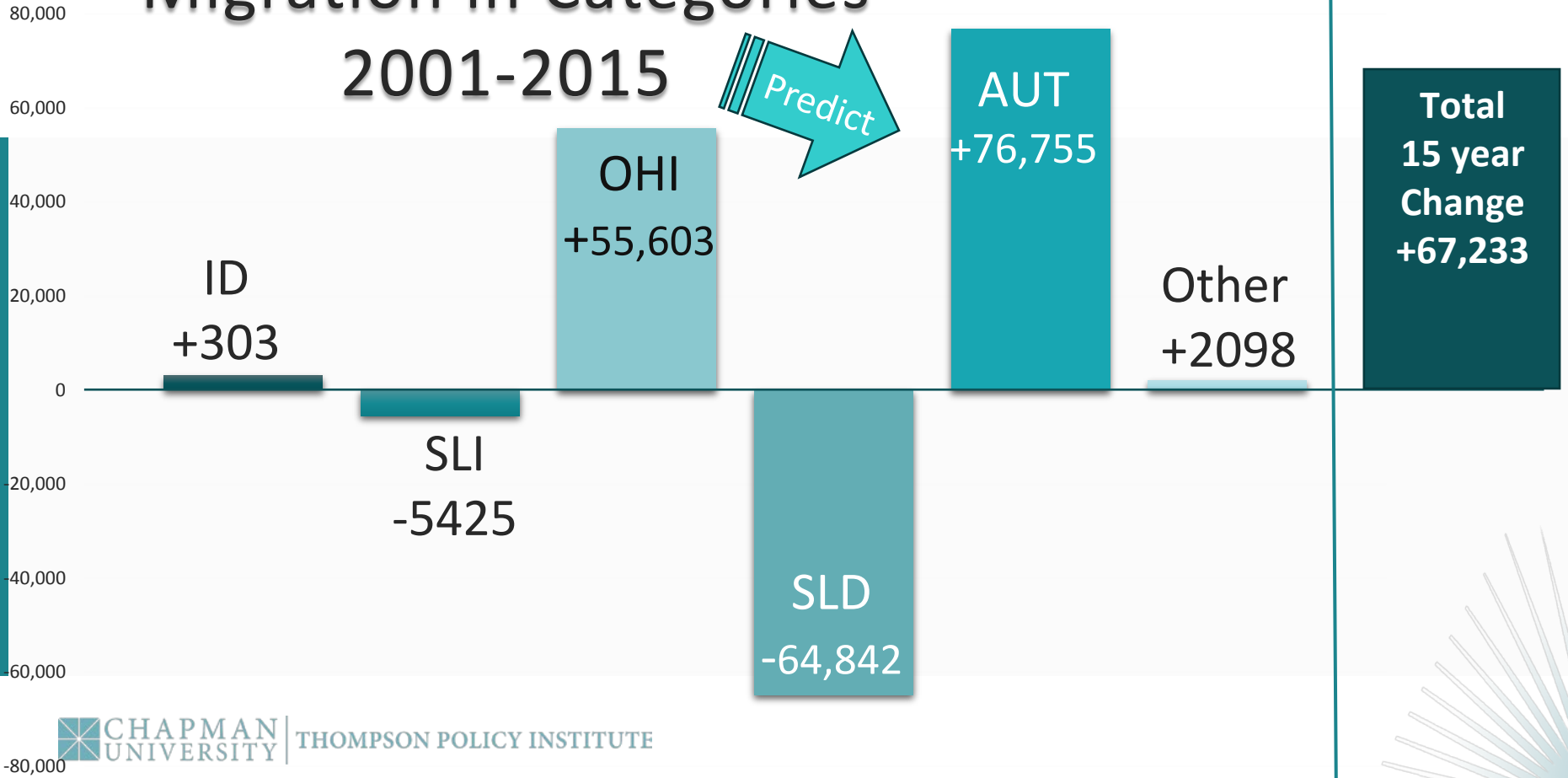
California SLD and AUT Trends



Orange County SLD and AUT Trends



Migration in Categories 2001-2015



Summary of findings

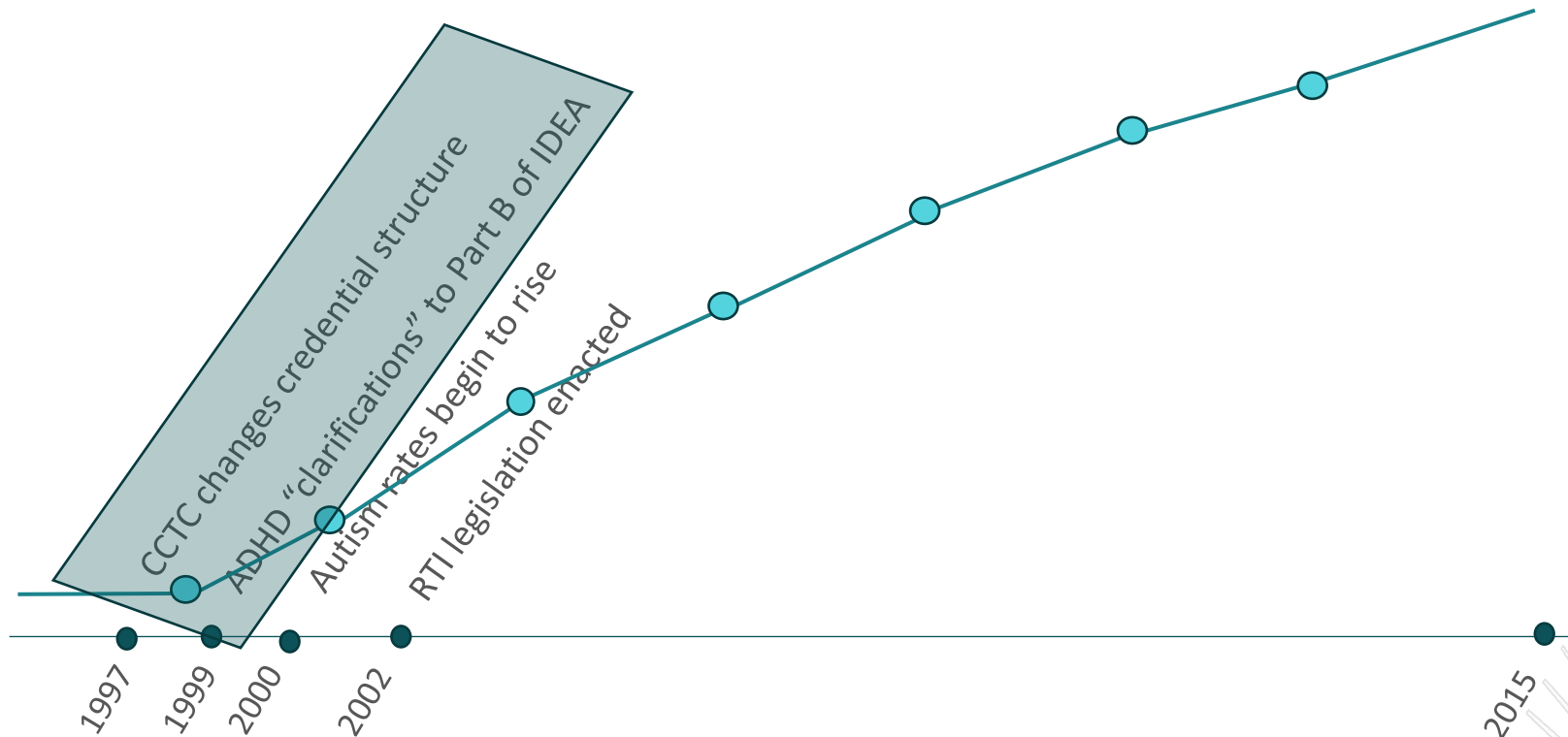
- Contrary to media reports, the increase of autism is not adding kids to the number of children with disabilities.
- The increased rate of autism can be strongly explained by migration within disability categories. Diagnostic Migration.
- Environmental and human contributions likely do not account for an important increase in autism rates.
- Other disability categories are as important as autism to consider in policy.










Policy matters

Diagnostic migration coincides with past policies



TPI research/action teams

-  Transition to work
-  Autism prevalence
-  Supported/independent living
-  School and community inclusion
-  Information clearing house



Importance of community partnerships

- Our transition study of family concerns has initiated meaningful community action.
- Without mailing lists from RCOC and other agencies, the study would not have been as effective.
- We are more credible and powerful together.
- Our work is not competitive, but collaborative. We are not teams, we are the team, together.



Thank You

Thompson Policy Institute
On Disability and Autism

Chapman University

