Presentation to the
Board of Directors
Orange County Regional Center

Thompson Policy Institute on Disability and Autism

September 1, 2016
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
TPI’s Community Action Plan
TPI
Community Action Plan

1. Identify community needs
2. Conduct research to further understand issues
3. Collect data to determine if action items are effective
4. Use findings to facilitate action in the community
5. Meaningfully analyze findings
6. Collect data to determine if action items are effective

CHAPMAN UNIVERSITY | THOMPSON POLICY INSTITUTE
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?”
“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?”
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.
Let’s learn the facts.

Is there really an alarming increase in autism?
### Identified Prevalence of Autism Spectrum Disorder

**ADDM Network 2000 – 2012**  
Combining Data from All Sites

<table>
<thead>
<tr>
<th>Surveillance Year</th>
<th>Birth Year</th>
<th>Number of ADDM Sites Reporting</th>
<th>Prevalence per 1,000 Children (Range)</th>
<th>This is about 1 in X children...</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>1992</td>
<td>6</td>
<td>6.7 (4.5 – 9.9)</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2002</td>
<td>1994</td>
<td>14</td>
<td>6.6 (3.3 – 10.6)</td>
<td>1 in 150</td>
</tr>
<tr>
<td>2004</td>
<td>1996</td>
<td>8</td>
<td>8.0 (4.6 – 9.8)</td>
<td>1 in 125</td>
</tr>
<tr>
<td>2006</td>
<td>1998</td>
<td>11</td>
<td>9.0 (4.2 – 12.1)</td>
<td>1 in 110</td>
</tr>
<tr>
<td>2008</td>
<td>2000</td>
<td>14</td>
<td>11.3 (4.8 – 21.2)</td>
<td>1 in 88</td>
</tr>
<tr>
<td>2010</td>
<td>2002</td>
<td>11</td>
<td>14.7 (5.7 – 21.9)</td>
<td>1 in 68</td>
</tr>
<tr>
<td>2012</td>
<td>2004</td>
<td>11</td>
<td>14.6 (8.2 – 24.6)</td>
<td>1 in 68</td>
</tr>
</tbody>
</table>
What about…
California and Orange County
Percent Autism in Special Education
Orange County and California  2000-2015

- Orange County: 2.16% to 18.71%
- California: 2.58% to 12.65%

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

584% over 2000 rate!
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?
Assessing the autism landscape
The initial ADDAP’s Model
Model of Hypothesized Contributing Factors

- Autism Prevalence
  - Regional Autism Rates
  - Regional Services
  - Parental Age
- Hypothesized to cause of autism
  - Regional Wealth
  - Vaccination/Regimen
  - Diagnostic Definition
  - Environmental Causes
  - Epidemic (contagion)
- Hypothesized increased rate of autism
  - Ethnicity
  - Diagnostic Process
  - Geography (live)
Our findings identify a process variable, Diagnostic Migration, as a strong explanation of the increase of autism rates.
California SLD and AUT Trends

- **Learning Disabilities**
- **Autism**

[Graph showing trends for Learning Disabilities and Autism from 2000 to 2014]
Orange County SLD and AUT Trends

89% of the increase in Autism in OC is accounted for by the decrease in SLD. (84.5% in CA)
Migration in Categories 2001-2015

- ID: +303
- SLI: -5425
- OHI: +55,603
- SLD: -64,842
- AUT: +76,755
- Other: +2098
- Total 15 year Change: +67,233
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

- CCTC changes credential structure
- ADHD "clarifications" to Part B of IDEA
- Autism rates begin to rise
- RTI legislation enacted
TPI research/action teams

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