



INAUGURAL
**DISABILITY
SUMMIT**

2016 SUMMARY OF FINDINGS



Dear Community Members:

As current or past legislators and decision-makers who attend to matters in disability, we wish to express how important it is to obtain independent and reliable information to guide decision-making in public policy. We especially need independent information that is targeted to specific matters of concern in disability, that is scientifically supported, and that is prepared with input from those with disabilities, their families, other caregivers, and professionals in the field.

Two reasons why independent, high quality and clear information is needed more than ever before:

- The amount of information on every topic has increased dramatically. Making sense of thousands of pages of data has become a much more complex task. To be able to rely on a credible group working daily to summarize this massive amount of data and present it in a fair and clear manner is central to making well-informed decisions.

- The popularity of social media has created a second critical issue. Often, certain information receives a disproportionate amount of attention in social media with the result that this, often incomplete, information is taken to be factual. A sense of urgency arises to develop policy to fix the *perceived* problem. Clear, rigorous and independent information on these topics will allow us to make reasoned and thoughtful decisions on important topics in disability, allowing us to separate sensation from facts.

Policy matters. It forms the basis for our social response to problems. The decisions we are charged to make can have a profound impact on people with disabilities. The more accurate, timely and useful the information we have, the better we can represent the disability community and thus society in general. We thank the Thompson Policy Institute for their commitment to providing this much needed, timely, clear and important information.



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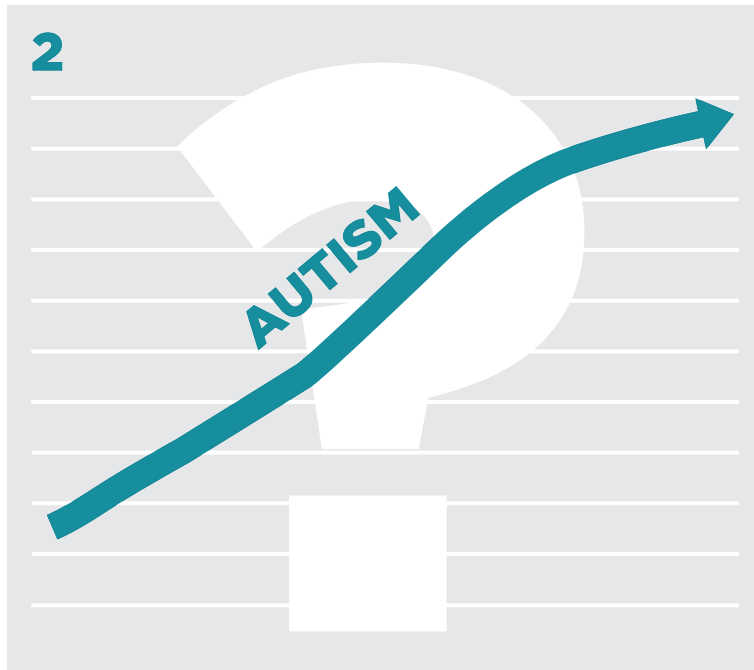
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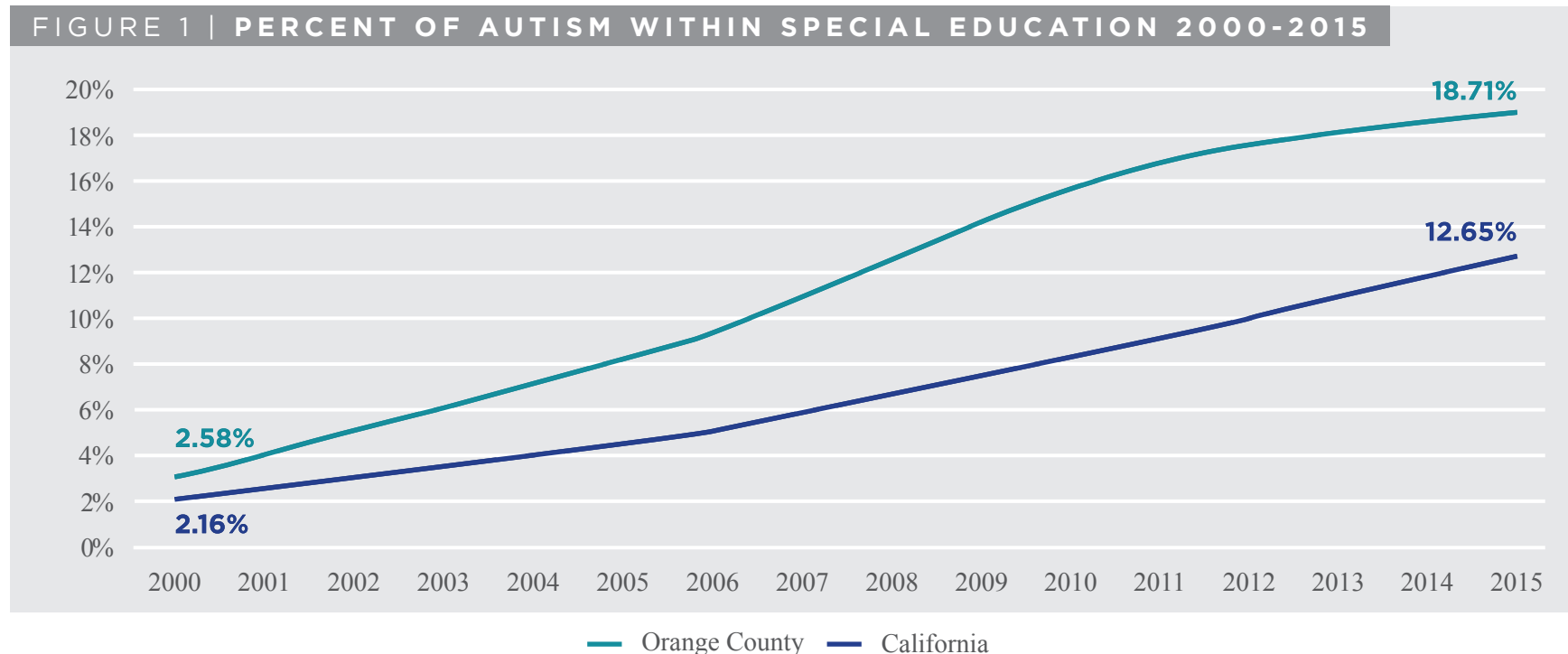
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WHY HAS THE RATE OF AUTISM INCREASED SO DRAMATICALLY? IT MAY NOT BE WHAT YOU THINK.

The substantial increase in the rate of autism in the U.S. and in many countries around the world has thoroughly grabbed the attention of every segment of our society. Most of the conversation is highly focused on the important question, what is causing this alarming increase in the rate of autism? Nearly every news source has covered the topic, and the professional literature has responded with study after study. The internet, social media and the blogosphere is loaded with speculation as to the cause of this condition that has so captivated our consciousness.

That the rate of autism as a diagnosis has increased at an unprecedented, and some say alarming, rate is without question. The most cited source is the Center for Disease Control and Prevention (CDC). The CDC's Autism and Developmental Disabilities Monitoring (ADDM) longitudinal study was updated in March, 2016, and again concludes the rate of autism prevalence is 1 in 68 in the U.S. The National Center for Health Statistics in 2015 reported an even more staggering rate of 1 in 45 and another CDC funded study reports 1 in 50 children has the



diagnosis of autism. One can easily see why the public and professionals are alarmed and often perplexed!

The results of the 2016 Thompson Policy Institute's (TPI) prevalence study conclude that in California the current rate is approximately 1 in 69 (68.68) among school age children and youth, and in Orange County, 1 in 50 (50.4), the highest rate in California and among the highest in the country. The Orange County autism rate is 19.8 per 1000 among school-aged children, rising from a rate of 2.46 per 1000 in the 2000 year. Orange County's rate of autism has multiplied by eight times since 2000. In terms of the rate of autism compared to all children in special education, the 2015 rate is 12.54% in California and 18.71% in Orange County. See Figure 1.

STUDY METHODS

TPI researchers created the ADDAP (Autism and Developmental Disabilities Analysis of Prevalence) model from the current literature to map what factors have been suggested and/or studied as contributing factors to explain the unexpected increase in the rate of autism. Since the topic is of international importance, we examined U.S. studies along with studies from other countries which published their results in

English. The model considers the conditions we found that reportedly try to explain the increase in rate of autism. We included them even when we felt the study was actually better designed to explain the reason autism exists, not why the rate has increased. Figure 2 shows the reported relationships of the conditions studied to the increased rate of autism. We did not include genetic-based studies since they did not explicitly state their results can help predict the increased rate of autism.

Each variable (condition) was evaluated by using the results within the existing literature or through new studies conducted by TPI. We systematically evaluated each study on their goodness-of-fit in explaining the increase in autism rate. Many of the studies we found or conducted ourselves provided useful insight, but they did not help explain the increase rate of autism. Vaccines, environmental influences, regional wealth, proximity to autism centers, ethnicity, etc., were interesting and do add to our understanding of other questions related to autism and other disabilities, but, again, they did not help explain the rate of increase of autism.

What seemed critical from the literature is the suggestion that the increase in autism rate was not due to environmental reasons, but through the diagnostic and categorical assignment processes. While studies as far back as 2002 (M.I.N.D. Institute) focused on changes to

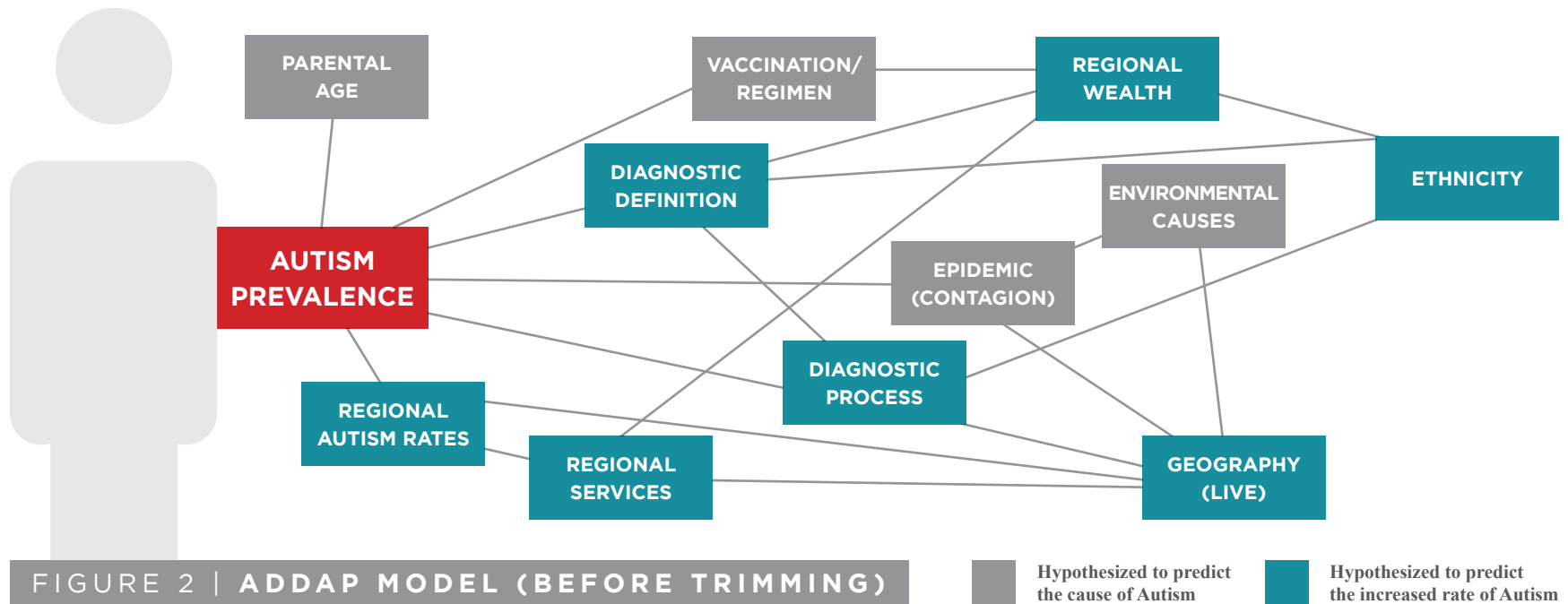


the Diagnostic and Statistical Manual of Mental Disorders (III and IV) found no significant relationship between the change and the increase in autism rate. A 2014 study completed in Denmark found that the diagnostic process had a significant and large impact on autism rate (Hansen, Schendel Parner, 2014). To examine this phenomenon in depth, we gathered data from the evaluation of children 3-22 years of age in California schools over the most recent 15-year period, 2000-2015. This analysis provided a sample of 717,233 students in special education in 2015. Across all 15 years, we analyzed data representing more than ten million student eligibility designations (the total special education population in California over the 15 year period).

WHAT ARE THE RESULTS OF THE TPI AUTISM PREVALENCE STUDY?

The TPI study of prevalence resulted in several revealing outcomes.

- The number and rate of children with autism, 3-22 years of age, in California and in Orange County has increased six and eight fold, respectively, over the latest 15-year period (see Figure 1).
- While the rates of autism have increased dramatically over this time, the total number of students in special education has not. In fact, the number of students in special education has increased



less than the general population, .69 percent per year in special education compared to .96 percent per year in the general California population. **Surprisingly, the increase in autism rate has not resulted in more students in special education.**

- Nearly all of the increase in the number and rate of children with autism has been found to be the result of a shifting of categories, a migration from one eligibility group to another. This migration does not mean a specific child's label has changed, but over time, children who would have been considered eligible for the category, specific learning disability, for example, were instead considered eligible for the autism category.
- Approximately 99 percent of the increase in autism can be statistically explained, $R^2=.987$, by the resulting decrease in Specific Learning Disabilities (SLD) and the increase in Other Health Impaired (OHI²).

WHAT IS THE KEY FINDING OF THIS STUDY?

The dramatic increase in rate of autism in both California and Orange County can be almost completely explained by a decrease in another eligibility (diagnostic) category (see Figures 3 and 4). There is no new significant group of children being removed from the general education population and being added to special education as some reports suggest. Instead, it appears that kids who are receiving the diagnosis

of autism today would have still been eligible for special education in earlier years, but within a different eligibility category, in this case, Specific Learning Disabilities. The category of OHI (ADHD2) has grown almost as much as has autism. This increase is also the result of the migration from the SLD category. We are calling this effect, Diagnostic Migration, which can account for almost all of the new cases of autism and ADHD. See Figures 5 and 6.

STATISTICAL ANALYSIS OF RESULTS

While we used many statistical analyses to get to this point, we present the results here of the multiple linear regression since it was used to predict the variance in the dependent variable, Autism Rate. Only three independent variables qualified to enter the equation, Specific Learning Disability (SLD), Other Health Impaired (OHI) and Speech Language Impaired (SLI). SLI did not serve to explain any additional variance in the dependent variable and thus was dropped from the model (but is worthy of future study). No other variable considered in the model, and for which we had data, had a significant single-order correlation to Autism Rate.

Our results indicated that when taken together, SLI and OHI explained 98.7 percent of the variance of Autism Rate ($R^2=.987$, $p<.01$). In the larger ADDAP Model (see Figure 2), we used an adjusted R square analysis to trim our model. Only Diagnostic Process survived the model trimming process. Diagnostic Process was then defined and



FIGURE 3 | CALIFORNIA SLD AND AUTISM TRENDS

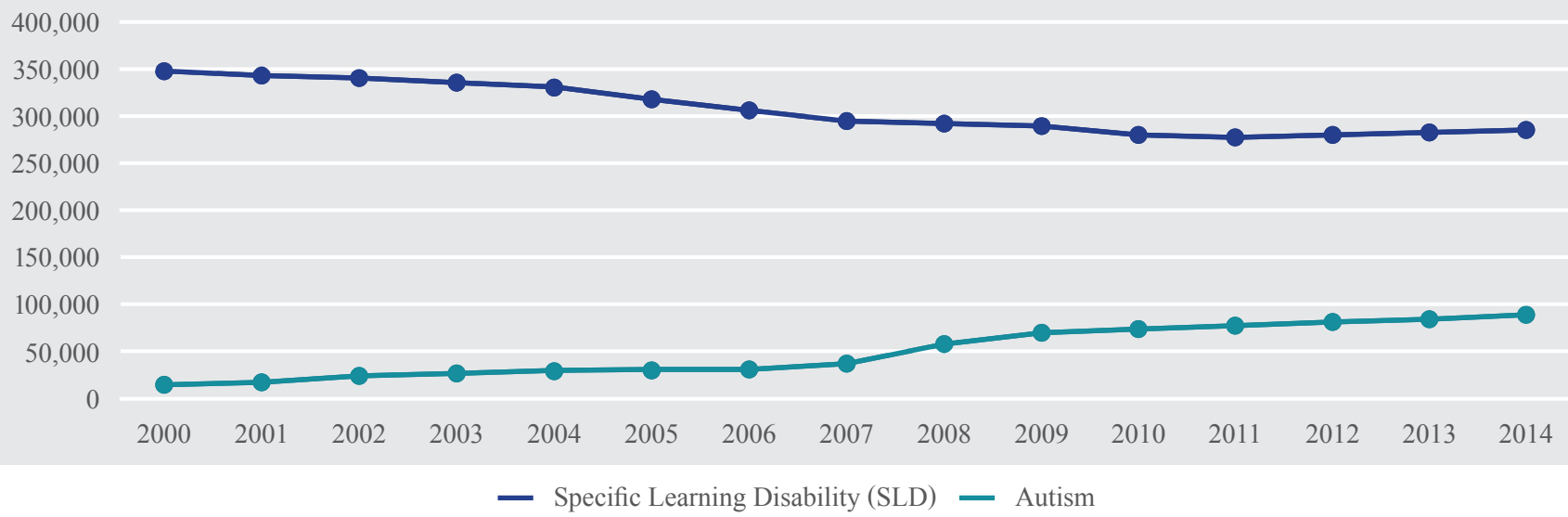
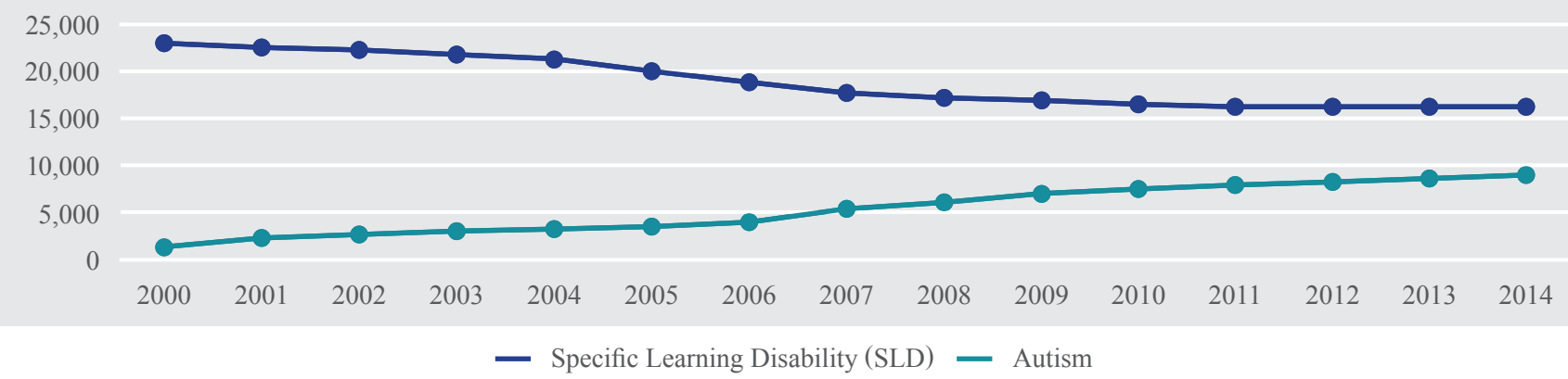


FIGURE 4 | ORANGE COUNTY SLD AND AUTISM TRENDS



data gathered for all 13 disability categories for California and Orange County, for all children 3-22 years of age over a 15-year period. No sampling methods were used, we only analyzed data from the full population representing over 10 million data points.

**UNDERSTANDING DIAGNOSTIC MIGRATION:
WHAT SPECIFICALLY IS GOING ON?**

- All children and youth in special education are assigned to a primary category, a label if you will. While the total special

education enrollment across all categories has remained constant when considering general population growth, the number of children in some categories have decreased and others, such as autism, have increased.

- Only one category has substantially decreased in numbers and proportion, specific learning disabilities (SLD). SLD has decreased by 64,842 kids since 2000. The SLD label is assigned to kids who do not have an intellectual impairment, but who perform below expectations on academic performance measures.

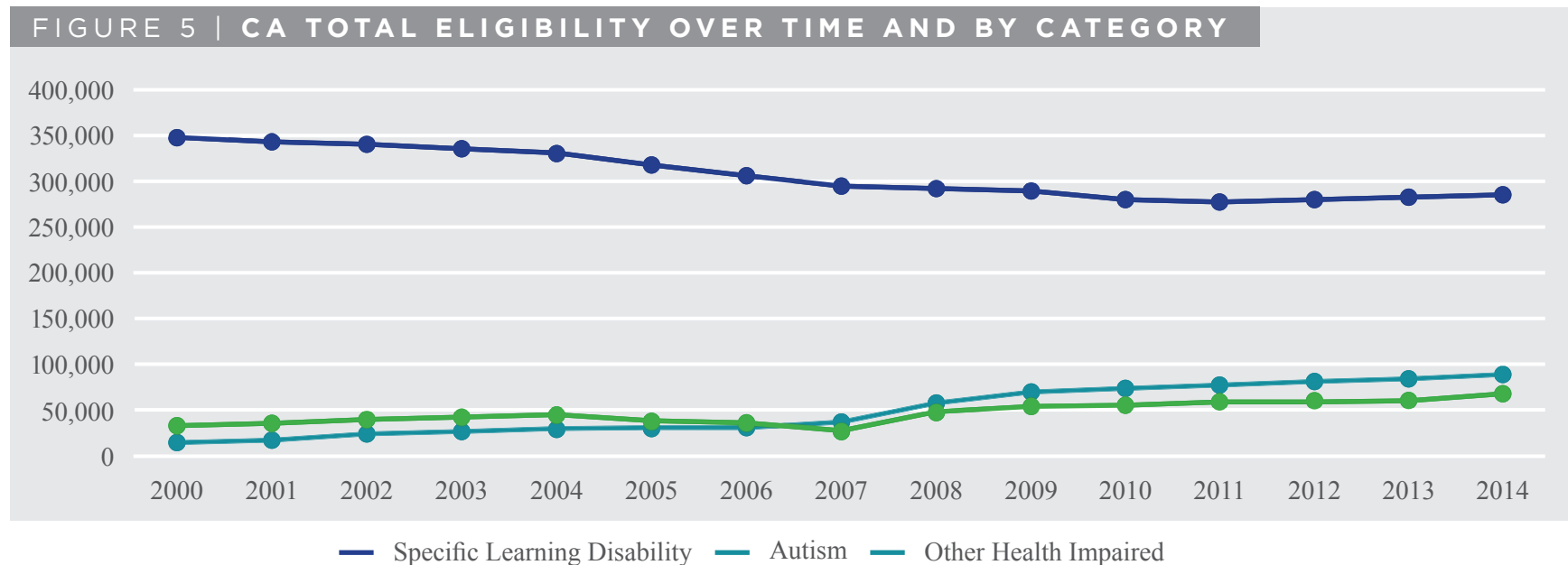
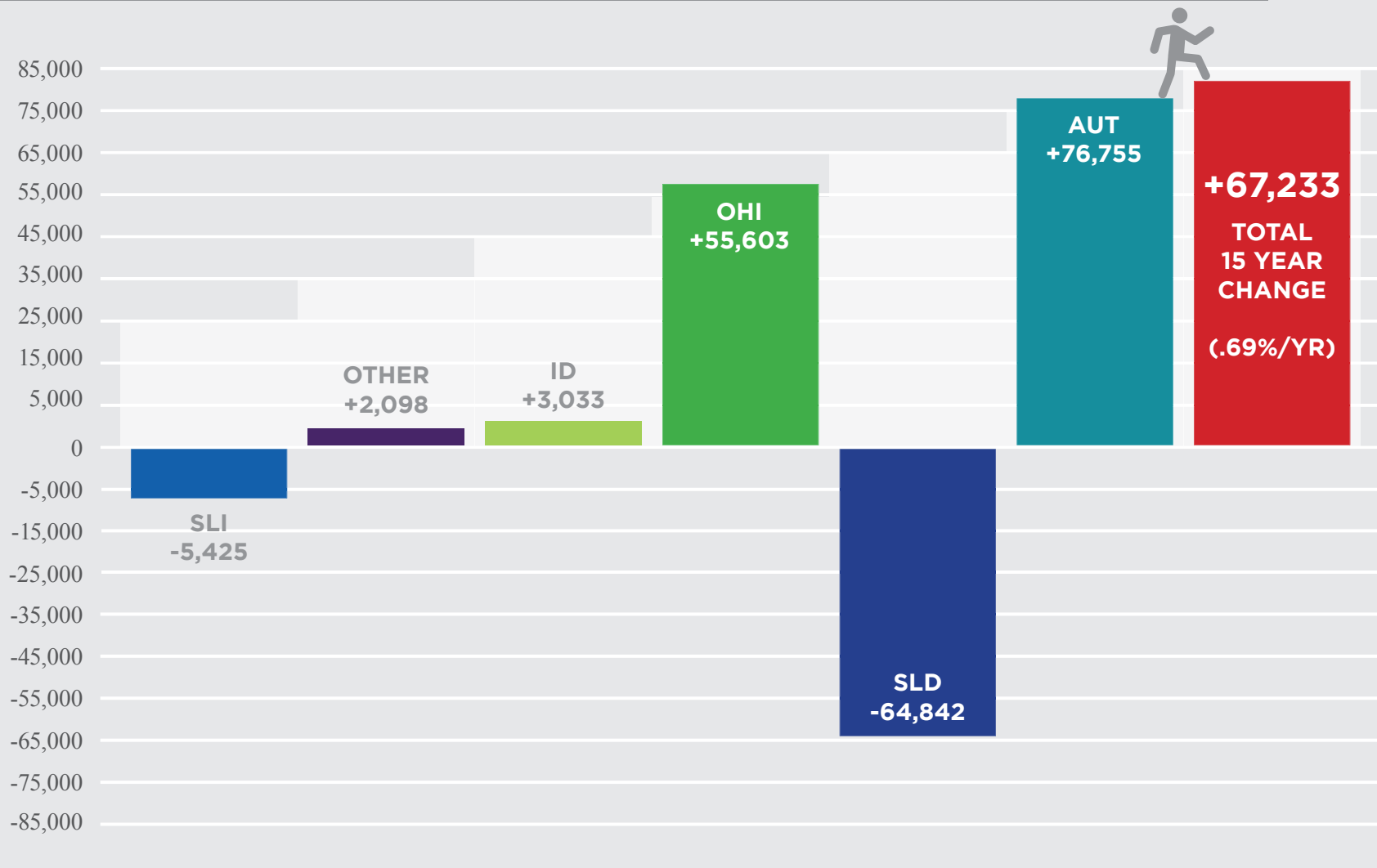


FIGURE 6 | DIAGNOSTIC MIGRATION BY ELIGIBILITY CATEGORY 2000-2015



- Two categories have substantially increased in numbers over the same time period. Autism has increased by 76,755, over six times the number in 2000. The category of Other Health Impaired (OHI) has increased by 55,603 kids, over four times the number of 15 years ago. We believe it is accurate to say that this increase in OHI is actually an increase in ADHD. (see Figure 6)
- The Diagnostic Migration strongly explains the alarming increase in the autism rate among children in California, and likely the nation, and draws attention to another significantly increased category of OHI (ADHD).

CAN THESE RESULTS GENERALIZE TO THE NATIONAL POPULATION?

Due to California’s demographics, large size, as well as the extremely large size of the TPI sample, we believe these results can be applied nationally. Even an international significance can be argued given the size of California is roughly five times the size of Denmark and about three-quarter’s the size of England, two countries that contribute significantly to the professional literature in understanding the increased rate of autism worldwide. Additionally, the total population of this current study, roughly 700,000 children per year, make the results compelling. However, additional research is needed on a national level.

USE CAUTION WHEN REFERRING TO THESE AND OTHER STUDY RESULTS

As researchers, we are trained to be cautious when examining the “cause” of any phenomenon. This current TPI study is no exception. It does not look at the cause of autism, rather, we are searching for the reason(s) for the increase in the rate of autism. These are very different, and we believe for policy and practical reasons, why the rate of autism has increased so dramatically is the main question on which to focus. The TPI analysis attempts to explain why there has been such an enormous increase in autism prevalence. But this does not explain the cause of autism.

WHAT ARE THE POLICY IMPLICATIONS?

Schools: The results of this current study strongly suggest that the eligibility categories for children in special education has dramatically shifted over the latest 15 years. The shift, or migration, in California is focused almost exclusively on three eligibility categories, SLD, Autism and OHI. In 2000, the mix of these three eligibility categories was 54%, 2% and 3%, respectively. Fifteen years later, the same mix migrated to 40%, 13% and 11%, respectively. Note that these three categories, as a combined number, still account for roughly the same proportion of the special education population, 59% in 2000 and 64% in 2015



(the majority of the increase from 59% to 64% was due to a decrease in the eligibility category, Speech or Language Impairment, over the same time). The migration shift in California has differentiated the largest single eligibility category in special education (SLD) into three categories. Orange County had a very similar pattern. The policy impact on teacher preparation to accommodate this migration is significant. As well, policies of school districts, special education local planning areas (SELPA) and county departments of education must ensure that they leverage this shift in how they assign least restrictive classroom assignment configurations. IEP teams as well can take advantage of this shifting eligibility by considering the more individualized accommodations that this greater specificity in categories provide. Taken together, if we properly align our policies and procedures to this new information, children will reap the rewards of a more specific and personalized education plan. Our current observation is that local school budgets are being forced to fund these new service models, especially in autism programs. However, no new state or federal money is being allocated to offset these additional costs. This potentiality, if not already a reality, must change or we risk the draining of funds in schools that are intended for other groups of kids. This is an unacceptable consequence of the diagnostic migration effect. New policy is needed and soon.

Adult Life: An eight-year-old receiving autism eligibility in the year 2000 would be an adult today. A sixteen-year-old would be 31 years old. It is not that an “autism bubble,” as some have called it, is about to land upon adult services, this group landed years ago, and they

keep populating adult services in even larger numbers. According to the Bureau of Labor Statistics, this is the most unemployed and underemployed group in America. Understanding what policies need to be developed or changed to create better supports for young and mature adults is an immediate need. We hear loud and clear that living accommodations and authentic work for a real livable wage are critical areas of need. Please see our initial work on Autism in the Workplace in this issue as a starting place.

SUMMARY OF FINDINGS

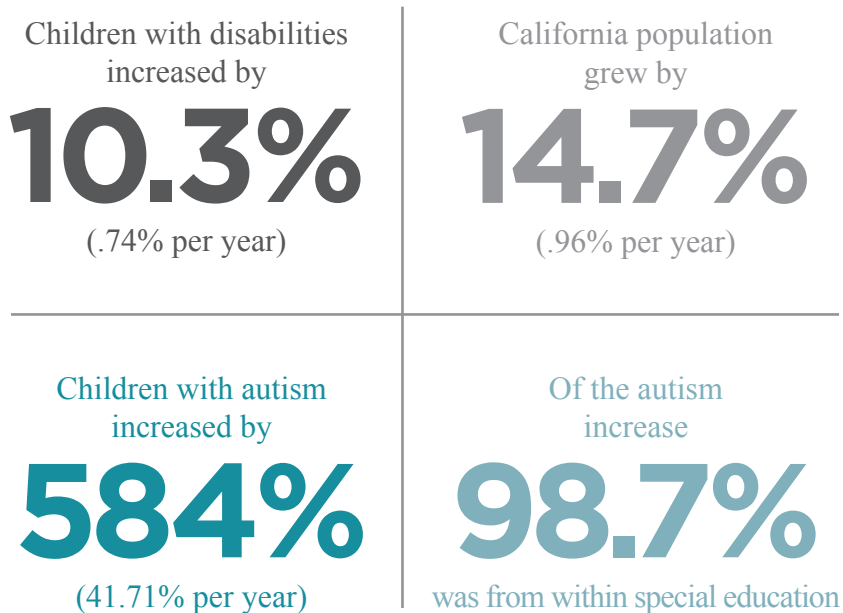
Figure 7 provides a graphic representation of our findings on autism prevalence. We have also included several points that summarize our findings and extend our thinking toward policy recommendations. The Thompson Policy Institute will continue our work with the community to help develop a plan to take advantage of this new information to provide positive change for people with disabilities.

- 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 do not account for an important increase in autism **rates**.



- Other disability categories are as important as autism to consider in policy.
- There are many more questions needing study before we fully understand autism. Medical research, educational practices, life supports and more are needed.
- Since diagnostic migration has added greater specificity to the eligibility process, we should begin developing public policy to leverage this new information.

FIGURE 7
SUMMARY FINDINGS 2000-2015



FOOTNOTES

¹ The correct phrase here, according to federal legislation, is determining “eligibility” for special education placement.

² While there are no specific data verifying that the OHI category increase is solely from students with ADHD, a recent survey of school psychologists in California strongly suggests that this is likely the population being represented by the OHI increase. Technically, OHI consists of individuals with chronic or acute health problems which adversely affects a child’s educational performance (34 CFR Part 300.5). However, Attention Deficit Hyperactivity Disorder is the largest group representing this primary disability category (using estimated prevalence rate from 2011 CDC study).

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S.N. Hansen, D.E. Schendel and E.T. Parner. *Explaining the increase in the prevalence of autism spectrum disorders: the proportion attributable to changes in reporting practices*. JAMA Pediatrics. Published online November 3, 2014. doi: 10.1001/jamapediatrics.2014.1893. Published online November 3, 2014.

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AUTISM IN THE WORKPLACE: A SPECIAL REPORT

Transitioning to increased levels of independence during young adulthood is an exciting and challenging time for everyone. For young adults with special needs, this transition period of new tasks and experiences can be particularly difficult. Over the next decade, about a half million people with Autism Spectrum Disorders (ASD) will reach adulthood¹. Many of these youth will be exiting their school district services and enrolling in post-secondary education programs, while others will be looking to enter the workforce. Most will continue to need some type of support to make progress and reach their goals.

The path to employment can be a significant concern for young adults with ASD and their families, as they navigate this unknown territory. Further, although many people with disabilities struggle to gain meaningful employment, recent research indicates that youth with ASD are experiencing increased difficulty in successfully transitioning to employment².

Some of the key outcomes experienced by this group include:

UNEMPLOYMENT, UNDEREMPLOYMENT AND LOWER PAY

Outcomes studies indicate that adults with ASD tend to have low rates of employment, are underemployed³ and for those who are employed they tend to have jobs that are poorly paid⁴. Furthermore, maintaining employment is of particular concern⁵.

EMPLOYMENT OUTCOMES INFLUENCE QUALITY OF LIFE OUTCOMES FOR THE YOUTH AND THEIR FAMILIES

As many aspects of our lives are interconnected, how we live, play, and work impacts our feelings of connection to our community and others. When young adults do not get a job or pursue post-secondary education they are referred to as disconnected. In a recent report, approximately, 37% of youth with ASD were disconnected, a much higher rate than their peers with other disabilities (less than 8% were considered disconnected).⁶ Meaningful employment is critical for adults with ASD, so that they may become engaged community members who lead happy and productive lives. Our employment experiences and choices are key ways in which we define ourselves in the community and are important in interacting with others.

85% of young adults with ASD still live with parents, siblings or other relatives.

The University of Miami/Nova Southeastern University CARD study, 2008

59% of children with ASD 16 years or older have not looked for work. **75%** of same age peers are already working.

Easter Seals' *Living with Autism Study*, 2008⁷



Related issues that need to be addressed include:

POOR COLLABORATION, COMMUNICATION, AND CONTINUED IMPLEMENTATION OF SERVICES ACROSS STAKEHOLDERS

Generally, there is a lack of collaboration between agencies that support young adults with ASD. Although some agencies are beginning to collaborate with one another in various parts of the country and there is some grant funding to support this movement, there is a significant need for enhanced communication and coordination across systems. In addition, some critical team players (parents, employers, the young adult with ASD, the local community, as well as the many service providers across the lifespan) are not always involved in the collaborations formed.

There are numerous evidence-based interventions available⁸ to assist in the employment of youth with ASD. In addition, many innovative employment models have been developed⁹, however, there appears to be a problem with successful implementation as well as a lack of continuation of services across systems. Some potentially useful and necessary services are lost or changed once these youth become adults. Investigators have found that nearly 40% of youth, who have benefited from services in the past, do not receive any mental health counseling, speech therapy, case management, or medical services related to their disability once they reach early adulthood¹⁰.

A LACK OF RESEARCH AND UNDERSTANDING ABOUT THE CAREER STAGES AND EXPERIENCES OF YOUTH WITH ASD

While much is known about early career stages for young adults without autism there is a dearth of research on the career stages of people with autism. It is imperative that we begin to understand the career stages and developmental experiences of youth with ASD so that we can identify successful paths to participation in meaningful employment.

\$268 BILLION

Cost per year for care of people with ASD in the US
Includes medical, nonmedical and productivity losses

\$1 TRILLION

Estimated cost by 2025

Journal of Autism and Developmental Disorders, 2015

\$1.4-2.4 MILLION

Lifetime cost of supporting a person with ASD

JAMA Pediatrics, 2014



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¹ Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

² Roux, A.M., Shattuck, P.T., Cooper, B.P., Anderson, K.A., Wagner, M., & Narendorf, S.C. (2013). Postsecondary employment experiences among young adults with Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(9), 931-939.

³ Taylor, J.L., & Seltzer, M.M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism & Developmental Disorders*, 41, 566-574.

⁴ See Reference #3

⁵ Taylor, J.L., Henninger, N.A., & Mailick, M.R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism*, 19(7), 785-793.

⁶ See Reference #1

⁷ Easter Seals' (2008). Easter Seals' Living with Autism Study. Accessed online on March 25th, 2016 at: http://www.easterseals.com/shared-components/document-library/key_findings_living_with_disabilities_study_low_res.pdf

⁸ Test, D.W., Fowler, C.H., Richter, S.M., White, J., Mazzotti, V., Walker, A.R., Kohler, P., & Kortering, L. (2009). Evidence-based practices in Secondary Transition. *Career Development for Exceptional Individuals*, 32(2), 115-128.

⁹ Gerhardt, P.F. (2009). The current state of services for adults with Autism. Accessed online on March 1st, 2016 at: http://www.afa-us.org/storage/documents/OAR_NYCA_survey_Current_State_of_Services_for_Adults_with_Autism.pdf

¹⁰ Shattuck PT, Wagner M, Narendorf S, Sterzing P, & Hensley M. (2011). Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatric and Adolescent Medicine* 165(2), 141-146.



A STEP IN THE RIGHT DIRECTION: UNDERSTANDING HOW A SUCCESSFUL TRANSITION TO MEANINGFUL EMPLOYMENT CAN BE ACHIEVED.

While there are organizations that focus on the school to work transition of young adults with ASD, little is known about quality and impact of the services received, as well as the young adults' pre-employment and employment experiences. Our study is designed to specifically focus on the current state of employment of youth with ASD in our community, Orange County and surrounding areas, as well as the availability and gaps in services required to support improved employment outcomes. Specifically, as it relates to young adults in our community we will be exploring the following general areas:

Family perceptions of:

- Young adult's pre-employment experiences during high school
- Youth's understanding of the world of work and career objectives
- Post-secondary education or training experiences
- Work experience/history
- Services used to gain employment or seek employment
- Challenges when searching for employment
- Types of services needed to assist in obtaining meaningful employment

There are no federal laws or regulations specifically designed to support adults with ASD in employment. Specific concerns related to employment and adults with ASD are generally incorporated under laws which provide protections for individuals with disabilities. Some of these include:

- The Individuals with Disabilities Education Act
- The Vocational Rehabilitation Act of 1973 and its subsequent Amendments (1988, 1992)
- The Americans with Disabilities Amendments Act
- The Ticket to Work and Work Incentives Improvement Act

There is some legislation at the state and federal levels that have the potential to help youth with disabilities make successful transitions to post-secondary education and employment.

Recent applicable legislation:

- Workforce Innovation and Opportunity Act
<http://www.dor.ca.gov>
- Adult Education Block Grant | <http://aebg.cccco.edu>
- CA Career Pathway Trust | www.connectedcalifornia.org



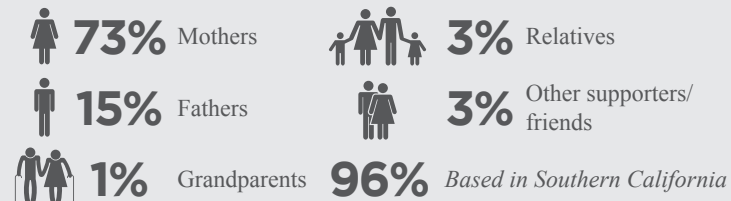
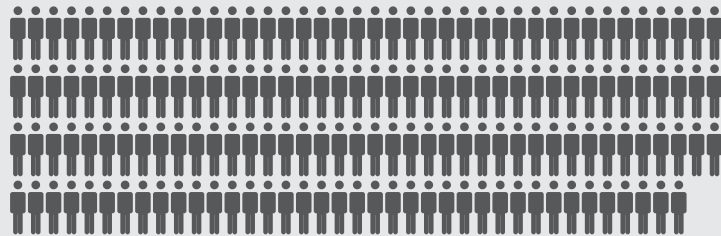
SUMMARY OF KEY FINDINGS

An electronic survey was sent to over 1000 family members who support young adults with ASD, as well as individuals with ASD who are transition-aged (18-30 years old).

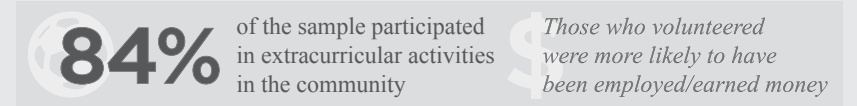
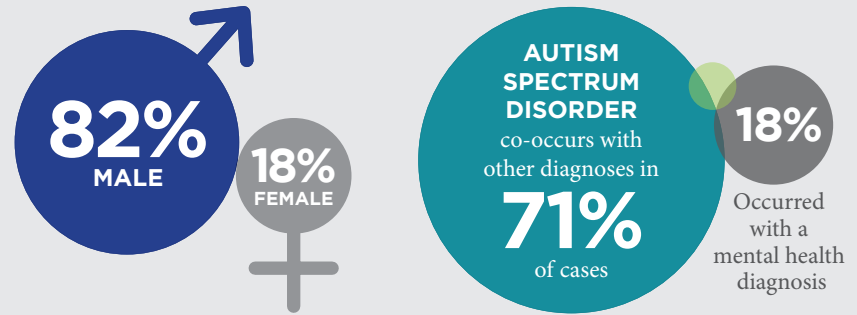
The following summary is based on information provided by 158 respondents, made up of: mothers (73%), fathers (15%) grandparents (1%), relatives (3%) and other supporters/friends (3%) of young adults with ASD. Most respondents were based in Southern California (96%). Unfortunately, we received only 9 responses from individuals with ASD, we hope to gather more information from the young adults themselves and include their responses in future research.

For up to date results visit our website www.chapman.edu/tpi

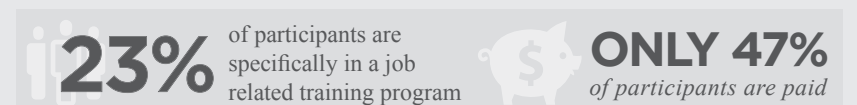
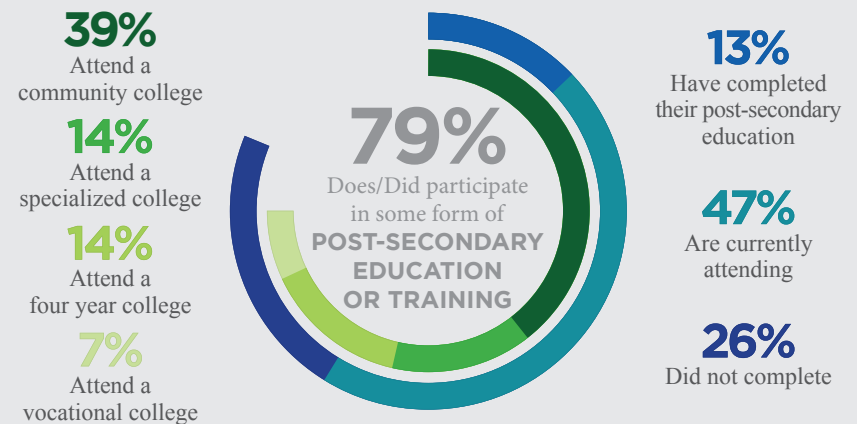
158 RESPONDENTS



GENERAL OUTCOMES



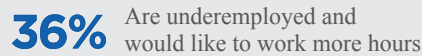
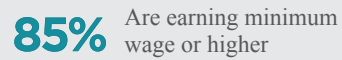
EDUCATION AND JOB TRAINING



PERSPECTIVES



JOB AND CAREER EXPERIENCES



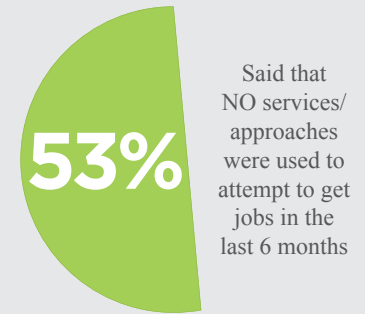
91% Have held 1-3 jobs

75% Have worked more than a year in total



*Sick pay, holidays, retirement

JOB SEARCH



JOB SUPPORT

Most challenging areas *(Extremely or very challenging)*

79%
Developing interviewing skills

80%
Finding a work environment that is supportive of a person with a disability

85%
Finding a job that allows for financial independence

Services most needed

- Help in finding a job (**80%**)
- Training in specific job skills (**79%**)
- Training in life skills needed for work (**77%**)

Change in services

Many services significantly decline following high school

- Speech and Language Services (**76 people in high school to 13 people after high school**)
- Mental health services (**61 people in high school, to 37 people after high school**)

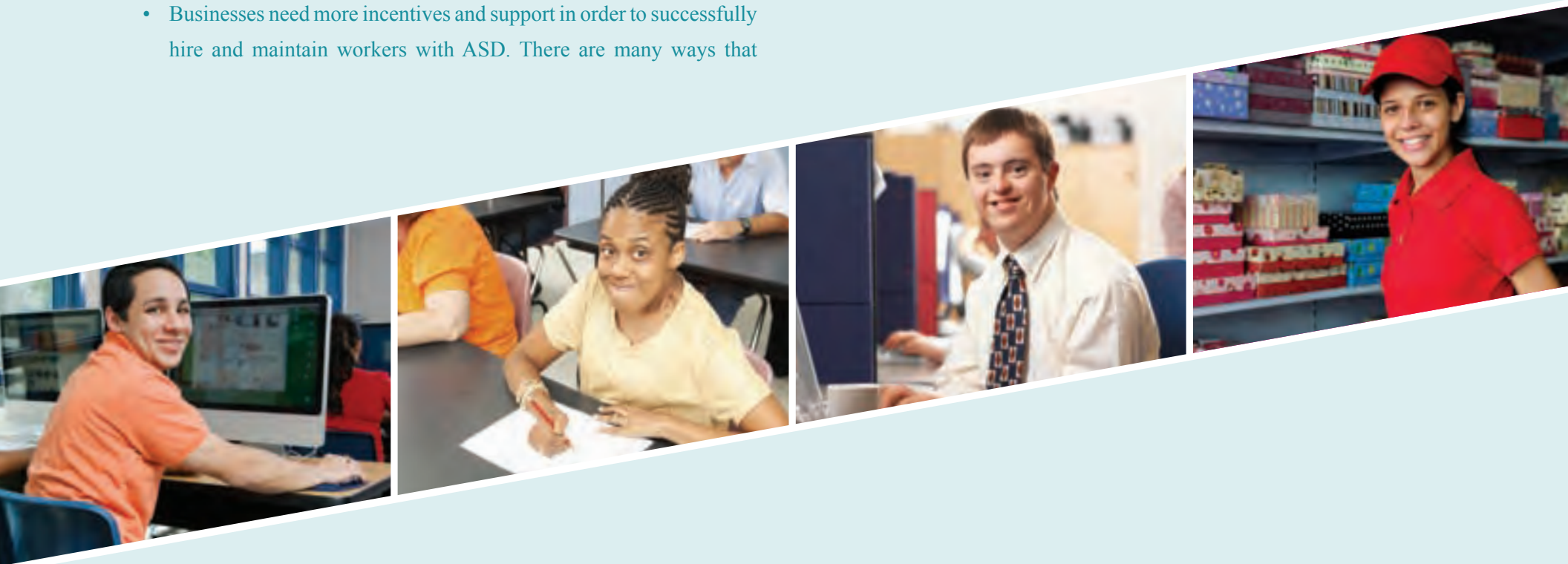
WHAT ARE THE POLICY IMPLICATIONS?

While many more policy recommendations will be developed with the community. Here is a list of policy implications to begin the discussion.

- In order to lead happy, healthy, and productive lives many adults with ASD will need access to quality health care, particularly mental health services. Given that many youth with ASD are unemployed and very few of those who are employed receive benefits, the accessibility of medical and mental health services needs to be evaluated and addressed immediately.
- Businesses need more incentives and support in order to successfully hire and maintain workers with ASD. There are many ways that

this could be structured and funded. One example of providing support could include funding coaches for companies. Rather than working directly with the adult with ASD, these coaches would help organizations prepare to hire and maintain adults with ASD in their businesses.

- In general, it is clear that more specific policies and legislation needs to be developed, based on research in the field, in order to guide adult services and support youth in obtaining both competitive and meaningful employment.



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THOMPSON POLICY INSTITUTE (TPI) on Disability and Autism at Chapman University gathers data and develops its own independent research to study critical issues in disability and autism. The TPI's purpose is to provide independent information on significant topics related to disability and facilitate action in areas that require community change. Throughout each year, the TPI will produce research that results in recommendations to decision-makers at the local, state and eventually national levels. The aim is to educate stakeholders on these topics towards improving the quality of life for children and adults with disabilities and their families.

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MAY 2, 2017