



Autism Society of California Executive Summary Impact of California's Autism Insurance Mandate Coverage Legislation

Autism is a complex developmental disability that typically appears during the first three years of life and among other symptoms, affects a person's ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a "spectrum disorder" that affects individuals differently and to varying degrees. Autism affects all races, ethnic and socioeconomic backgrounds. The Autism Society of California estimates there are over 85,000 individuals living in California with autism.

On July 1, 2012, the Autism Health Insurance Mandate, SB 946, (Steinberg) went into effect. This law states that California state regulated health care plans fall under the guidance of the new Autism Health Mandate. Those plans that provide hospital, medical, or surgical coverage shall also provide coverage for behavioral health treatment for pervasive developmental disorder or autism. Behavioral health treatment (BHT) includes applied behavior analysis (ABA) and other evidence-based behavior intervention programs. This law does not apply to health care plans that do not deliver mental health or behavioral health services to enrollees, to participants in the Medi-Cal program, the Public Employees Retirement System (CalPERS),

California's former Children's Health Insurance Program (CHIP), or Healthy Families.

This law is groundbreaking in that there are no limits regarding the age of the child, limits or caps on the number hours of Behavior Health Therapy (BHT), or caps on dollar amount for coverage. Eligibility for BHT should be determined individually by medical necessity.

This mandate opened the door for services to thousands of families with individuals with autism who were not able to access these services before – both Regional and non-Regional Center clients.

In an effort to capture the issues surrounding the autism community, including the impact and issues related to the Autism Health Insurance Mandate, the Autism Society of California designed an online survey and distributed it through its affiliates and over 50 collaborating California autism organizations. A total of 1,615 individuals responded to the survey - both Regional Center and non-Regional Center families of all ages, all abilities, and from each of the 21 Regional Centers, and 44 of the 59 counties in California (76%).

However, we realize that there are some limitations to this data including the number of respondents; that this survey was only available online and not available in other languages; and though a total of 1,615 responses were gathered, we realize that this represents only 1.9% of the projected autism population in California. Respondents to this survey tend to be of higher socioeconomic status, lower portion of non-English speakers, and higher proportion of Regional Center clients than is representative in California.

Summary of Findings:

1. Increased Access to BHT.

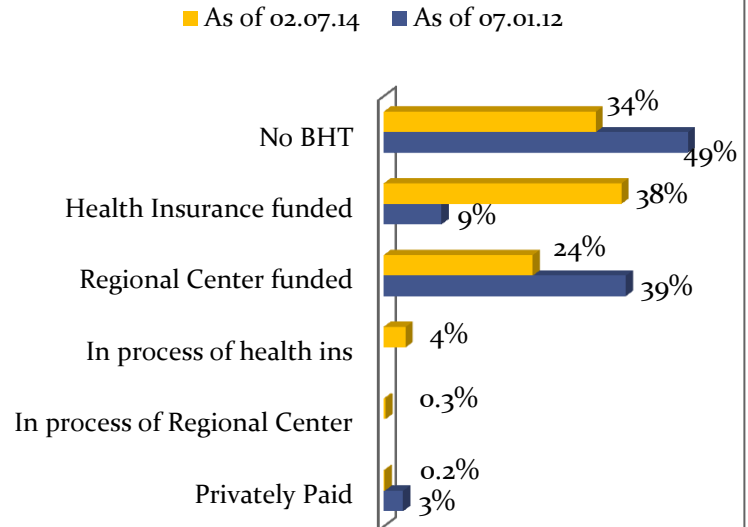
a. **Regional Center Families:** The number of Regional Center families accessing BHT increased from 51% as of 07/01/12 to more than 62% with another 4% in the process of applying for BHT. The survey also showed that previously less than half the Regional Center families in the critical age group of 0-5 years were accessing BHT; that has since increased to 88% in this age group.

b. **Non-Regional Center Families:** The number of non-Regional Center families accessing BHT prior to the Autism Insurance Mandate was reported at 22%. That has actually decreased to 19% with another 4% in the process of applying for BHT through their health insurance. The lack of change in access to BHT could indicate that Regional Centers played a critical role in helping families to access BHT through insurance. It would be worth exploring how to provide some support for awareness and assistance to access BHT through insurance to non-Regional Center consumers as well.

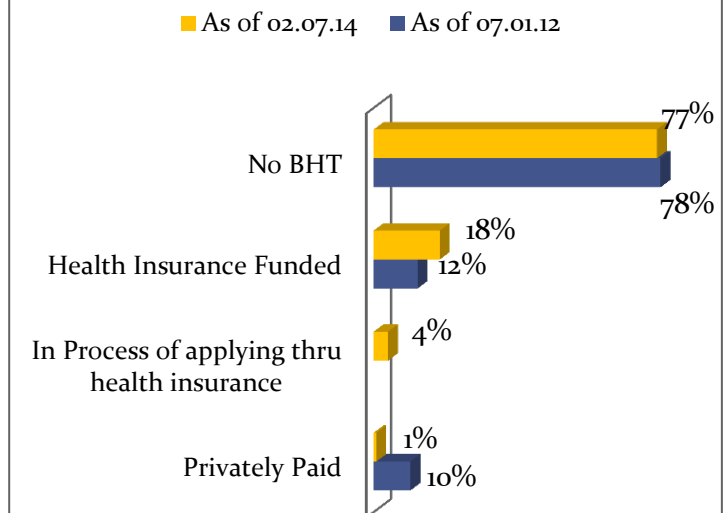
2. Shift in Funding.

a. **Regional Center Families:** The largest shift in funding for Regional Center families was a shift from Regional Center funded BHT to insurance funded BHT. Insurance funding of BHT has increased from 9% as of July 2012 to 38% as of February 2014. Conversely, Regional Center funding of BHT has fallen from 39% to 24% over the same time period.

Regional Center Families - BHT Status, Before and After Insurance Mandate



Non-Regional Center Families- BHT Status, Before and After Autism Insurance Mandate



b. **Non-Regional Center Families:** The largest shift in funding for non-Regional Center families was a reduction in private payment for BHT. Insurance funding of BHT has increased from 12% as of July 2012 to 18% as of February 2014. Conversely, private funding

of BHT has fallen from 10% to 1% over the same time period.

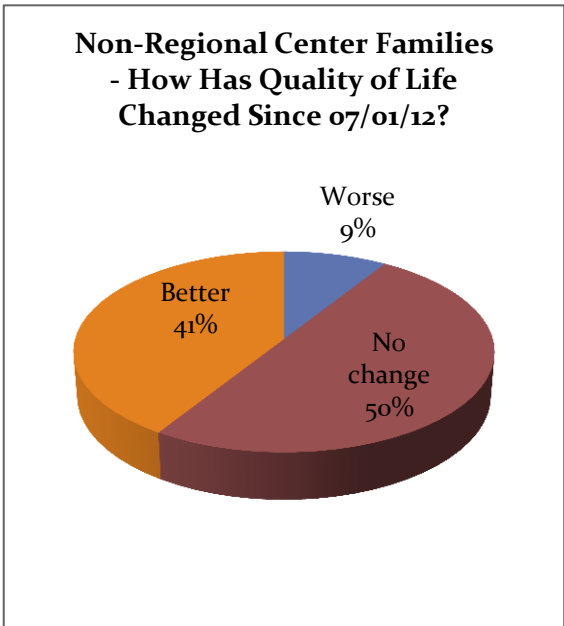
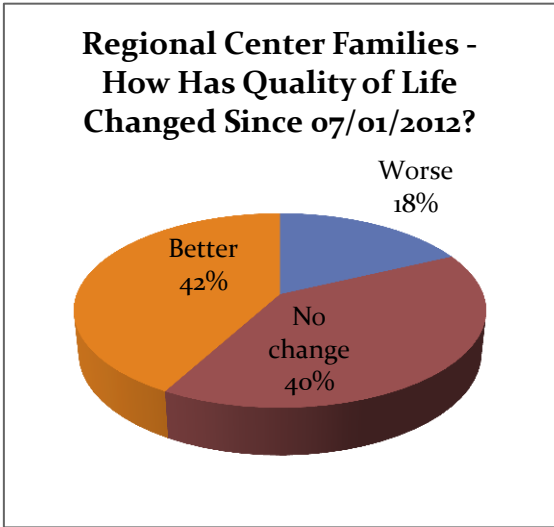
- c. **Comparison:** There is only a 50% increase in insurance funded BHT for non-Regional Center families compared to a 400% increase for Regional Center families. Less than half as many non-Regional Center families have insurance funded BHT (18% vs 38%). There clearly needs to be some education and assistance provided for non-Regional Center families to access health insurance in the same way Regional Center clients have.

3. Overall Higher Quality of Life.

Overall, the autism community reports a having a better quality of life since the start of the Autism Insurance Mandate; 42% of Regional Center families and 41% of the non-Regional Center families report that their life has improved.

While in both groups more families are better off than worse off, twice as many Regional Center families are worse off than non-Regional Center families (18% vs 9%), primarily due to issues with co-pays and deductibles (see financial barriers.)

- 4. **Financial Barriers.** The Welfare and Institutions Code 4659.1 Section 7 enacted July 1, 2013, states that Regional Centers may no longer pay for a family's deductible, with no exceptions, and may pay co-pay/co-insurance for services only if the family's annual gross income does not exceed 400% of federal poverty level, with limited exceptions for extreme hardship. While the survey showed that this did not impact a large portion of the Regional Center families in 2013 (11% received financial assistance with their deductible in 2013 and 35% received assistance with co-pays), of all Regional



Center families, 66% expected or have experienced significant negative impacts to BHT such as having to reduce therapy or supervision hours, having to discontinue BHT completely, or having to reduce other services to keep BHT.

Instead of shifting 90% of the costs from Regional Centers to private insurance, which was the intent of the SB 946, the co-pay and deductible changes in the Budget Act change the impact of the Autism Insurance Mandate and result in shifting the cost of BHT from Regional Centers to shifting to insurance companies AND families. This reduces the benefit of the Autism Insurance Mandate to families and reduces the potential savings to the state by disincentivising Regional Center families from pursuing

insurance as aggressively as they otherwise would and, in some cases, shifting the entire burden of BHT back to the Regional Centers.

5. **Denial Reasons Still Not Appropriate.**

Focusing on the CA regulated plans that should be covering BHT, 14% were still denied BHT. Of those denials, 44% were due to advanced age, despite the law having no age caps; 33% of denials were due to low cognitive function, and 22% due to high cognitive function, despite no basis under the law for such limitations; 22% of denials cited location of service, which also is not an appropriate denial reason as SB 946 requires coverage of all medically necessary BHT. Most alarming, 39% of denials still claimed BHT as experimental and 11% as not a covered benefit despite SB 946 clearly establishing it as a required benefit when medically necessary.

6. **Timely Access.** California law requires health plans to provide timely access to care. The Timely Access Regulations state that requests for treatment be processed within 5 days, and Rule 1300.67.2.2 requires that services should be available to start within 10 days.

The 2014 ASC Survey showed that only 15% of California families received authorization within the required 5-day time frame; 58% of California families had a delay greater than 14 days; 34% indicated that services took more than 31 days.

7. **Excessive Requirements for Approval.**

Families indicate that insurance companies are requesting significant documentation before authorizing BHT, including IEPs, speech and occupational therapy reports, psychological and medical reports, IQ testing, full diagnostic reports, and new assessments to confirm diagnosis. These are all above

and beyond the requirements in the Autism Insurance Law, which are diagnosis, prescription and treatment plan with measurable objectives. These excessive requirements are irrelevant to determinations of medical necessity, add to the time required to authorize treatment, and are burdensome for families and providers. California Department of Insurance has addressed some of these issues, such as the requirement for IQ testing, in regulations passed in early 2013, but this data suggests many of the problems persist.

8. **Need for Awareness.** Overall, 82% of Regional Center families were aware of the Autism Insurance Mandate vs. only 71% of non-Regional Center families. ASC suggests a requirement for California regulated insurance companies to contact policy holders and advise them that this benefit is now available by law. Education and assistance provided to non-Regional Center families will allow them to access health insurance in the same way Regional Center clients have.

9. **Improve Awareness.** Because of the small sample size we collected, we would call for Regional Center to collect this data and publish it on a larger scale to verify if access, quality and the financial issues are being impacted as predicted by this report.



For more information on autism spectrum disorders in California, visit the Autism Society of California website at www.autismsocietyca.org
1-800-869-7069