



Autism Society of California Executive Summary

Impact of California's Autism Insurance Mandate Coverage Legislation- Revised March 2014

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. CalPERS and Healthy Families began covering BHT in late 2012 through regulation. The Healthy Families' BHT coverage was short lived as the program was merged into Medi-Cal, which does not cover BHT, in 2013

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 Treatment (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% as of 2/2014 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.

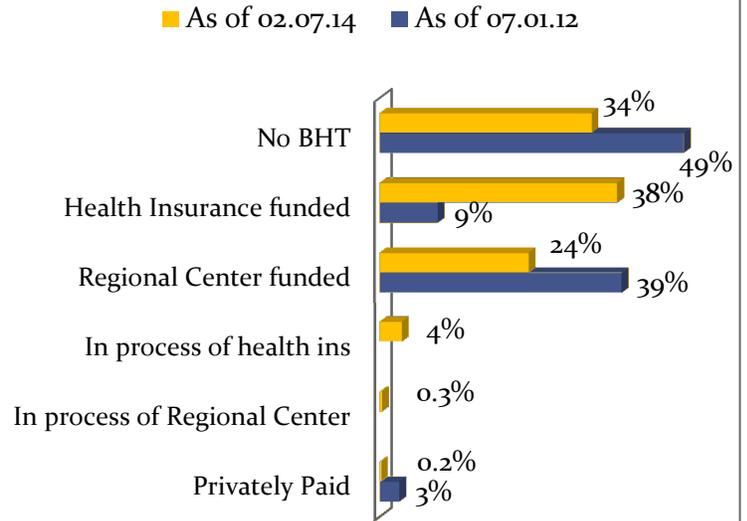
b. **Non-Regional Center Families:** The number of non-Regional Center families accessing BHT prior to the Autism Insurance Mandate was reported at 30%. That has increased to 38%.

c. **Comparison:** While the improvement in access to BHT was similar for Regional and non-Regional Center families (27% versus 22%, respectively), overall access to BHT is still much lower for non-Regional Center families (38% vs 62%). This suggests education and assistance provided to non-Regional Center families would allow them to access health insurance similarly to how Regional Center clients have, gaining more access to BHT through health insurance.

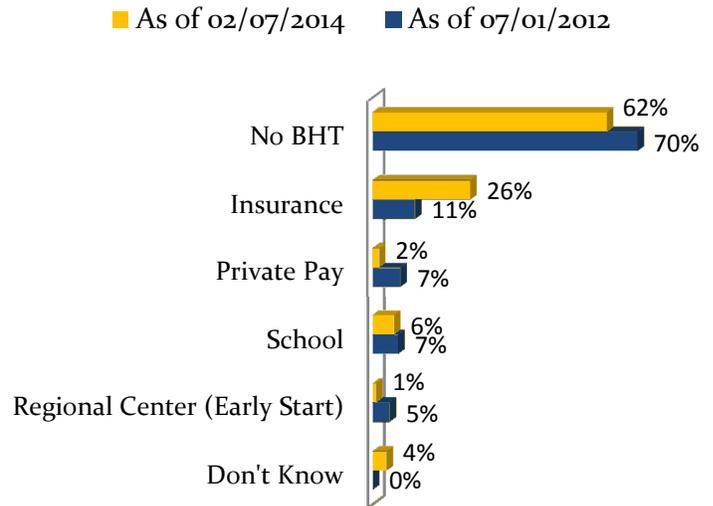
2. Shift in Funding.

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 Access to BHT Before and After Insurance Mandate



b. **Non-Regional Center Families:** There have been meaningful reductions in both private pay funding (7% to 2%) and Regional Center funding through early start (5% to 1%). The reduced private and Regional Center funding was replaced by a significant increase in health insurance funding (11% to 26%).

As with Regional Center families, the financial savings to families who privately paid and to Regional Centers came despite improved access to BHT overall.

- c. **Comparison:** While insurance funding for both non-Regional Center and Regional Center families dramatically increased, (240% and 400%, respectively); the increase in insurance for Regional Center families was more dramatic.

And while insurance funded BHT programs for non-Regional Center families began higher than those for Regional Center families (11% vs 9%), insurance funded programs for non-Regional Center families ended nearly 50% lower than those for their Regional Center counterparts (26% versus 38% higher).

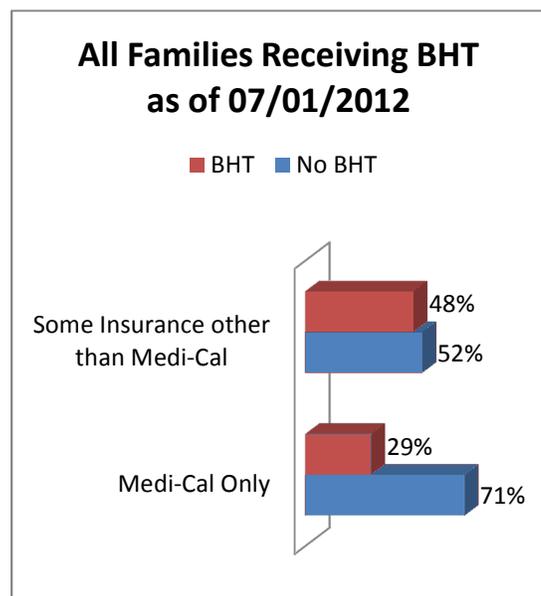
- 3. **Knowledge of Mandate.** Overall, 82% of Regional Center families were aware of the Autism Insurance Mandate vs. only 71% of non-Regional Center families. ASC suggests a requirement for California regulated insurance companies to contact policy holders and advise them that this benefit is now available.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

- 4. **Overall Higher Quality of Life.** Overall, the autism community self-reported 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.)

- 5. **Negative impact on Medi-Cal Families:** Medi-Cal families should not have been affected by the transition to insurance, and Regional Center should have continued funding Regional Center client’s BHT services. However, the Regional Center families on Medi-Cal who took the survey reported the highest perception of being worse off (30%) since the Autism Insurance Mandate took effect.

This is particularly concerning since the survey showed that both Regional Center and non-Regional Center families with Medi-Cal only were already worse off than families with any other type of insurance in July, 2012 (71% were without any BHT vs 52% who had any other insurance). This could suggest a disparity for families of lower socioeconomic status.



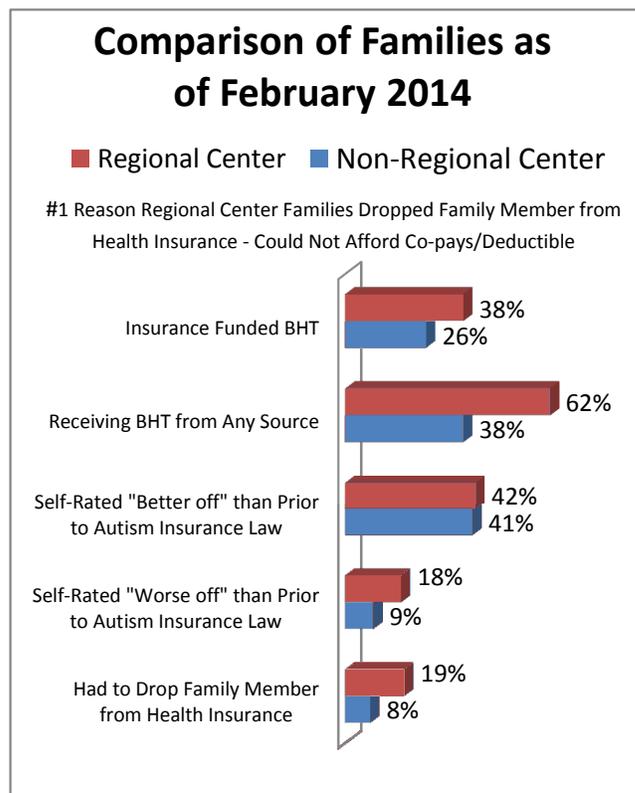
6. **Financial Barriers.** The Welfare and Institutions Code 4659.1 Section 7 enacted July 1, 2013, states that Regional Centers may no longer pay for a family's deductible, with no exceptions, and may pay co-pay/co-insurance for services only if the family's annual gross income does not exceed 400% of federal poverty level, with limited exceptions for extreme hardship. Therefore, very few families were able to secure financial assistance from Regional Centers for co-pays and deductibles: 11% received financial assistance with their deductible in 2013 and 35% received assistance with co-pays). Of all Regional Center families, 66% expected to 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. Others had services discontinued and several went to the extreme of discontinuing their private insurance, transferring the entire cost of their BHT and medical care to the Regional Center and Medi-Cal, respectively.

Instead of shifting 80-90% of the costs from Regional Centers to private insurance, which was the intent of SB 946, the co-pay and deductible changes in the Budget Act dramatically changed the financial impact of the Autism Insurance Mandate on families. The Budget Act resulted in shifting the cost of BHT from Regional Centers not only to insurance companies BUT ALSO to 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 have and, in some cases, shifting the entire burden of BHT back to the Regional Centers.

Autism Society of California is calling for the 2013 Budget Act Trailer Bill Language to

be amended to read, "Regional Center shall pay co-pays and deductibles for IPP/IFSP services with no means testing.

7. **Dropping Private Insurance.** Overall 1 out of 10 families dropped the individual with ASD from their health insurance policy (19% Regional Center families, 8% non-Regional Center families). The single most common reason that an individual was dropped from a health insurance plan was in order to keep BHT through the Regional Center due to the inaffordability of co-pays and deductibles, especially for Regional Center families (21% of Regional Center families vs 5% of non-Regional Center families).



8. **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.

9. **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.

There was further delay between authorization and services actually beginning. Only 34% of families accessing

BHT through insurance were able to start within 14 days of authorization – close to the 10-day required time frame. 66% of families were unable to start services until more than 14 days and 42% were unable to start until more than 30 days after authorization. These delays are added to the delays in receiving approvals described above and indicate either an inadequate network of providers, problems with the approval and start up process, or both.

10. **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.

11. **Improve Data Collection.** 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.

How Long Did It Take You to Start BHT Once the Health Ins Company Notified You of Your Approval?

