

Impact of California's Autism Insurance Legislation – 2014 Survey



Compiled by the Autism Society of California
March 2014

 **AUTISM SOCIETY**
Improving the Lives of All Affected by Autism
California

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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.

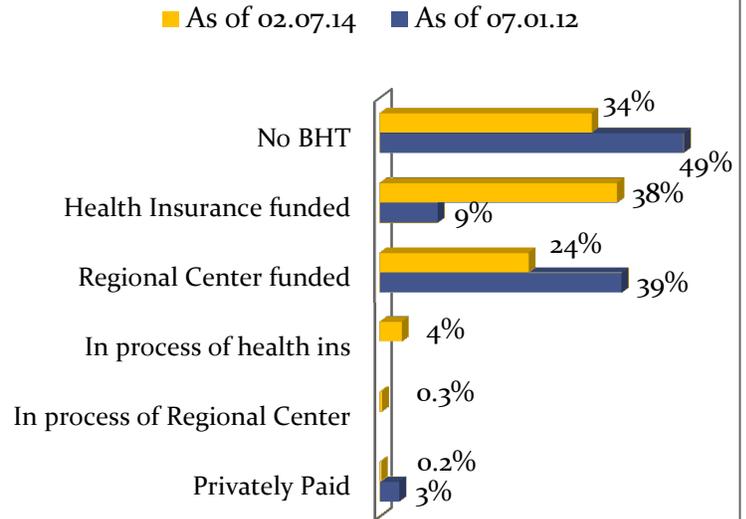
Summary of Findings:

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.

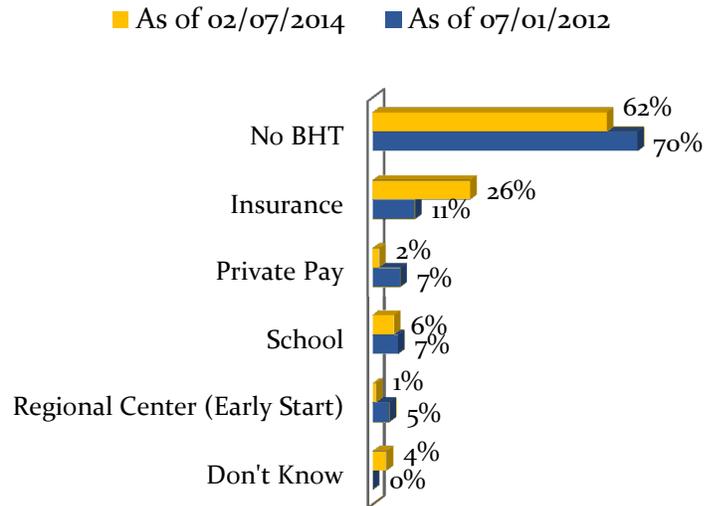
2. Shift in Funding.

- 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).

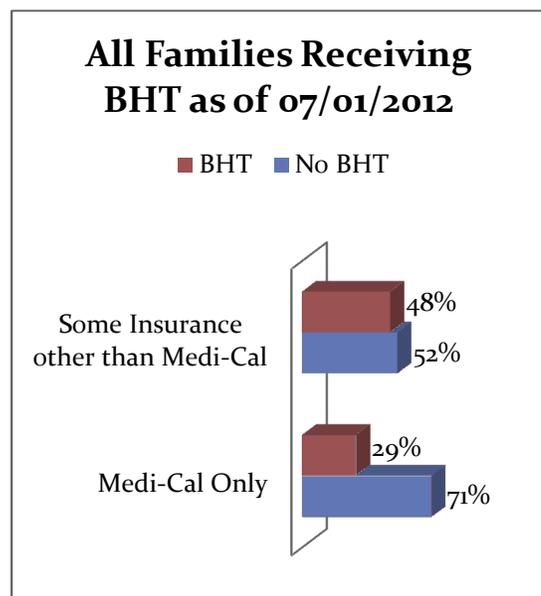
- 3. **Knowledge of Mandate.** Overall, 82% of Regional Center families were aware of the Autism Insurance Mandate vs. only 71% of non-Regional Center families. ASC suggests a requirement for California regulated insurance companies to contact policy holders and advise them that this benefit is now available. 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.



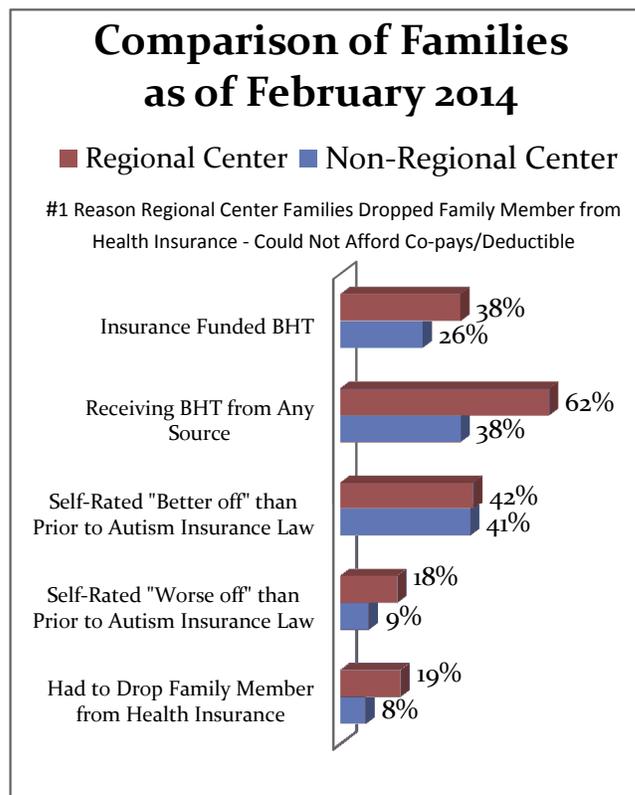
6. **Financial Barriers.** The Welfare and Institutions Code 4659.1 Section 7 enacted July 1, 2013, states that Regional Centers may no longer pay for a family's deductible, with no exceptions, and may pay co-pay/co-insurance for services only if the family's annual gross income does not exceed 400% 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.

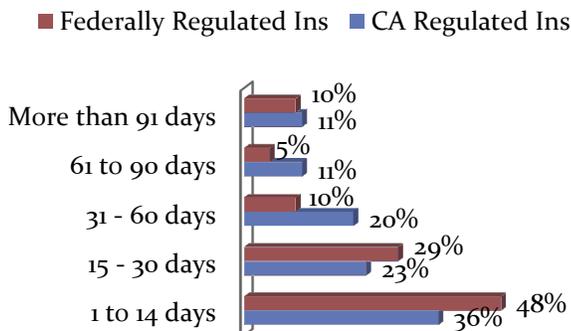
There was further delay between authorization and services actually beginning. Only 34% of families accessing

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?



www.autismsocietyca.org
1-800-869-7069

Introduction



In March 2012, the Centers for Disease Control and Prevention released their estimate that 1 in 88 children in the United States have been identified as having an autism spectrum disorder (ASD). This is equivalent to 1% of the general population.

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. There is no known single cause of autism, but increased awareness and funding can help families today.

The national office of the Autism Society estimates that the lifetime cost of caring for a child with autism ranges from \$3.5 million to \$5 million, and that the United States is facing almost \$90 billion annually in costs for autism (this figure includes research, insurance costs and non-covered expenses, Medicaid waivers for autism, educational spending, housing, transportation, and employment, in addition to related therapeutic services and caregiver costs). While children do not "outgrow" autism, studies show that early diagnosis and intervention lead to significantly improved outcomes.

California continues to lead the nation in the highest number of individuals with ASD. We estimate there are over 85,000 individuals living in California with a form of ASD. The California Department of Education reports there are 78,624 students as of December 2013 identified with ASD who qualify for special education services. There is no current data available from the Department of Developmental Services, however, as of 2007, DDS reported they had identified 6,000 adults with autism. We believe 85,000 is a conservative number as it does not include most children under the age of 3 who have not received a formal diagnosis, the adults with ASD who do not qualify for DDS services, and the school-aged children on the spectrum, who do not qualify for special education services.

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 (also known as fully funded or fully insured 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.

The Department of Managed Health Care passed an emergency regulation in September of 2012 that was finalized in April 2013 concluding that CalPERS HMOs and Healthy Families were required to provide BHT under the existing California Mental Health Parity Law (H&S Code 1374.72), which was previously

being ignored by most health plans and insurers. This regulation confirmed existing law and effectively extended the BHT benefits described in the Autism Insurance Mandate to enrollees of CalPERS HMOs and, for a brief time, enrollees of Healthy Families until it was folded into Medi-Cal during 2013. Starting in 2014 CalPERS has extended coverage of BHT to enrollees of its self-funded PPO.

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 is 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, an online survey by the Autism Society of California was distributed through its affiliates and partners. The survey was sent to over 50 California autism organizations for distribution and was open for a 24-day period (01/15-02/07/2014).

A total of 1,634 individuals responded to and participated in the survey including: 1,426 (87%) parents/guardians; 62 (4%) individuals on the spectrum; 120 (7%) other family members; and 119 (7%) other caregivers. There were respondents from each of the 21 Regional Centers and 44 of the 59 counties in California (76%). Multiple responses were permitted so numbers add to more than 100%.

The survey was similar to surveys conducted by the Autism Society of California (ASC) in 2009, 2012, and 2013. The objective was to gather information on services and supports in California to determine a course of action to assist individuals and families living with ASD in California.

Percentages were rounded up to whole numbers to make this report more user friendly. In many cases, respondents were permitted to provide more than response. In those cases, percentage totals may add to more than 100%. Comments from respondents in the survey will be italicized.

Limitations of Data Reporting

The 2014 ASC Survey was distributed online and in English. Respondents to this survey tend to be of higher socioeconomic status than is representative in California. According to the Henry J Foundation Report Distribution of the Total Population by Federal Poverty Level (above and below 400% FPL), approximately 68% of Californians are below 400% poverty level, whereas the ASC Survey captured 53% of households under 400%.

Respondents were primarily from English speaking households - 96%, from Spanish speaking households - 3%, and other languages made up less than 1%.

Due to the fact that this survey was available only online, we are aware that families and individuals without access to the internet, or those of lower socioeconomic status may have been excluded. We continue to investigate effective ways of reaching this population.

This survey also includes a higher number of respondents who are Regional Center clients than the entire California population. (74 % in the survey vs approximately 26% of ASD population (source: CHBRP Analysis SB 126 (Steinberg) pgs 96-97).

Due to a logic error in the survey, families receiving Early Start services (44% of respondents) were not directed to fill out the question on type of insurance. The Early Start group appears to have had at least some meaningful differences from the non-early start group, such as whether or not they received BHT services before July 2012. However, we have no reason to believe that Early Start families would have different types of insurance compared to families not receiving Early Start; therefore, we do not believe this error meaningfully affects the results or conclusions of this survey.

Acknowledgments

This survey would not have been possible without the scores of hours of hard work and dedication of Beth Burt, First Vice President of the Autism Society of California and President of the Autism Society Inland Empire. From the first draft of the survey through the final analysis and presentation of the resulting data, Beth has shepherded this project with meticulous attention – something most of us would never dare expect from a volunteer – and I am so grateful to have you working by my side.

In addition, I would like to express my deepest appreciation to Kristin Jacobson, President of Autism Deserves Equal Coverage, for her depth of knowledge surrounding autism and insurance issues, and the technical assistance she provided to us in analyzing data and assisting in the writing of this document.

I would like to thank Senator Darrell Steinberg for his vision and leadership regarding SB 946-Steinberg and his commitment and dedication to individuals with autism and related disorders and their families. Special thanks to Dr. Lou Vismara, Policy Consultant to Senator Darrell Steinberg, and Bob Giovati, Committee Consultant, Senate Select Committee on Autism & Related Disorders, for their support and guidance as we prepared this document.

Many thanks to Sandra Shove, Second Vice President of the Autism Society of California, for her assistance with editing and proofreading.

I would like to express my sincere thanks to the many volunteers who make up the Autism Society of California Affiliates and provide information, education, awareness, advocacy and support to individuals with autism spectrum disorders, their families and the professionals who serve them. Special thanks to the rest of my volunteer Board Members Penne Fode, Secretary, Gregory Fletcher, Past President and Regina Moreno, Treasurer.

My deepest appreciation goes out to the many members of the Alliance of California Autism Organizations and all of the other organizations and agencies who assisted us with the distribution of this survey.

Most importantly, I would like to thank the many individuals and families who took time out of their extremely busy lives to participate in and complete the survey. Without you, this would not have been possible. So, for all who are living with autism, I offer the wise words of Pulitzer prize winning columnist, Ellen Goodman, "The central struggle of parenthood is to let our hopes for our children outweigh our fears."

Marcia J. Eichelberger, President
Autism Society of California

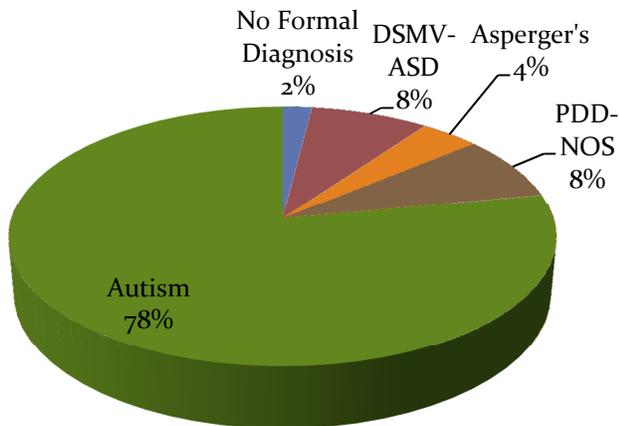
Survey Demographics

Respondents were from each of the 21 Regional Centers and 44 of the 59 counties in California (76%).

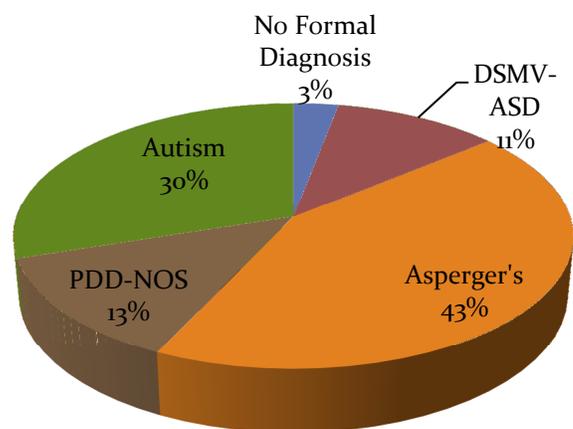
Overall trends were similar to past surveys. The majority (66%) of the families indicated that autism was the primary diagnosis; Asperger's 13%; Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) diagnosis 9%; 9% of the newly created DSM5 diagnosis of Autism Spectrum Disorders; and 3% indicated they had not received a formal diagnosis.

Diagnostic Breakdown			
	2014	2012	2009
Autism	66%	68%	67%
Asperger's	13%	18%	19%
PDD-NOS	9%	16%	10%
DSM5 - ASD	9%	n/a	n/a
No formal diagnosis	3%	5%	3%

Regional Center Families



Non-Regional Center Families



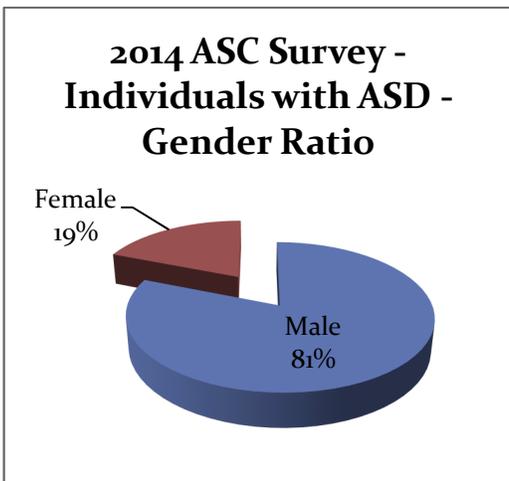
Regional Centers are one of the major service systems for families with autism; however, not all families with autism receive Regional Center services. To be eligible for services through the Regional Center, a person must have a disability that begins before the person's 18th birthday, be expected to continue indefinitely and present a substantial disability as defined in Section 4512 of the California Welfare and Institutions Code. Eligibility is established through diagnosis and assessment performed by each Regional Center. Regional Centers have some flexibility in determining who is eligible for these services.

While each person with autism is unique, the profiles of individuals with autism who are Regional Center clients may be different from those who are not. Regional Center families tend to have a larger percentage of individuals with autism who may have more maladaptive behaviors and substantial communication deficits. Non-Regional Center families may be dealing with issues related to academic

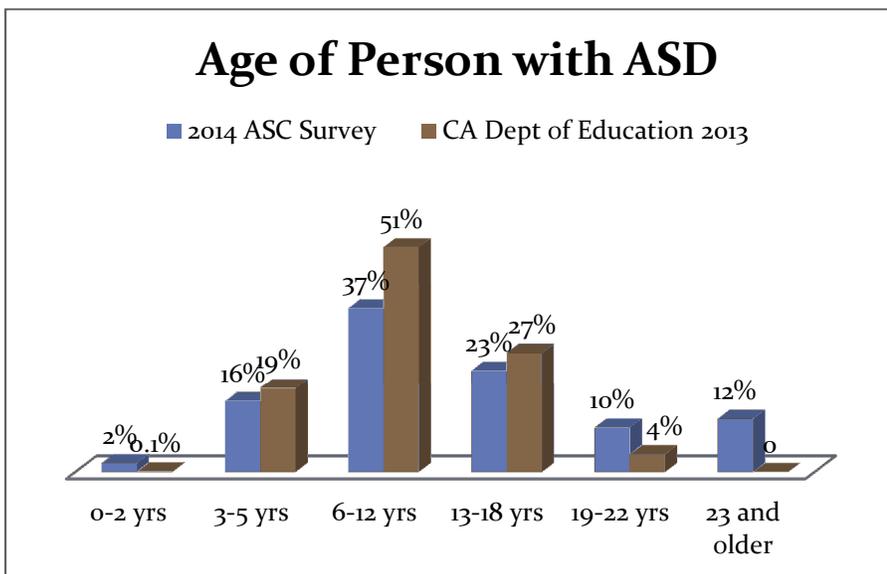
performance, social skills and pragmatic language deficits, and issues related to mental health (anxiety, depression, and other mood disorders).

The survey showed Regional Center families were composed primarily of 78% of individuals with autism compared to 30% of individuals with autism for non-Regional Center families. Likewise, only 4% of the Regional Center families with individuals with Asperger’s were Regional Center clients compared to 43% of non-Regional Center families with individuals with Asperger’s. Seventy-four percent (74%) of the survey respondents indicated the individual with autism is currently a Regional Center client. This is consistent with past showing 70% in 2012 and 77% in 2009.

However this and past surveys include a higher number of respondents who are RC clients than the entire California population, at least as estimated by the California Health Benefits Review Program (CHBRP) that analyzed SB 126, the extension of SB 946.



Males continue to outnumber females; 81% males to 19% females, keeping with the national average cited by the CDC. ASDs are more than 4 times more common among boys.



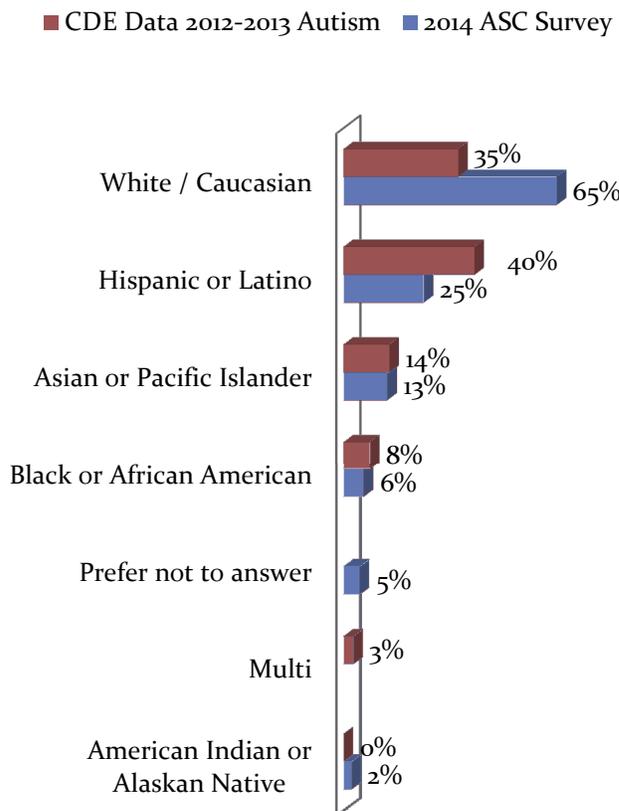
Seventy-eight percent (78%) of the respondents indicated the person with ASD was under the age of 18, while 22% were over the age of 18 years. This is similar to the demographics of our 2012 survey (77% under 18 and 23% over age of 18 yrs).

We compared the 2014 survey data to data from the California Department of Education (CDE) 2012-2013 School Year for Students with Autism.

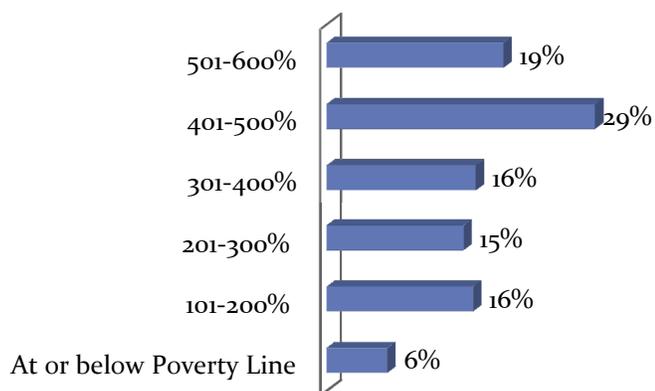
White/Caucasian families were overrepresented in the 2014 Survey (65% ASC Survey vs. 35% CDE Autism Special Education population) and families that were of Hispanic ethnicity were underrepresented (25% ASC Survey vs. 40% CDE Data).

Families and individuals who answered this survey were more likely to have higher family income than Californians as a whole.

Ethnicity of Person with ASD



Distribution of Household Income by 2014 Federal Poverty Level (FPL)



Approximately 53% of the 2014 ASC Survey respondents indicated they had a FPL of less than 400%. This compares to 68% of families statewide published by the Henry J Kaiser Family Foundation (KFF). The KFF report was based on information gathered from The Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2012 and 2013 Current Population Survey (CPS: Annual Social and Economic Supplements).

We acknowledge that financially impacted families were less likely to have access to the internet and the online survey and therefore were less likely to participate in this survey.

An Overview of Health Insurance in the California Autism Community

Type of Insurance	2014 ASC Survey (Autism)	2013 Packard Foundation Report (All Special Needs)
No insurance	3%	4%
Private & public Insurance	26%	8%
Medi-Cal	29%	28%
Private Insurance	68%	60%

The initial findings on the type of insurance families with autism have are consistent with the Lucile Packard Foundation for Children’s Health & Child and Adolescent Health Measurement Initiative Report (2013), *Children with Special Health Care Needs in California: A Profile of Key Issues*. This report chronicles data gathered through telephone interviews with parents of individuals with chronic physical, developmental, behavioral, or emotional conditions and who also experience consequences due to their condition, such as above-routine use of health and related services. This report advised that among children with special needs statewide, 60% had private insurance, 28.1% had public insurance,

and 8.3% had both private and public insurance in 2009-10.

However, one area in the 2014 ASC Survey showed a large discrepancy with the Packard Foundation report – 26% of families in the Survey indicated that they had Medi-Cal as their secondary insurance compared to 8% of all children with special needs in the Packard report.

Federally Regulated vs State Regulated Health Insurance

On July 1, 2012, the Autism Health Insurance Mandate, (SB 946 - Steinberg), went into effect, requiring California state regulated health care plans which provide hospital, medical, or surgical coverage to also provide coverage for behavioral health treatment (BHT) 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.

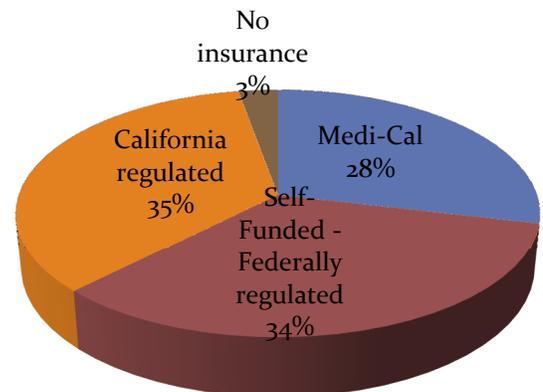
The Department of Managed Health Care passed an emergency regulation in September of 2012 that was finalized in April, 2013 concluding that CalPERS HMOs and Healthy Families were required to provide BHT under the existing California Mental Health Parity Law (H&S Code 1374.72 and Insurance Code 10144.5). This regulation effectively extended the BHT benefits described in the Autism Insurance Mandate to enrollees of CalPERS HMOs and, for a brief time, enrollees of Healthy Families until it was folded into Medi-Cal during 2013. Starting in 2014 CalPERS has extended coverage of BHT to enrollees of its self-funded PPO.

State mandates are inapplicable to policies regulated by the federal government and therefore those policies are inconsistent as to whether or not they cover BHT. While more and more federally regulated health insurance companies are covering BHT, the vast majority do not.

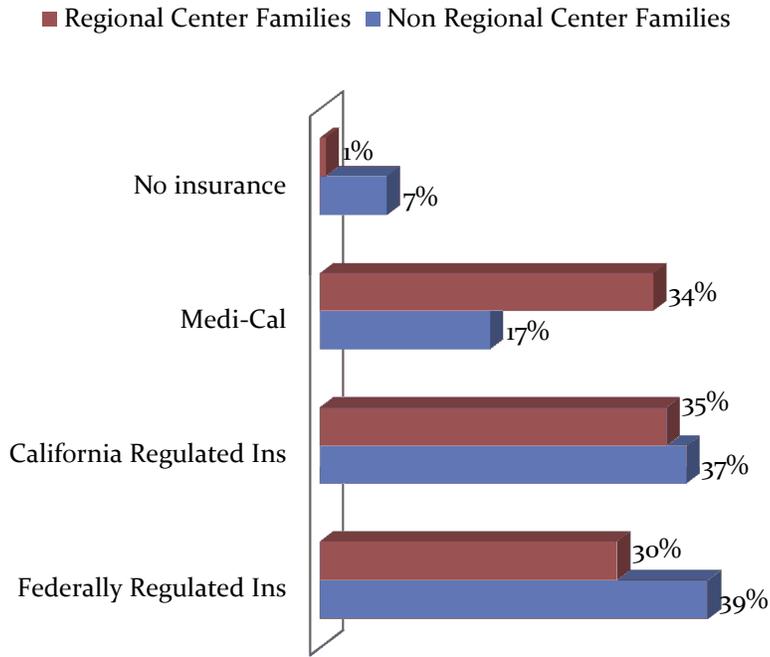
Families indicated a consistent distribution between federally regulated and state regulated health plans; 34% reported that their plans were federally regulated vs. 35% reported state regulated plans.

Medi-Cal remains the single state insurance plan that does not cover BHT and, based on CHRBP figures, covers 42% of the children in California (Source: CHRBP Resources: Estimates of Sources of Health Insurance in California for 2014, March 25, 2013)

All Families - Insurance Breakdown for Individuals with ASD



Type of Health Insurance Policy - Regional Center vs Non Regional Center Families



There was a slight discrepancy between Regional Center and non-Regional Center families in carrying federally regulated and California regulated insurance: 35% of Regional Center families had California regulated (compared to 37% for non-Regional Center families) and 30% of the Regional Center families had federally regulated policies compared to 39% of the non-Regional Center families.

There were almost double the amount of families with Medi-Cal in Regional Center (34% Regional Center vs. 17% non-Regional Center), likely due to Regional Center efforts to enroll families in the Medi-Cal waiver in order to access federal matching funds. Furthermore, non-Regional Center families were seven times more likely to have no insurance.

Families identified over 30 different federally regulated health plans and 23 state regulated plans that they are currently using.

For state regulated plans – Kaiser Permanente accounted for 50% of these plans, followed by Blue Shield of California HMO (12%) and Anthem Blue Cross PPO (10%). Families reported the most used federally regulated insurance providers were Blue Cross companies (32%) and Anthem (16%), followed by Aetna and United Healthcare at (9%).

Most Used State Regulated Plans		Most Used Federally Regulated Plans	
Kaiser Permanente-Northern CA	26%	Blue Cross companies	32%
Kaiser Permanente-Southern CA	24%	Anthem	16%
Blue Shield of California - HMO	12%	Aetna	9%
Anthem Blue Cross PPO	10%	United Healthcare	9%

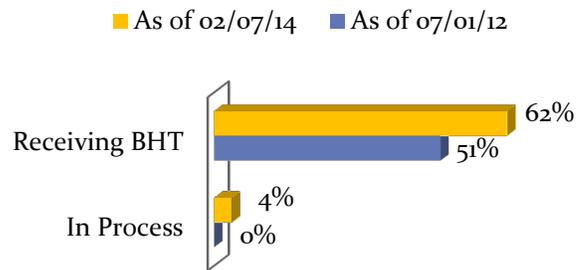
Regional Center Families

There are twenty-one Regional Centers in California which provide services to individuals with developmental disabilities, including autism based on eligibility criteria. The Lanterman Developmental Disabilities Services Act outlines the services that may be provided by Regional Centers. These services include the right of Californians with developmental disabilities to receive "treatment and habilitation services and supports in the least restrictive environment", and make choices in their own lives, including "program planning and implementation." This includes behavior training and behavior modification programs.

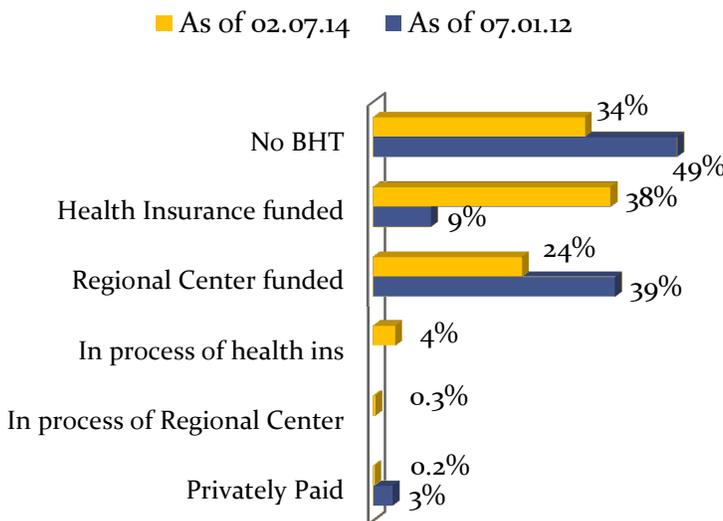
Access to BHT – Regional Center Families

Regional Center families showed a vast improvement in accessing BHT. Prior to the Autism Insurance Mandate, approximately half (51%) of the Regional Center families were accessing BHT. This was reported to increase to more than 62% with another 4% in the process of applying for BHT.

Regional Center Families - BHT Status Before and After Insurance Mandate (All Funders)

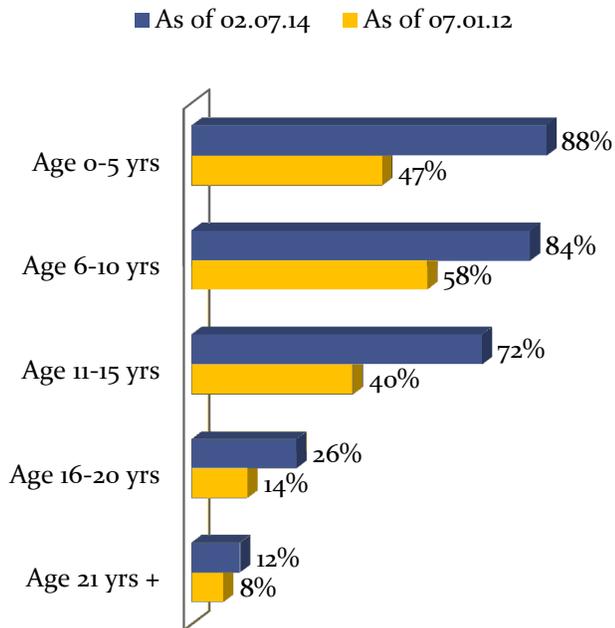


Regional Center Families - BHT Status, Before and After Insurance Mandate



The funding of BHT for Regional Center families also dramatically changed since the implementation of the Autism Health Insurance Mandate. Health insurance funded BHT programs increased almost four fold, from 10% to 38%, while Regional Center funded programs decreased from 39% to 24%. The small percentage of families that privately paid prior to July 2012 experienced relief as insurance funding reduced the privately funded programs to essentially zero. The financial savings to Regional Centers and private families came despite improved access to BHT overall. Currently only 34% of Regional Center families have no BHT compared to 49% in July 2012.

Regional Center Families Receiving BHT (All Funders) - Before and After Mandate by Age



Survey responses also showed that the older the person with ASD, the less likely they were to access BHT. This graph shows that an improvement was made for families trying to access Early Intervention services (0-5 yrs). Previously less than half the families in this critical age group were accessing BHT according to the survey. Now nearly 90% of Regional Center families with children ages 0-5 have access to BHT.

“It has changed our lives! Thank you...for addressing one of biggest crises of our time. We receive the appropriate services for our son. He works hard, is an integral member of our family, and is succeeding in school.”



Regional Center Families Who Did Not Pursue BHT

The above graph illustrates that over half the Regional Center families who were not receiving BHT as of 07/01/2012, did not pursue BHT. This was not an area that was explored in depth on the survey but comments on this question indicated various reasons ranging from the age of the person with autism:

“At age 25 seemed to no longer apply”

To lack of need:

“My son does not have behavior issues.”

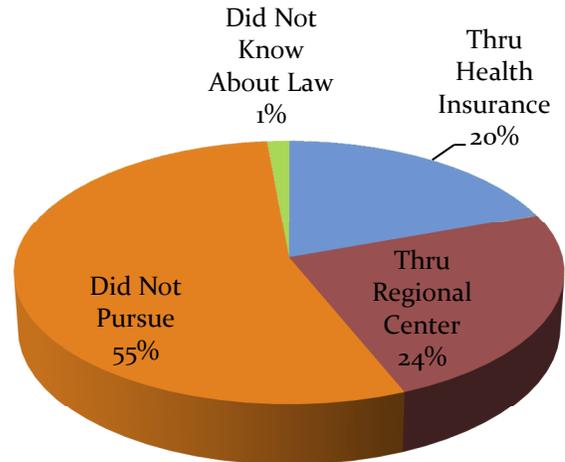
“Did not want it, as child receives through school.”

To confusion or misinformation:

“I was told it is no longer available to my son.”

“Does it apply for adult?”

Regional Center Families That Did Not Have BHT As of 07/01/12 - Did You Pursue BHT?

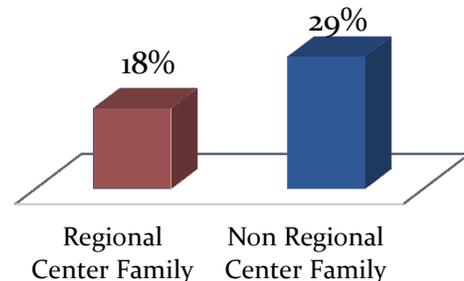


Awareness of Mandate – Regional Center Families

Overall, Regional Center families were more aware of the Autism Insurance Mandate (SB 946 – Steinberg) than non-Regional Center families (82% of Regional Center families were aware of the Mandate vs. 71% of non-Regional Center families).

Out of the Regional Center families that were not aware, 37% were on Medi-Cal, 24% on California regulated insurance and 26% had federally regulated insurance.

Not Aware of the Autism Law



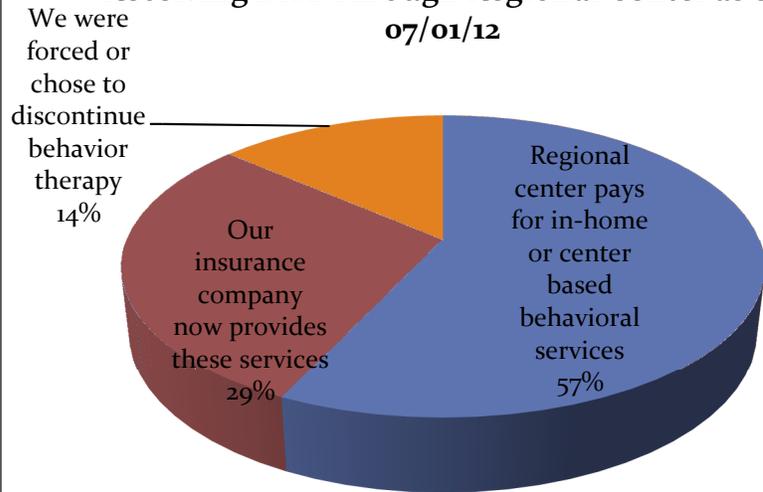
Issues Surrounding the Transition Process for Regional Center Families Receiving BHT as of 07/01/12

Families that are Regional Center clients are required apply for BHT first through their health insurance, because the Regional Center is the payer of last resort. If families present denial letters from the insurance company, Regional Center may provide medically necessary treatments as part of the Individual Program Plan (IPP). This new process resulted in a considerable transition for families who were already receiving BHT through Regional Center.

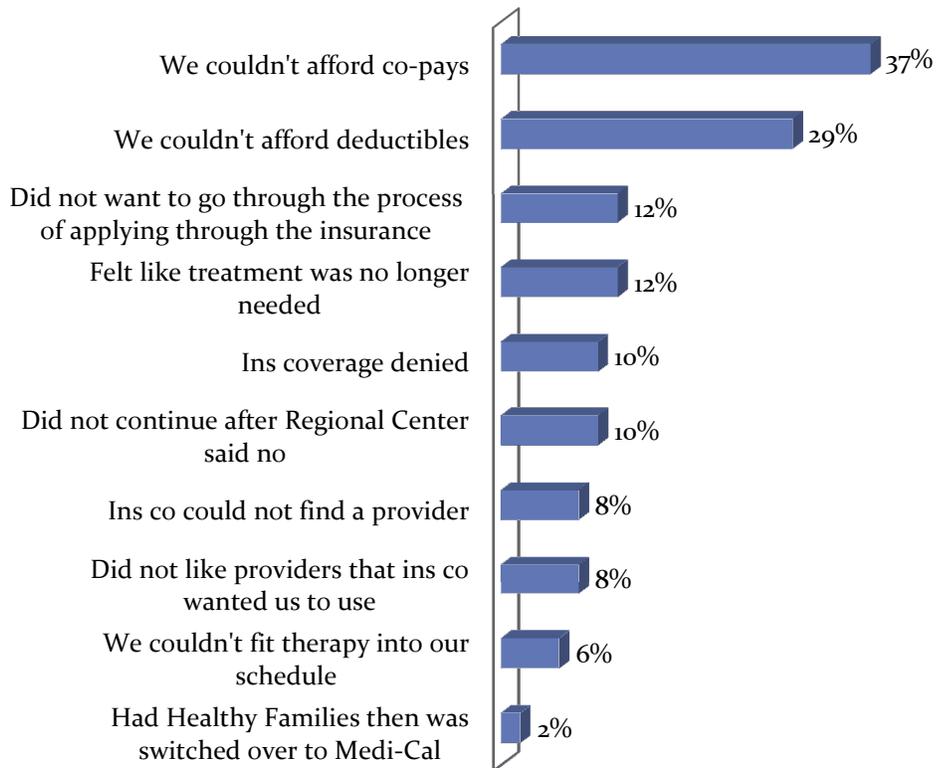
Of the families that were receiving BHT funded through Regional Center as of 07/01/2012, 14% ended up discontinuing BHT; 29% have BHT funded through their insurance company, and 57% continued services with Regional Center.

Sixty-six percent (66%) of these families who discontinued BHT stated their decision was due to financial hardship – 37% could not afford co-pays and 29% could not afford their deductible.

Regional Center Families Who Were Receiving BHT Through Regional Center as of 07/01/12



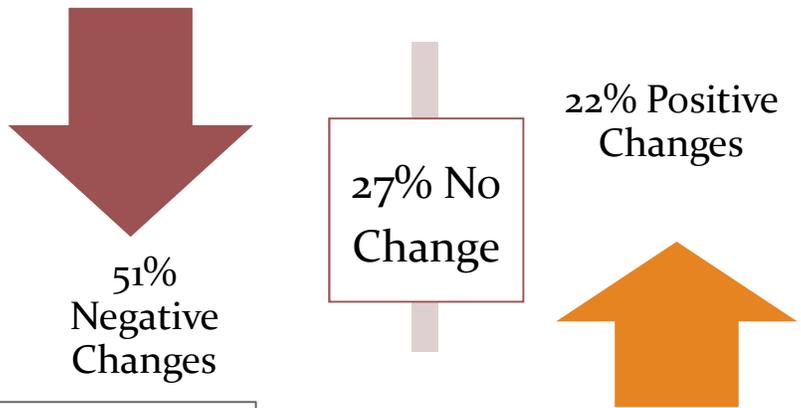
Regional Center Families Receiving BHT As of 07/01/12 - Why Was BHT Discontinued?



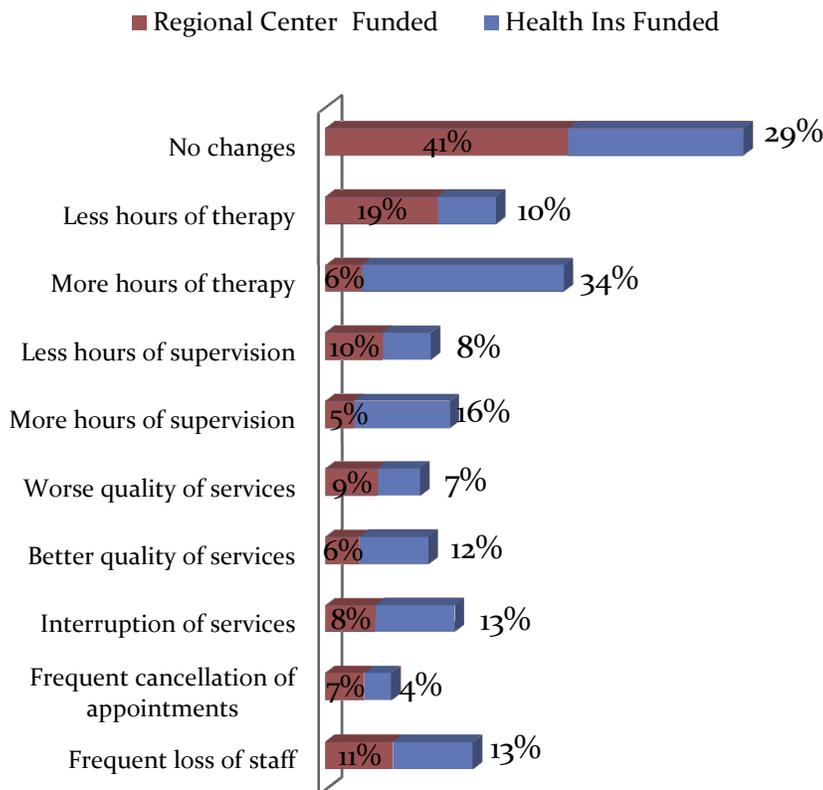
Financial hardship due to 2013 Budget Act changes relating to co-pays and deductibles was a significant impediment for families who were receiving these services fully funded by Regional Center prior to July 2012. This is discussed in more detail in the Deductible and Co-Pay sections later this report.

Of the Regional Center families who had BHT funded by Regional Center as of 07/01/2012, there were more than twice as many reported negative changes as positive changes; 51% vs 22%.

Regional Center Families That Had Existing BHT Programs as of 07/01/12 - Quality of Your BHT Program Since 07/01/12



Regional Center Families Already Receiving BHT- What Changes Have Taken Place in Your BHT Since 07/01/12?

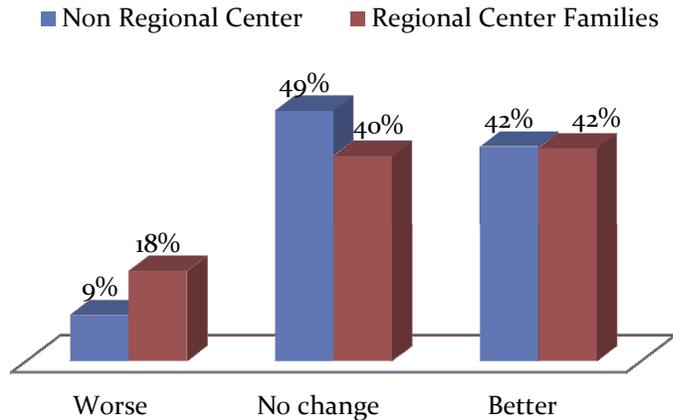


When we look at the detailed breakdown of those changes, 34% of the Regional Center families who had been receiving Regional Center funded BHT services prior to 07/01/2012, report that they are now receiving more hours of therapy now that they have switched to health insurance funded services. Conversely, 19% of those who stayed with Regional Center funded BHT, reported that they were receiving less hours of BHT post transition.

However, families also report having had an interruption of service during the transition period, frequent cancellations of appointments, frequent loss of staff and in some cases, a worse quality of service overall.

Quality of Life - Regional Center Families

How Has Your Quality of Life Changed Since 07/01/2012?



On the whole, Regional Centers families report an improvement in their quality of life since the passage of the Autism Insurance Mandate; 42% of Regional Center families stated that their life has improved.

"I have 2 sons with autism had it not been for Regional Center I would not have survived raising my sons the guilt the uncertainty of our future felt grim[sic]now we have faith trust and understanding."

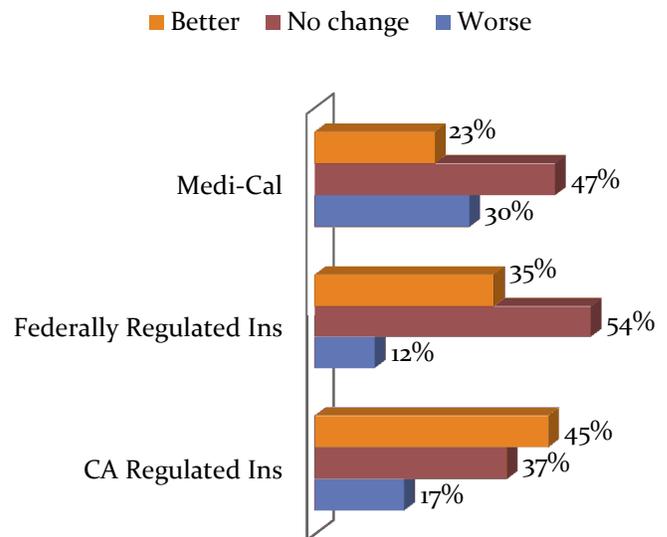
"The ABA treatment we have received from this law has been life changing. We hope the sunset will be removed somehow."

While overall, more Regional Center families reported a higher quality of life, when looking at the quality of life by type of insurance, more Regional Center families with California regulated health insurance report a worse quality of life than families with federally regulated health insurance (17% California regulated vs 12% federally regulated), primarily due to issues with co-pays and deductibles. More striking, twice as many Regional Center families are worse off than non-Regional Center families (18% vs 9%). These differences are primarily due to issues with co-pays and deductibles due to the 2013 Budget Act and the administrative burden of accessing insurance.

"He was already getting ABA therapy paid for by the regional center, for free, when this law passed. Now unfortunately, we have to pay co-pays for daily services. We were better off prior to this law passing!"

The parent is the person providing the 24hrs of service...the behaviorist trains us. But now we are paying and doing insurance paperwork which added to our burden.

Regional Center Families - Self-Rate Quality of Life, By Type of Insurance - As of 02/07/2014

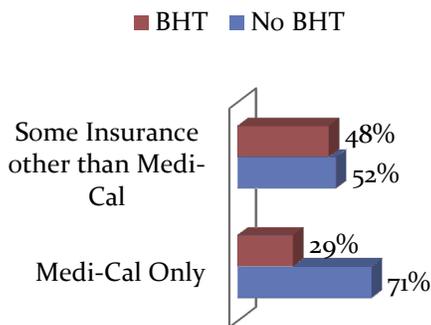


Other families indicated their frustration with time delays, service providers and feeling that they have to do more work when they are already stretched thin:

“Although I agree with the intent of the law, our child’s age is such that we got caught in a horrible gap of coverage and changing policies that were not applied well or quickly. Neither [the Regional Center] nor my insurance would take responsibility and it was our child that lost out. The time it takes to get a diagnosis and THEN start the regional center process, get ANOTHER DX through the regional center, then wait 6 weeks, then start to get on a wait list for an ABA provider - all while not knowing WHO will fund the therapy - is terribly time consuming when you’re trying to get intervention in a critical ‘window of opportunity’.”

Regional Center Families Who Have Medi-Cal

Receiving BHT as of 7/2012



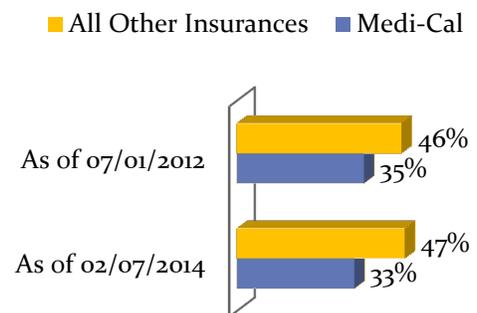
The graph on the left illustrates how all Medi-Cal families (Regional Center and Non-Regional Center) were affected by the Mandate. These families should not have been affected by the transition, and Regional Center should have continued funding these Medi-Cal families’ BHT services. However, the Regional 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 Medi-Cal families began worse off than families with any other type of insurance (71% were without any BHT vs. 52% who had some other insurance). Conversely, very few families on Medi-Cal were receiving BHT (only 29%) in 2012, and they continued to become even worse off after the Mandate.

Regional Center families with only Medi-Cal were not as badly off as Medi-Cal only families with no Regional Center eligibility. 65% were without any BHT compared to 54% of Regional Center families who had some other insurance and 71% all Medi-Cal only families.

Very few families on Medi-Cal were receiving BHT in 2012, and not surprisingly did not show increased access to BHT since they were excluded from the Mandate. However, while all other subgroups had more people better off than worse off - 19x, 5x and 3x for non-Regional Center state regulated, non-Regional Center federally regulated and Regional Center state regulated, respectively (see charts on page 21 and 27) respectively, the Medi-Cal Regional Center subgroup had almost 2 x more people worse off than better.

Regional Center Families Medi-Cal and Have Accessed BHT

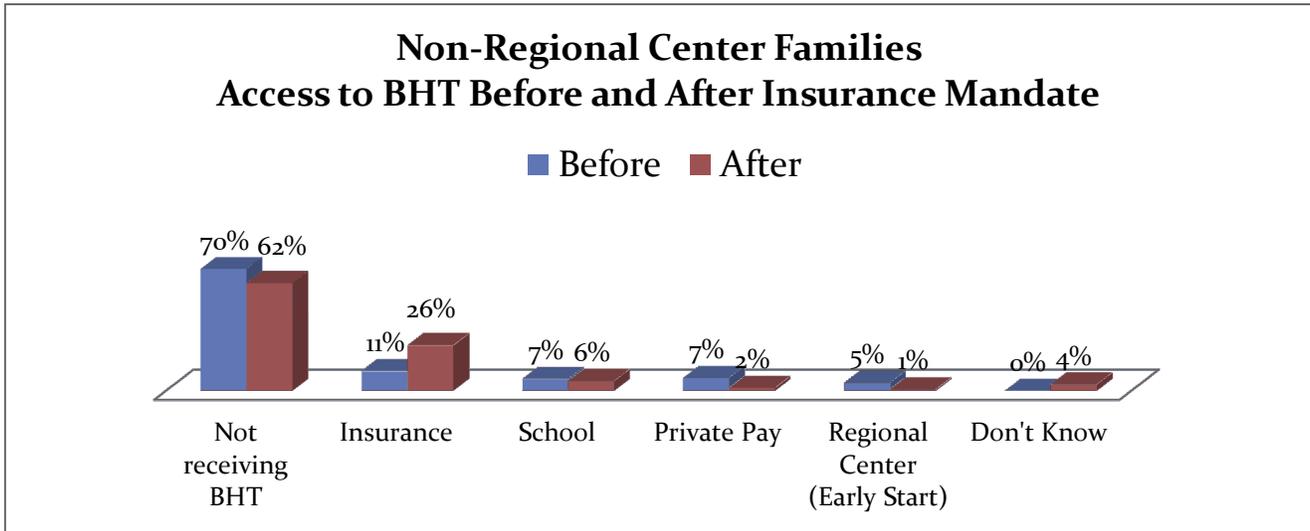


“It would of been better if we weren’t part of the Healthy Families transition to medical and if the state funded medical insurance was not exempt from the state mandated law it would have been WONDERFUL but because it is dealing with another state funded nonprofit privately owned agency is EXHAUSTING!!!”

“Hours reduced with IRC when not covered by Insurance.”

Non-Regional Center Families

Access to BHT – Non-Regional Center Families



The 2014 ASC Survey showed that the biggest impact the Autism Insurance Mandate (SB 946 - Steinberg) has had on the non-Regional Center family population is an increase in access to BHT (from 30% to 38%).

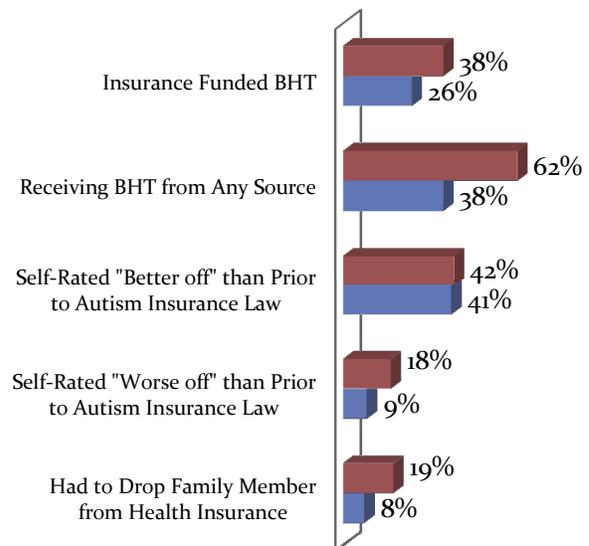
Equally important was a meaningful reduction in private pay funding (7% to 2%) and, while much less significant than for Regional Center families, a reduction in Regional Center funding through early start (5% to 1%). The reduced private and Regional Center funding was replaced by a significant increase in health insurance funding (11% to 26%). As with Regional Center families, the financial savings to families who privately paid and Regional Centers came despite improved access to BHT overall.

While insurance funding for both non-Regional Center and Regional Center families dramatically increased, (240% and 400%, respectively), the

Comparison of Families as of February 2014

■ Regional Center ■ Non-Regional Center

#1 Reason Regional Center Families Dropped Family Member from Health Insurance - Could Not Afford Co-pays/Deductible



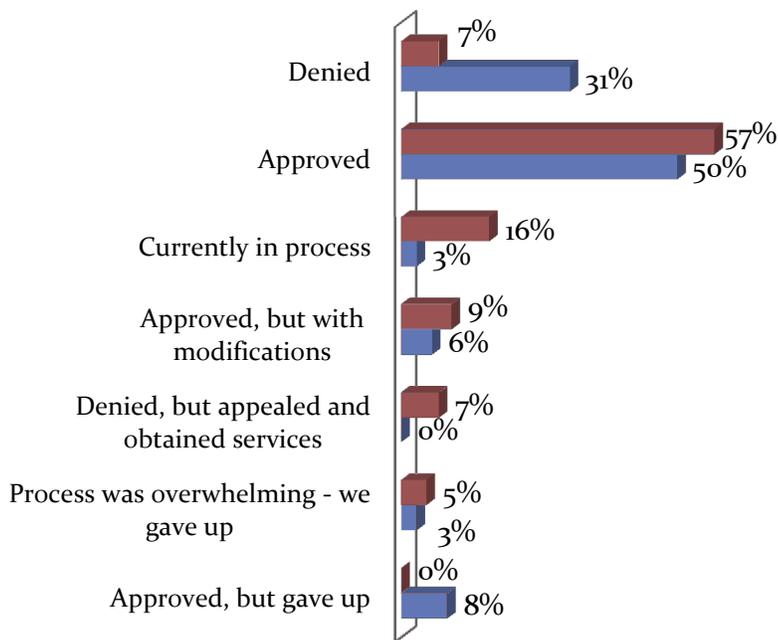
increase in insurance for Regional Center families was more dramatic.

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).

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 insurance.

Non Regional Center Families Who Pursued BHT Since 07/01/12

■ State Regulated ■ Federally Regulated



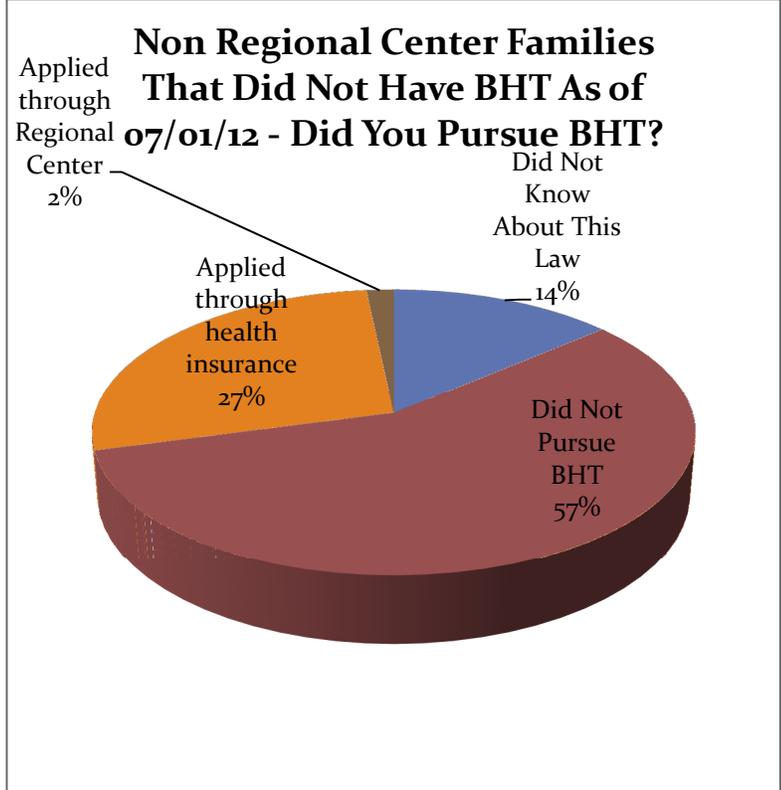
Overall, for the non-Regional Center families that did pursue BHT (those who were privately paying and those who were not receiving BHT) with state or federally regulated health insurance, nearly 60% were approved for BHT services.

However, more than 18 months after the passage of the Autism Insurance Mandate, 43% of individuals with California regulated health insurance have had moderate to severe trouble accessing services: 7% were denied, another 7% were denied and successfully appealed, 9% were approved but with modifications, 5% gave up because the process was overwhelming, and 16% are still in process.

Non-Regional Center Families Who Did Not Pursue BHT

As stated above, there was not as a large a shift for families that were not receiving BHT. Out of the 78% of non-Regional Center families that did not have BHT as of 07/01/2012 – less than 1/3 pursued BHT (27% pursued health insurance and 2% pursued Regional Center for BHT).

While the survey did not examine this point in detail, we do know that 14% of this population did not know about this law. Many of the comments we received showed the diversity of possible causes for this, including that families were interested in services to support employment and independent living, the person with autism does not need this type of service at this time, to not understanding what BHT is and the services associated with this type of therapy.

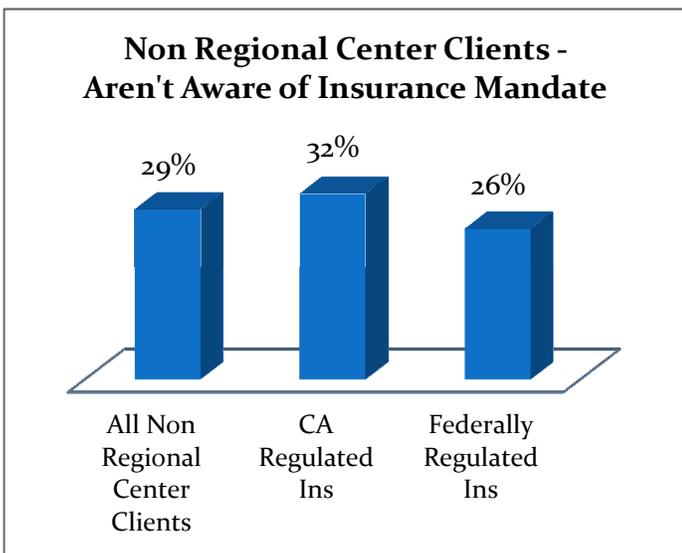


"I'm not sure what law this is, but the person with Autism is doing very well..."

"Where is the access for the help for young adults?"

"I was told he would not qualify for behavioral modification because he had aspergers [sic] not autism (at the time)"

"looking for job coaching and Independent Living support"



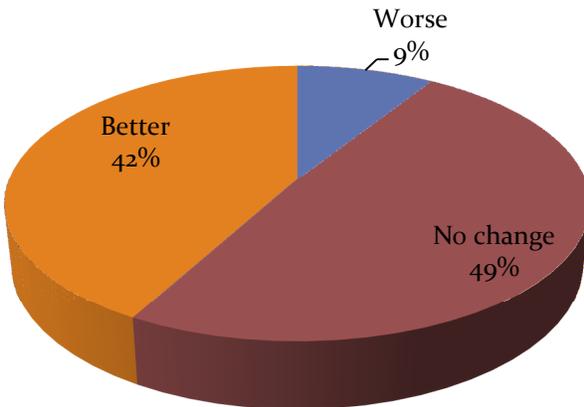
Awareness of Mandate – Non-Regional Center Families

Compared to Regional Center clients, non-Regional Center clients were less likely to know about the Autism Insurance Mandate; 29% of non-Regional Center clients were unaware versus 18% of Regional Center clients). Nearly a third of non-Regional Center families with State Regulated Insurance were not aware of this law.

This sample was not sufficient to obtain information on how non-Regional Center low income or non-English speaking households were affected.

Quality of Life - Non-Regional Center Families

Non Regional Center Families - How Has Quality of Life Changed Since 07/0/12?



Forty-two percent (42%) of the non-Regional Center families advised that their quality of life has improved since the passage of the Autism Insurance Mandate (SB 946-Steinberg). Of these families who reported a better quality of life, over 90% of them applied for BHT through their insurance company since the passage of the Autism Insurance Mandate.

"[Before SB 946] We were one payment away from defaulting on our mortgage - and we consider ourselves lucky because we had a home to mortgage. Now families with a newly diagnosed child who are fortunate to have CA regulated insurance have an option that doesn't involve the financial terror on top of the stress and uncertainty of navigating a new diagnosis."

"The school district used to pay for all my son's ABA (both at school and at home) before the Autism insurance Law passed. The school was going to cut off his home ABA but insurance enabled us to continue the medically necessary home services for another year so his medical goals could be met. He [is] a best case scenario because of the intervention he received from the regional center, the school district and FINALLY insurance and is mainstreamed in 6th grade entirely without an aide"

"Our son was diagnosed after the law went into effect. I am very grateful that we have not had some of the hardships that I have heard others facing. Our insurance covers 100% of our son's ABA costs. We would not be able to afford ABA otherwise."

Out of the 49% of the non-Regional Center families who indicated that there was no change in their quality of life, many respondents cited their frustration that Medi-Cal or federally regulated policies were not affected:

"Nothing seems to have changed with Medi-cal... They're still denying everything we apply for."

"We have self-funded insurance through my company and the law specifically excludes those policies, so the law has had NO effect on me, it is no help at all."

For the families who have indicated that their quality of life has gotten worse (3% of families with California regulated insurance), comments indicated that some of the difficulty was due to the high demand for services:

“The law caused a huge influx of new clients and our vendors were completely unprepared.”

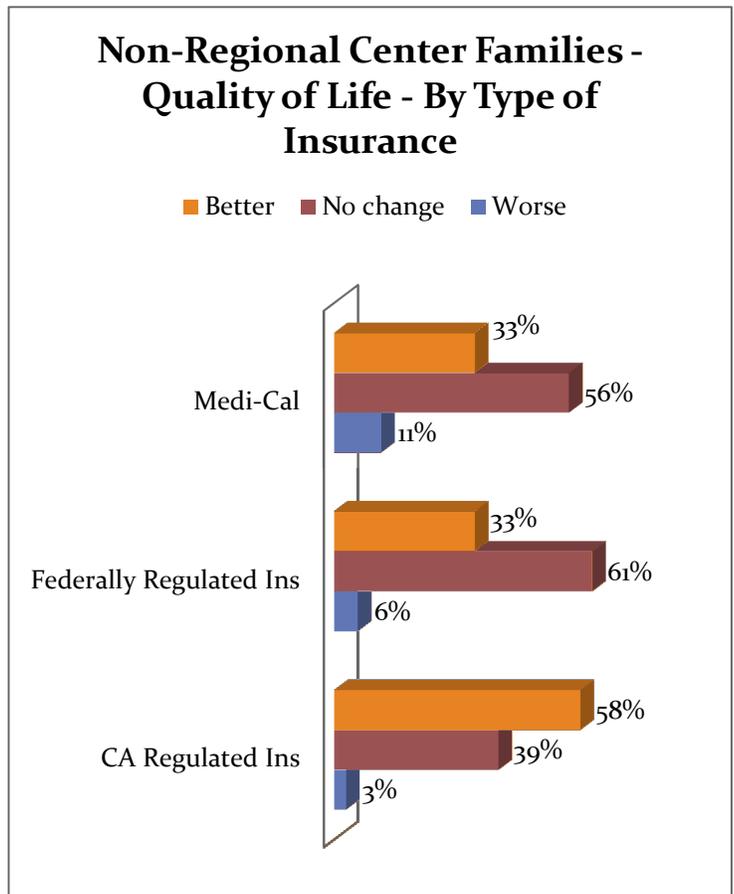
Fifty-eight percent (58%) of non-Regional Center families with California regulated insurance felt they were better or much better off after the Insurance Mandate. This percent is strikingly similar to the 64% of families with California regulated health insurance who applied for and received BHT.

Overall, non-Regional Center clients with California regulated insurance are nearly 19 times more likely to feel they are better off than worse off. The positive effect of the Insurance Mandate can also be seen for those families with federally regulated insurance.

While not as big a difference, five times more non-Regional Center families with federally regulated insurance feel they are better off than those who feel worse off. This improvement may be explained by the fact that some self insured companies have voluntarily chosen to follow state law and have added an autism insurance benefit.

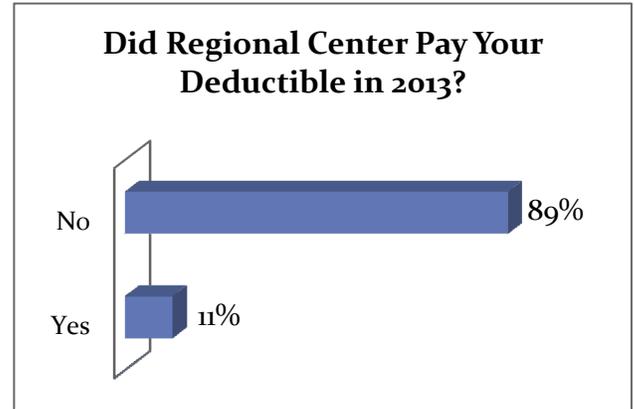
Unfortunately for Regional Center families, the benefit of the autism insurance law is significantly lower than for non-Regional Center families. Even though a higher percentage of Regional Center families accessed new behavioral services through insurance, only 2.6 times more Regional Center families feel better than worse off. Comparitively, 7 times more non-Regional Center families believe they have a positive effect from the Autism Insurance Mandate than a negative one.

Autism Society of California expects the significantly less positive impact for Regional Center families despite better access is because of the issues with co-pay and deductible issues described in the following section.

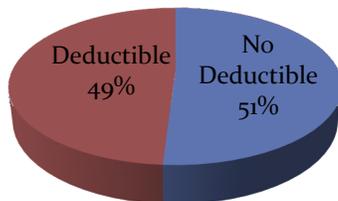


Impact of Prohibiting Assistance with Deductibles

Welfare and Institutions Code 4659.1 Section 7 was signed into law on June 27, 2013 prohibiting Regional Center from paying any health insurance policy deductibles. Before W&I Code 4659.1 was passed, few families had been able to get help from Regional Centers with deductibles. Therefore, in 2013, very few families were able to secure financial assistance from Regional Centers for their deductibles. The survey showed that 11% of families received financial assistance with their deductible in 2013.

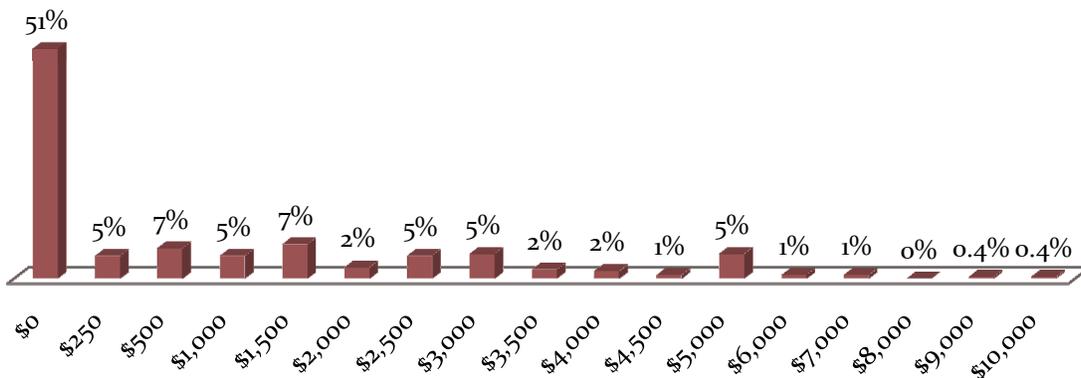


Regional Center Families Receiving BHT - Do You Have a Health Insurance Deductible for BHT?



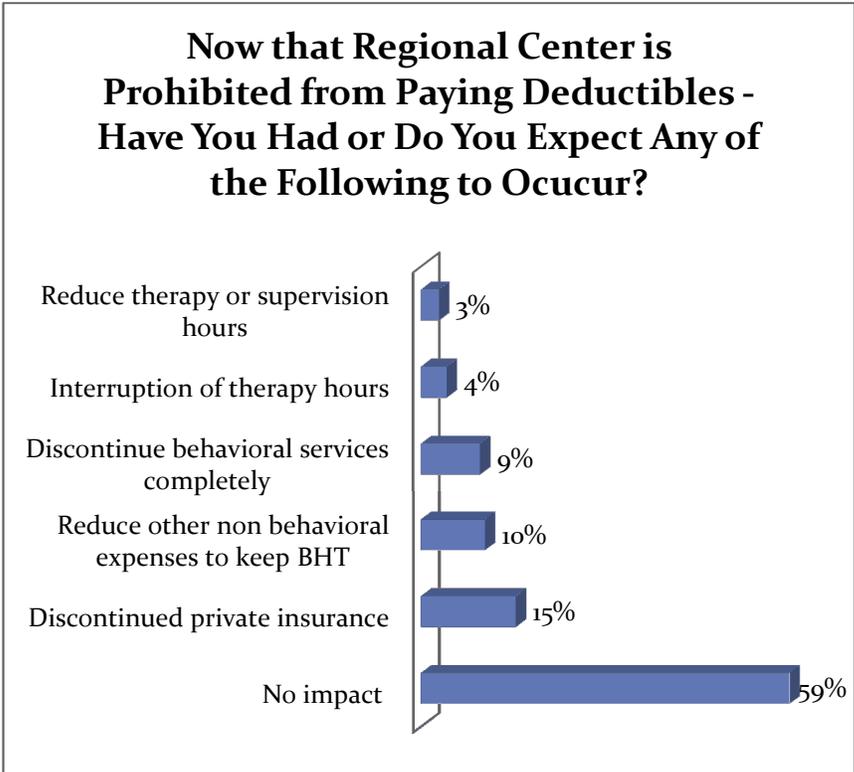
It is important to note that not all families accessing BHT have deductibles. The survey showed that less than half the Regional Center families have any deductible before they can access BHT. For the families that do, the average deductible was \$2,382.35 with the most common deductibles at \$500 and \$1,500 (tied with 7% of respondents).

Regional Center Families - What Is Your Health Insurance Deductible for BHT?



One of our concerns is that more families will be impacted as we get further into 2014, for the reason that at the start of a new calendar year, a new deductible must be met.

While 59% of Regional Center families with BHT reported that they expected no impact, 18% had to, or expect to, reduce therapy or supervision hours, 9% of the families had to, or expect to, discontinue BHT completely and another 10% reduce other services to keep the BHT. Four percent (4%) had an interruption, or expect an interruption, in therapy (stopped therapy for a time) and 15% went to, or plan to, go to the extreme of discontinuing their private insurance, transferring the entire cost of their medical care to the state, the BHT to the Regional Center, and the other medical care to Medi-Cal.



Personal Comments from Respondents:

“We had a 10k deductible with a \$60 copayment per session. Have since put [our son] on medical and ourself on ACA because private insurance was not affordable.”

“Two children with autism--will have \$1500 in deductibles per month until we hit insurance max [sic]. We will pay but it will be difficult.”

“Financial hardship on family as our deductible is \$5,000”

“our insurance company is responsible for picking up the behavioral services, HOWEVER we must first meet our insurance deductible, pay visit copays & co insurance cost BEFORE the insurance company will financially cover this service. Estimated cost out of pocket is over \$5000 annually. We financially cannot support this out of pocket expenditures! Our family currently does not have a company sponsored insurance plan. We cover (purchase) our families monthly premium health insurance cost.”

Issues Surrounding Co-Pays

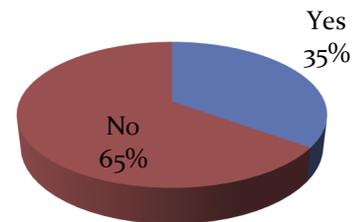
In addition to prohibiting Regional Centers from paying deductibles, Welfare and Institutions Code 4659.1 Section 7 stated that Regional Centers may pay co-pay/co-insurance for services specified on the IFSP/IPP if all three conditions:

1. Consumer is covered by an insurance plan
2. Annual gross income does not exceed 400% of federal poverty level.
3. There is no 3rd party liability for cost of service

It then goes on to say that an exception can be made to the income requirement if family provides proof of one of the following: (A) Extraordinary event that impacts caregiver’s ability to provide care, or pay the co-payment (event not specified), or (B) Catastrophic loss (natural disaster, accident involving major injury to immediate family member that has direct economic impact, or (C) Significant unreimbursed medical expenses for another child who is also a consumer.

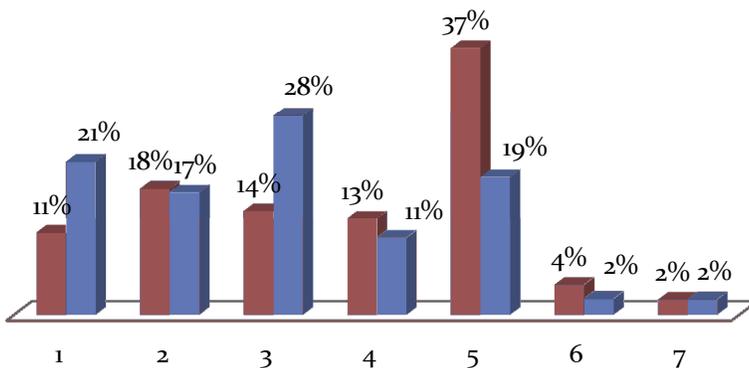
Prior to the passing of W&I Code 4659.1, Regional Center was able to assist ALL families with co-pays and deductibles, however implementation was inconsistent across the Regional Centers. Many families had reported not being able to receive assistance with their co-pays. Since the Budget Act was passed consistency has improved, but many families are prohibited above 400% FPL with very limited exceptions.

Regional Center Families - Did Regional Center Pay for Your Co-Pay in 2013?



Families Using Health Insurance to Fund BHT - Number of BHT Sessions A Week

■ Regional Center Family ■ Non Regional Center Family

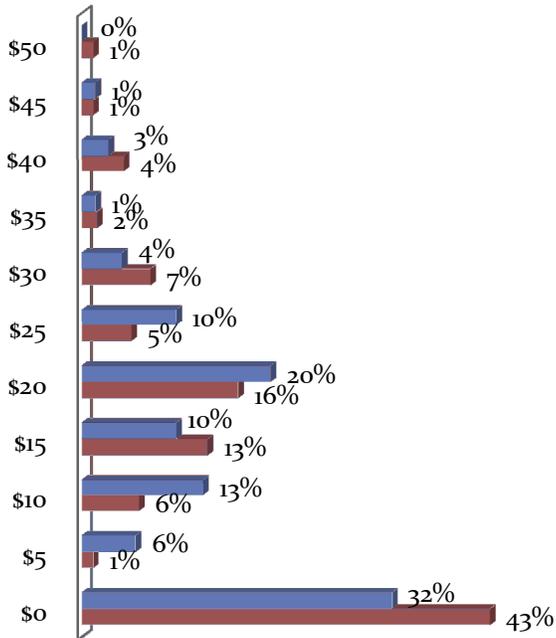


Regional Center families indicated that 35% of of them received assistance from Regional Center with their co-pay last year.

Over half (56%) of the Regional Center families with insurance have BHT treatment 4 or more times a week, with 5 times a week being the most common for these families. Non-Regional families reported 3 times a week being the most common number for BHT. The survey did not capture the reason

Co-Pays for Families with Health Insurance Receiving BHT

■ Non Regional Center Families
 ■ Regional Center Families



for this discrepancy.

The majority of both the Regional and non-Regional Center families have no co-pay for this service (43% Regional Center families, 32% non-Regional Center families).

Of the families that have co-pays, 16% of the Regional Center families have a co-pay of \$20 each visit. This is a significant cost for the families above the 400% federal poverty level.

For a single mother with two children, one with autism who makes \$78,200 annually, this newly enacted Budget Act would require her to pay the \$20 co-pay at each of the BHT visits. Using the most common of 5 days a week, that would require her to pay \$400 per month just for BHT for her child. If out of pocket maximums are not applied to BHT, total out of pocket costs for a typical family would be copays of \$5280 (\$400 x 12 months) plus the deductible (average of 2,382.35) for a total of \$7662.

In fact, 75% of Regional Center families feel that paying the co-pays and deductibles pose a financial hardship on their family; 57% strongly agree that it does. We received many comments emphasizing this:

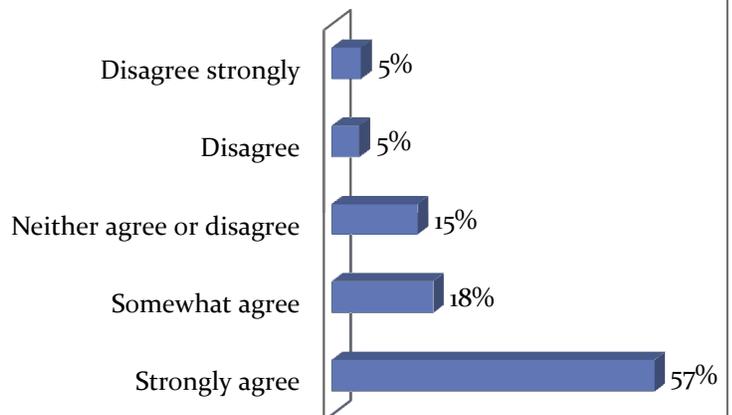
“We pay \$6500 a year in co-pays for ABA and speech therapy- 260 sessions a year.”

“had to drop other therapies in order to pay for ABA”

“This would cause a huge interruption in my son’s therapy. The cost would amount to \$400 a month which is a huge bill for our family. It would be unreasonable to ask families to pay the deductibles especially because our kids need ABA therapy on a daily basis.”

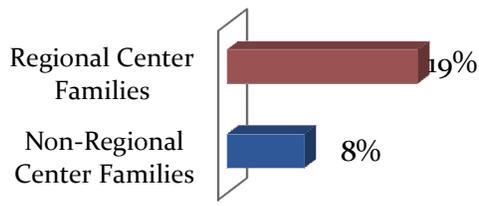
“We are going to have to reduce all therapies now that Regional Center will not pay copays.”

Regional Center Families - Is Paying the Co-pays and Deductible for BHT a Financial Hardship on Your Family?



Dropping Individuals with Autism from Health Insurance Plans

Had to Drop Person with Autism from Health Insurance



In looking at those families who dropped the person with ASD from their health insurance plan, the survey showed that 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 ABA through the Regional Center due to the inaffordability of co-pays and deductible costs, especially for Regional Center families (21% of Regional Center clients vs 5% non-Regional Center clients).

Instead of shifting 90% of the costs from Regional Centers to private insurance, which was the intent of the law, The Budget Act co-pay and deductible changes the Autism Insurance Mandate from shifting the cost of BHT from Regional Centers to insurance companies AND families.

This reduces the savings to the state by disincentivising Regional Center families from aggressively pursuing insurance as they otherwise would. Further, the financial burden of co-pays and deductibles caused by the 2013 Budget Act changes shift the entire cost of BHT AND medical care for those who dropped private insurance (15-19% of RC families) to the Regional Center and Medi-Cal, respectively, likely far offsetting any hoped for savings.



These are widespread and serious consequences that significantly undermine the positive effects of Autism Insurance Mandate (SB 946 – Steinberg) for Regional Center families.

Many families were forced to reduce or discontinue BHT and other services, and 15-19% dropped the Regional Center client from private health insurance or dropped the policy altogether because of the 2013 Budget Act.

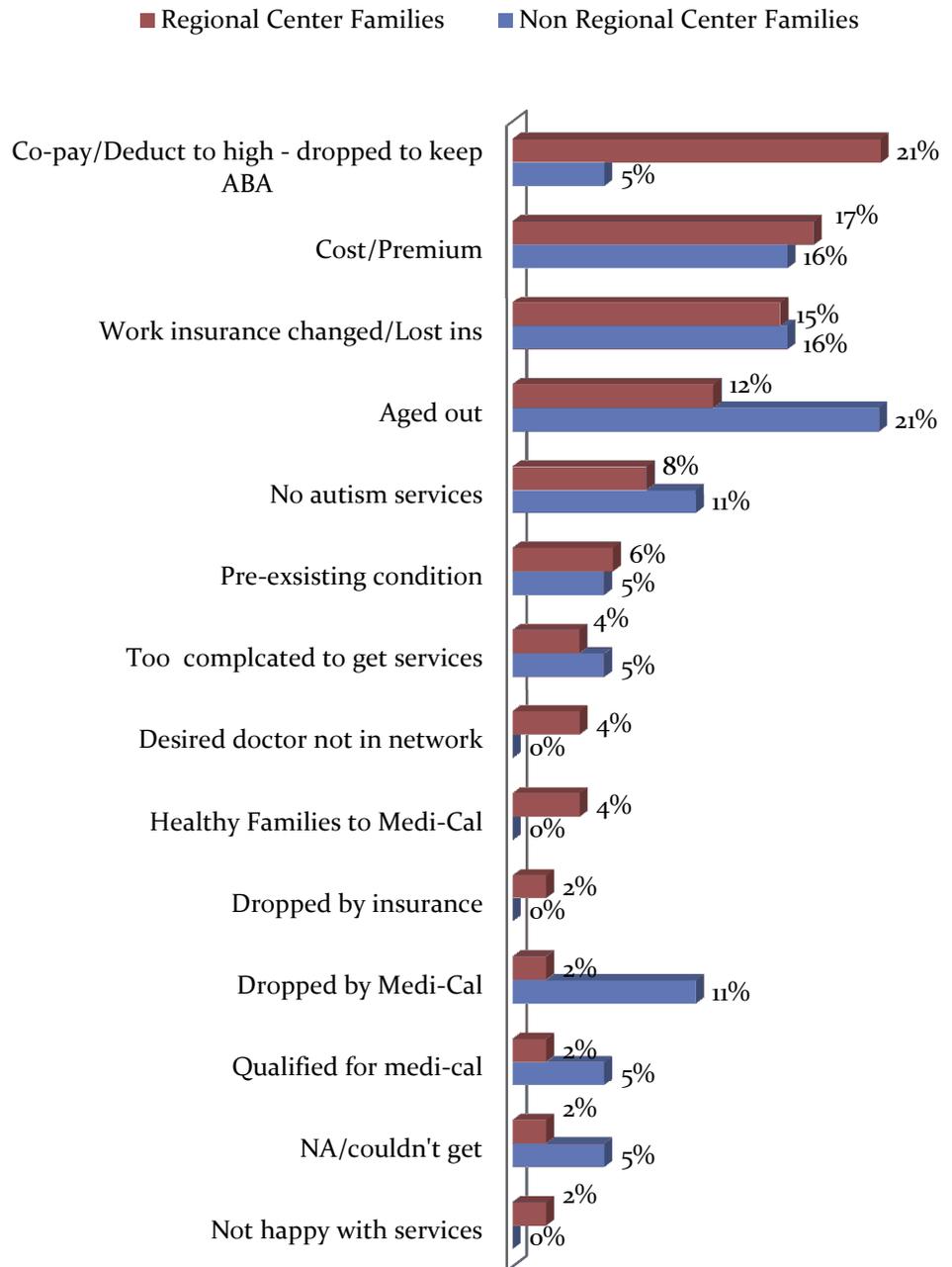
“could not afford copayment and deductibles for services”

“Extremely high deductible that we cannot pay/high copays for ABA”

“Co-pays too expensive, gaps/delays in service, too much hassle.”

“long battle with insurance company ensued after diagnosis of two of our three children. we later insured our autistic child separately from rest of family.”

Had to Drop Person with ASD from Health Insurance



Navigating The Health Insurance Process for Behavioral Health Treatment (BHT)

Timely Access

California law requires health plans to provide timely access to care. The Knox Keen Act advises that requests for treatment be processed within 5 days, and The Timely Access regulations [Rule 1300.67.2.2 subsection (c)(5)(e)], requires that mental health appointments should be available within 10 days.

The 2014 ASC Survey showed that only 11% of families with California regulated plans received authorization within the required 5-day time frame, 79% of California families had a delay greater than 14 days; 64% indicated that services took more than 31 days.

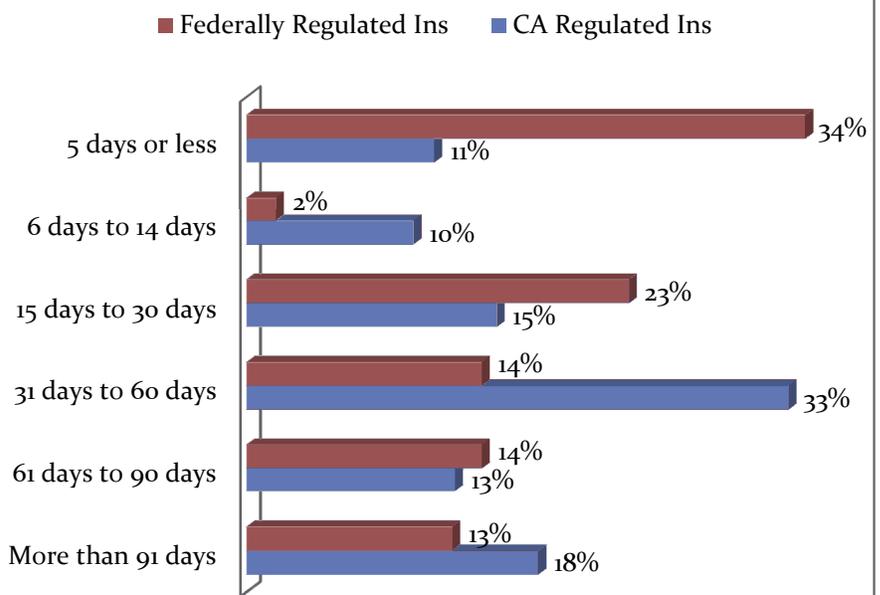
This is only a small improvement from the ASC 2013 Health Insurance Survey where 75% of families with California regulated plans indicated that insurance plans took more than 31 days to provide BHT.

Further, it compares unfavorably to federally regulated plans that meet a 5-day timeline 34% of the time and exceed 14 and 31 days 64% and 41%, respectively.

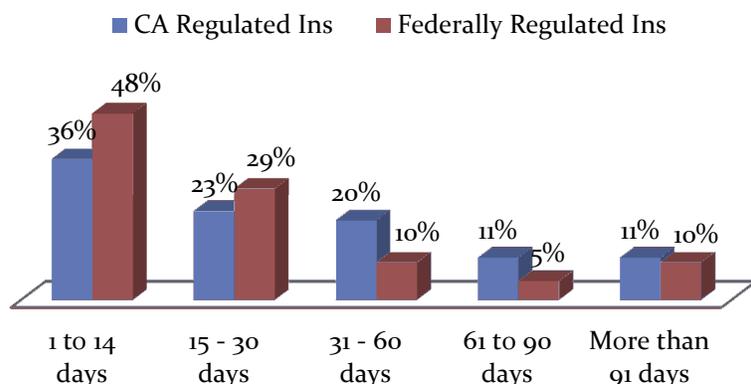
“Requested service in Nov. 2013, currently waiting for help.”

“We applied in Sept we are waiting to start next week - 1/27/2014”

All Families with Insurance - How Many Days Did It Take The Ins Company to Process Whether You Were Approved or Denied for BHT?

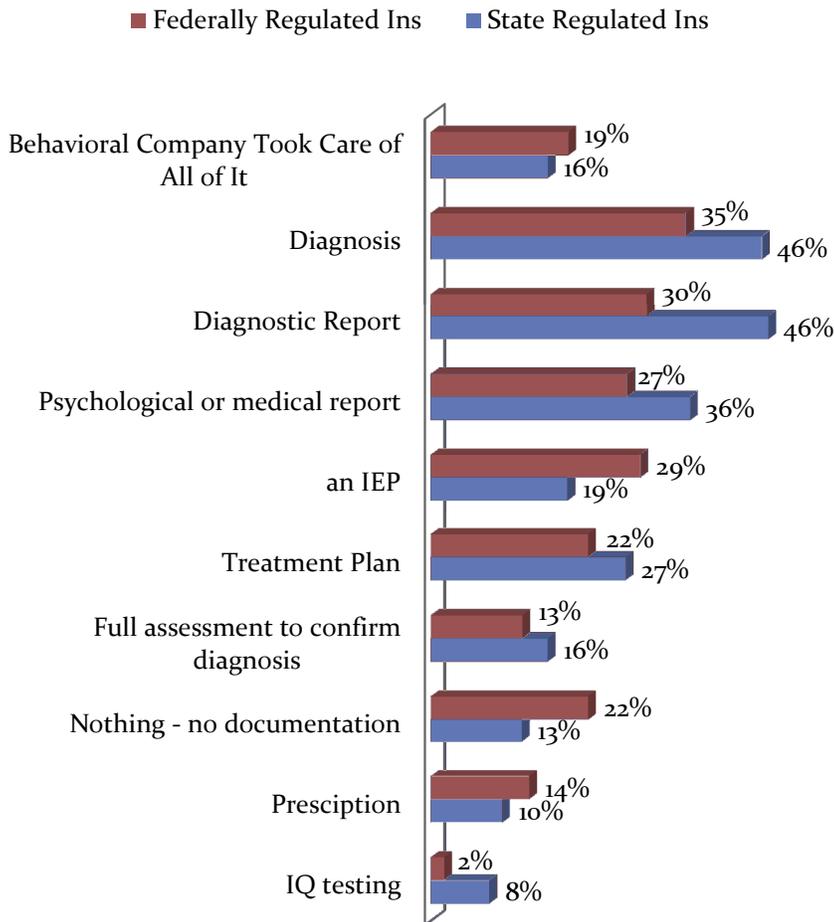


All Families with Insurance - How Long Did It Take to Start Therapy Once You Were Notified on the Approval?



Excessive Requirements for Approval

All Families with Insurance - What Documentation Did the Insurance Company ASk for to Process BHT?



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.

“Home based was not working as the students they had working could never agree on a plan. I had had enough. We were supposed to start ABA with professionals and we are still waiting... since at least last June.”

Denials

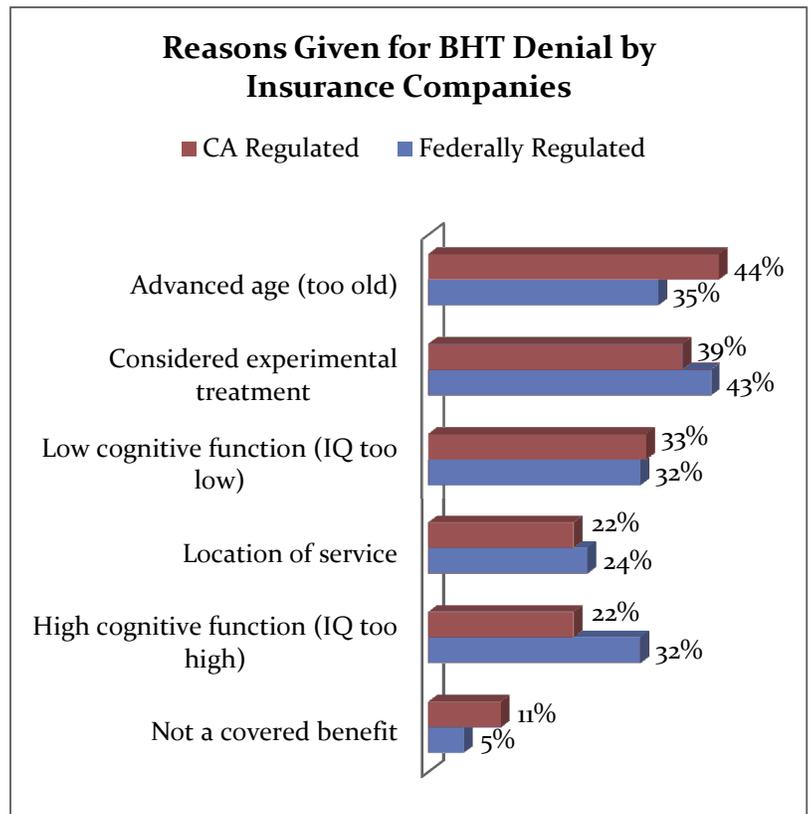
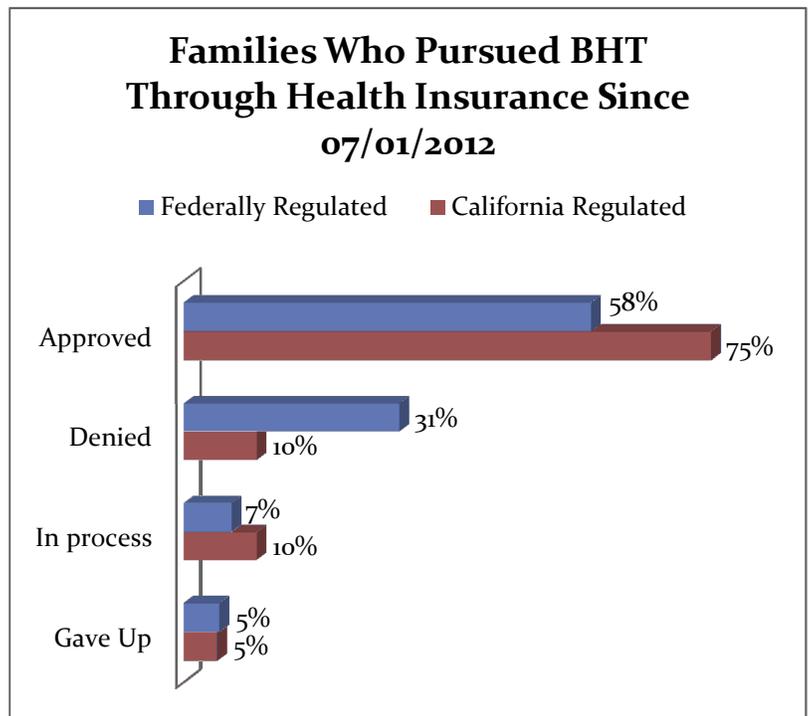
Focusing on the California regulated plans that should be covering BHT, 10% of families were still denied BHT.

Forty-four percent (44%) of denials were due to advanced age despite the law having no age caps. Thirty-three (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. The Autism Insurance Mandate requires improvement in functioning to the maximum extent practicable. The significant number of inappropriate denials due to cognitive function has led the California Department of Insurance (CDI) to pass emergency regulations (ER-2013-00001), specifically prohibiting, among other issues, denials or delays based on cognitive function, IQ and/or developmental testing preauthorization requirements.

Also concerning, location of service was cited as a reason for denial in 22% of cases. Location of service is not an appropriate reason for denial, as the Autism Insurance Mandate requires coverage of all medically necessary BHT.

Most alarming, 39% of denials still asserted BHT was experimental and 11% of the families were advised that BHT was not a covered benefit. This despite the Autism Insurance Mandate clearly establishing BHT as a required benefit when medically necessary, with over 90% of denials being overturned by DMHC and CDI since 2008, and CDI's May 17, 2011 all-plan notice stating that BHT was "now recognized as the standard of care for autism."

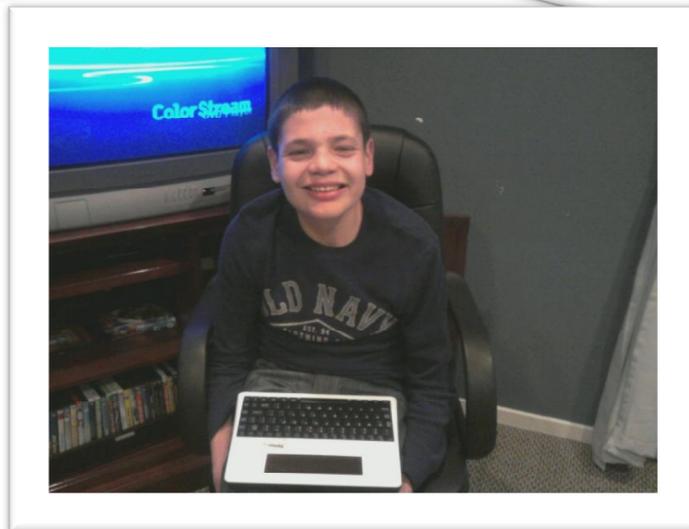
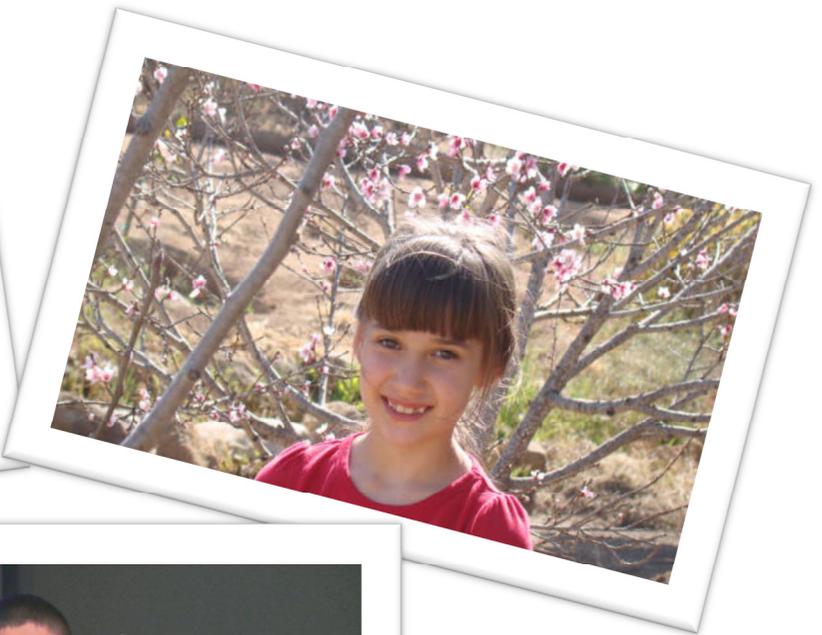
Another concern that surfaced within the comments is that health plans and insurers are modifying therapy requests, such as hours of therapy,



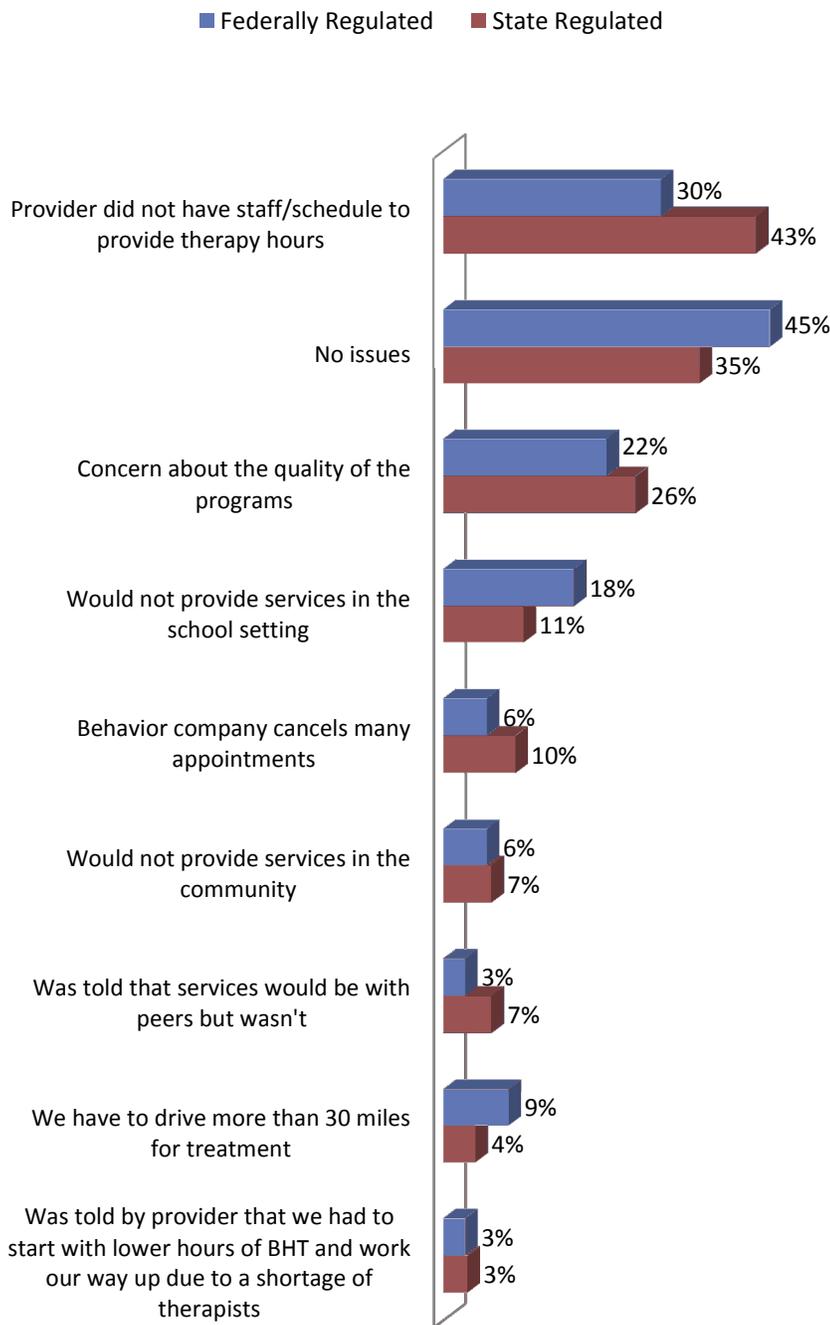
hours of supervision and duration of services without issuing denials. Under the Knox Keene Act IMR statute [Subsection (e) of Health and Safety Code Section 1374.30], modifications are considered denials and must be treated as such by insurance companies, including informing the family of the right to an independent medical review. If enrollees are not issued denials for modifications, enrollees are not even informed there was a denial nor of their right to appeal and seek an independent medical review. The regulators are also unaware of and unable to regulate these types of denials.

“Our provider requested 6 months of medically necessary treatment and our health plan only approved 2 months but did not issue a denial letter. We had to get approval for ABA every 2 months for nearly a year.”

“My son’s supervision hours were reduced from what was requested. Neither the provider nor I even realized it for several weeks because no denial letter was issued.”



**Families Who Utilize Health Insurance for BHT -
What Issues Have You Encountered With BHT
Providers?**



Adequate Network

Under the Autism Insurance Mandate (SB946 – Steinberg), every health insurer must maintain an adequate network that includes qualified autism service providers, who can be either certified by a national entity, such as the Behavior Analyst Certification Board, or licensed under Division 2 of the California Business & Professions Code.

The Regulators’ concern about healthplans and insurers having adequate networks of BHT providers was sufficient that the Department of Managed Health Care issued emergency regulations (Rule 1300.74.73 – Control Number 2012-3681) very soon after the effective date of the Autism Insurance Mandate requiring health plans to document that their networks were adequate. At the same time, the California Department of Insurance verified health insurers’ BHT networks.

Health plans have made progress developing their BHT networks. 35% of families with state-regulated plans had no provider issues, somewhat less than those with federally regulated plans, of whom 45% experienced no provider issues.

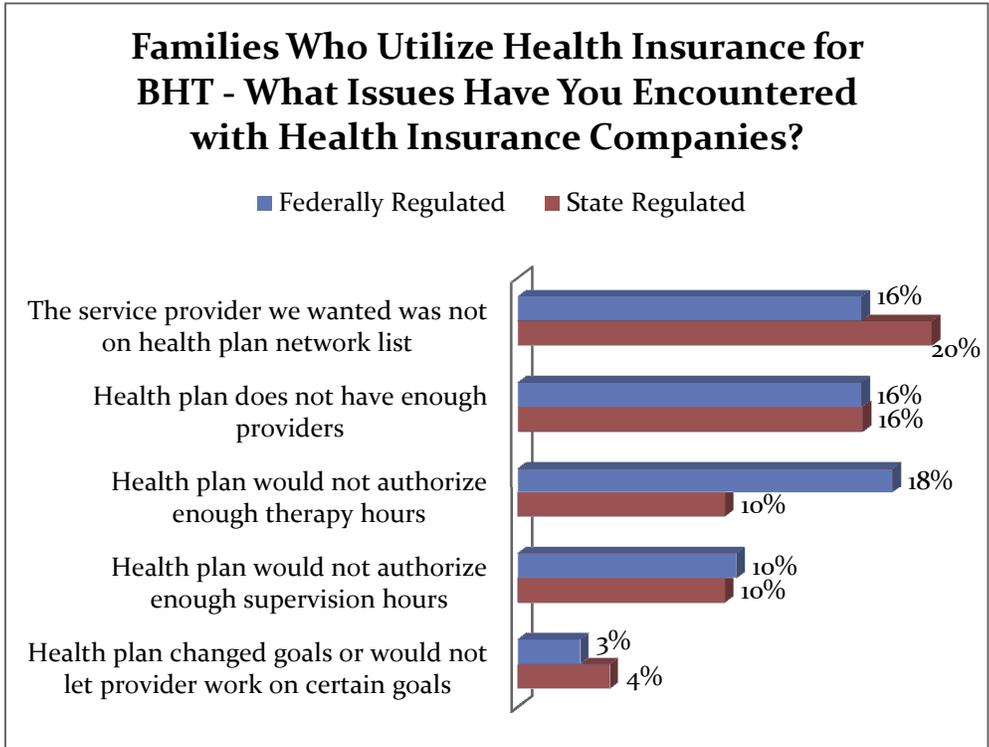
However according to the survey respondents, there were numerous provider issues that appear to be emblematic of inadequate provider networks. Problems included insufficient staff (43% versus only 30% for federally regulated), concern

about quality (26%), frequent appointment cancellations (10%), services were not delivered with peers despite approvals (7%), distances more than 30 miles (4%) and starting with reduced hours due to

provider shortages (3%). Except for travel distance, all network and provider issues were experienced more in networks of state-regulated plans than those of federally regulated.

Eleven percent (11%) and 7% of families, respectively, were refused services in the school setting and community. This latter point may not be a reflection of network inadequacy but rather a policy restriction.

Respondents also reported that their preferred providers were not in the network (20%), the plan did not have enough providers (16%) and they could not get enough therapy or supervision hours. The approval and service initiation delays described in the Timely Access section BHT are also symptoms of network inadequacies.



Personal Comments from Respondents:

“We were approved, however [our insurance company] uses [vendor] as the only vendor and they did not have enough staff/therapists to provide services. It was a mess, confusing, and unprofessional to say the least. I had to file a grievance and request that the previous vendor be authorized to continue the services. The authorization was approved, however it was for a limited time and the ABA services were cut-off abruptly based on that deadline.”

“we are currently in crisis due to lack of consistent ABA and lack of available adult qualified ABA”

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

