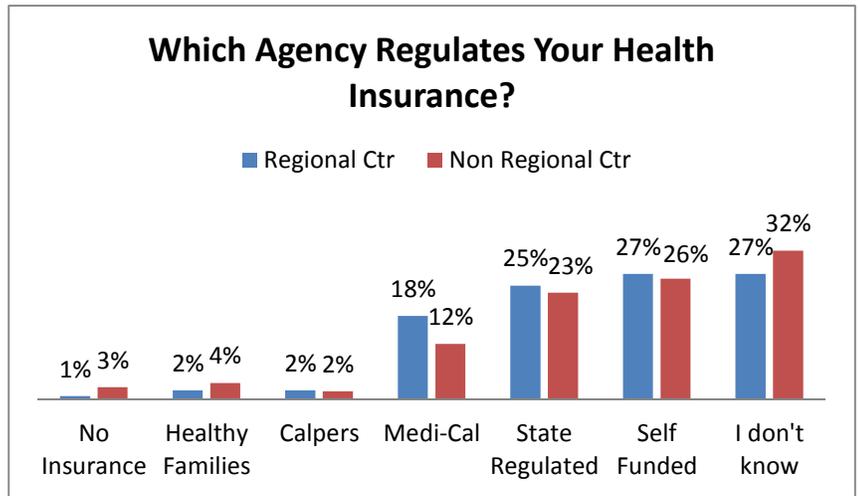


California Autism Insurance Law Survey Highlights

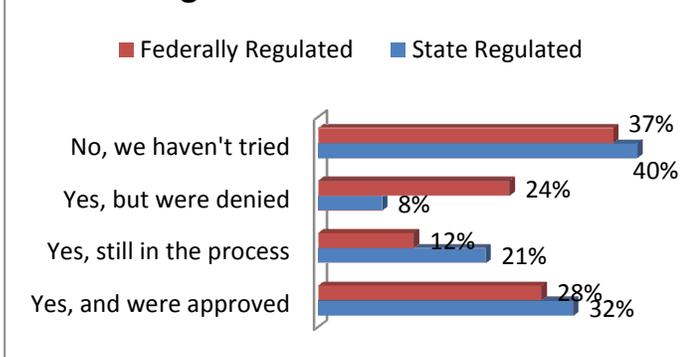
In March 2013, the CDC announced that 1 out of 50 children aged 6 years to 17 years have an autism spectrum diagnosis. There are currently over 72,000 individuals with autism in California. On July 1, 2012, the Autism Health Insurance Mandate (Steinberg SB946) went into effect requiring California health plans to provide coverage for behavioral health treatment, including, but not limited to, applied behavioral analysis (ABA) therapy. In an effort to capture the issues surrounding health insurance in the autism community, an online survey was sent out by the Autism Society of California through its affiliates and partners for a 5 week period (02/08-03/15/2013).

- 621 people participated in this survey representing 19 of the 21 regional centers. The average age of person with ASD was 11 years old.
- 78% of survey respondents were regional center clients
- 60% of the families were already receiving ABA services before July 1, 2012 -45% of them paid through regional centers, 12% school districts and 9% paid by private insurance.

1. This law had a large impact on the autism community. It variably impacted families that were regional center clients and provided much needed services for those who weren't regional center clients. Overall, 25% of the respondents indicated that they had California state regulated insurance.



Because of the New Law, Have You Tried to Obtain Services Through Your Medical Insurance?



2. Due to the publicity surrounding the new law, almost 2/3 of the families asked their insurance providers, California regulated or otherwise, for ABA services:

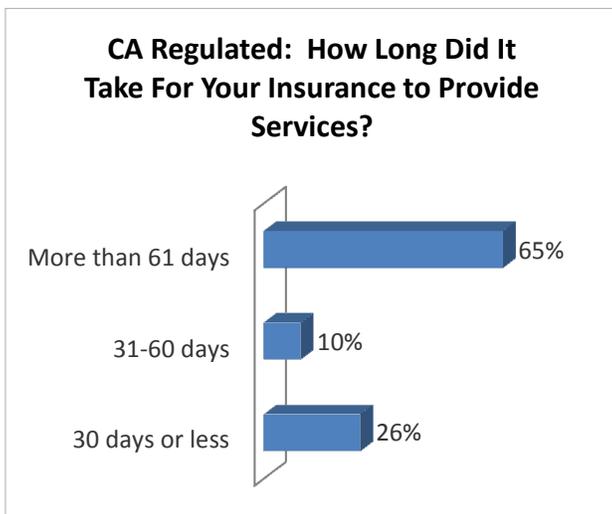
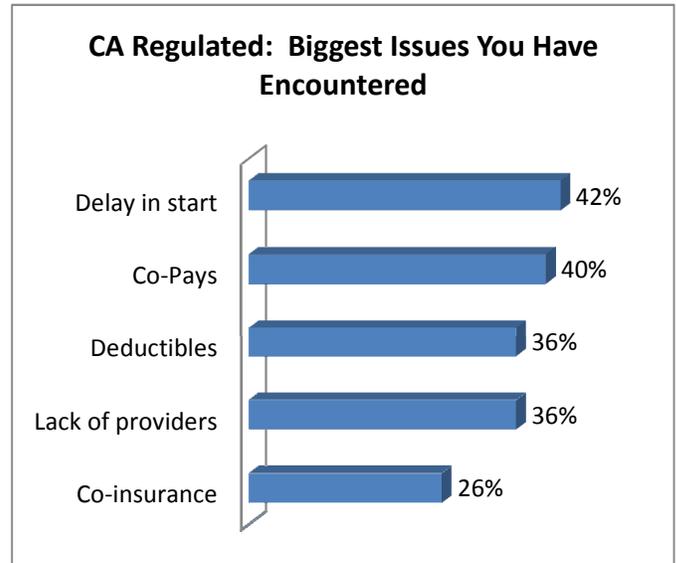
a. 60% of families with California regulated plans tried to obtain ABA services. However, only 32% were approved.

b. 63% of families with federally regulated plans tried to obtain services, with 28% approved.

3. Issues Faced. For families with a California regulated plan, over one-third faced major problems implementing ABA services: **42% of them reported a delay in starting services; 40% financial hardship from co-pays, 36% with deductibles and 26% with coinsurance; and 36% reported a lack of providers.** Additional topics in the comments section included: poor quality providers, incomplete hours, scheduling problems and interruption in treatment.

“Wish regional center would help cover deductibles (or at least partial) since now we will be canceling ABA as a result of how much money out of pocket this is costing our family.”

“We chose to remove our son from the medical insurance plan that we has as a family in order to retain the services through the regional center. What a great law it is when it compels families to remove their child from their medical insurance just to keep the same services they had prior to the enactment of the law.”



4. Delay in starting: 65% of families with California regulated plans indicated that insurance plans took more than 61 days to provide ABA services, even though California law requires health plans to provide timely access to care. The Timely Access Regulation, Rule 1300.67.2.2, requires that services should be starting within 10 days. Many families expressed exasperation:

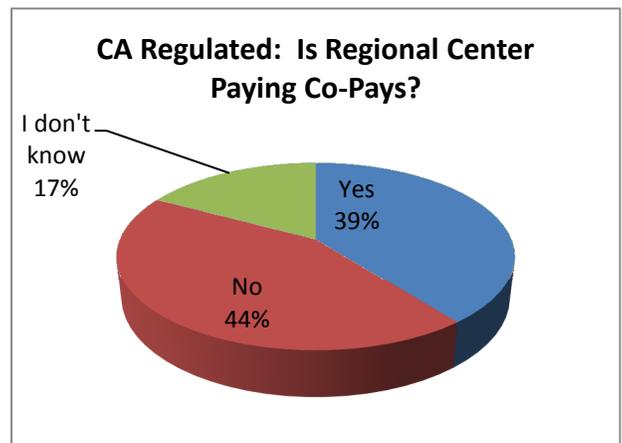
“It took us over 7 months to get approved and a lot of hard work.”

“HealthNet is overwhelmed with the number of request for ABA services, The third party provider has been extremely slow to cover ABA services.”

5. Copays: 39% of families indicated that regional center was paying their co-pays.

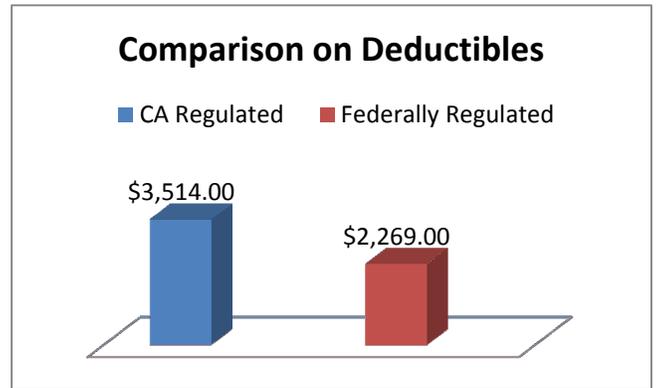
“Couldn't afford our end with insurance so we lost ABA”

“We were given form to sign from our Regional Center Contractor stating that we would pay for their services and co-payments if our insurance company did not pay and the Regional Center did not make the co-payments. That was not acceptable for us. We cannot afford to take the financial responsibility for payment of the services.”



6. Deductibles: Families reported that the average deductible was \$3,514 for state regulated insurance (compared to \$2,269 for federally regulated insurance). This was a hot topic for many families and some indicated that they had to give up ABA services because of the financial demands :

“Our deductible is so high, the cost is still too much for us to afford at this time”



7. Providers: For the families with California regulated plans, 26% of families had to change ABA providers. Of those, 40% say they are receiving better services, 33% report no change and 27% worse. The single most common complaint that was noted about service providers was a lack of providers offered by Kaiser.

“Kaiser forces you to use their own vendor: Easter Seals. You have no choice in the matter which is VERY frustrating. My child has regressed since changing vendors due to Kaiser’s policy of only using one company.”

CA Regulated: How Have You Handled Issues?	
Had to take further action	57%
Spoke with customer service representative at insurance co	48%
Spoke with regional center caseworker	33%
Consulted with insurance advocate	24%
Filed IMR with Dept of Managed Health Care	14%
Filed official complaint with plan	19%

8. Families need to be strong advocates when navigating the health care system. When asked if they have had an issue with their health insurance in the last year, 57% of families with state regulated plans have had to take further action.

“I despise the insurance agencies now. I don’t know how they can treat families like this. Special needs families have the least amount of time and it’s all so overwhelming. I hate that if you don’t know who to complain to or if you don’t have Mom friends to tell you the next steps that you are left to deal with the

insurance. Obscene language enters my head when I think of the (insurance company). I want it to stop....”

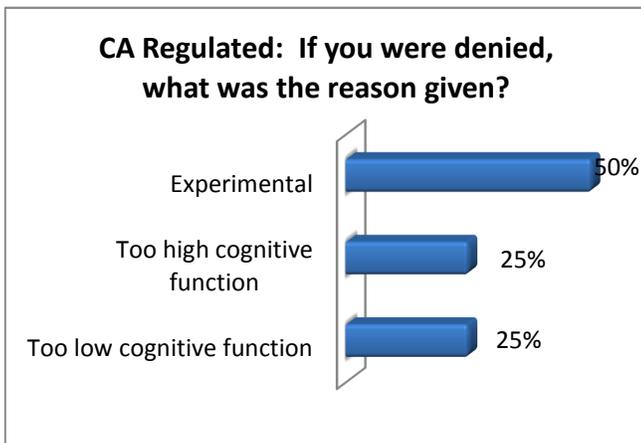
9. Insurance companies are asking for the following documentation, some of which is not legal to request. SB946 requires that services be provided upon information of diagnosis, treatment plan and prescription.

Families with CA Regulated Plans	
IQ Test	9%
Nothing	13%
IEP	23%
Treatment Plan	38%
Diagnostic report	41%
Psychological or medical report	46%

10. Families with California regulated plans are still being denied for ABA, being told that it is “experimental” or that their loved one is either “too high cognitively” or “too low cognitively.”

“We were in process of being approved when ABA ended because of good progress. We wanted to start a new program but did not pursue because of the exhausting process of getting insurance approval”

“Anthem Blue Cross did not review medical records only school records they denied coverage from a diagnosis from a neurologist”



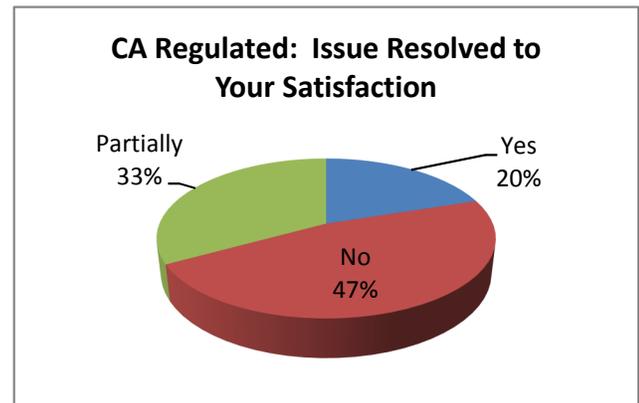
11. Only 20% of families with California regulated plans are happy with the resolution of these issues.

10 families received modifications or denials with NO written denial or notice for them to appeal.

“[Regional Center] terminated services because of the new law. And Anthem Blue Cross denied!!!!!!!!!!!!!!”

“We were told that they have not utilized ABA for adults and never got back to us”

“I can't get the help my son needs because our insurance only covers 30 sessions a year including for medication. I was also told that Asperger's is not under the autism spectrum.”



In Conclusion...

While it is heartening that 60% of both regional center and non-regional center families with medical insurance have tried to access ABA services because of SB946, less than 1/3 have been approved.

However, it's concerning that almost 40% of families with medical insurance have not attempted to access this coverage. It appears that families are unable to access services either because they are not aware of the new health law or do not understand their health care coverage.

For those that have accessed coverage through California regulated insurance, there are a number of concerns that families are facing including:

- cost of copays, co-insurance and deductibles
- lack of providers
- delay in providing services or transitioning to new providers
- frequent denials for reasons that are inappropriate
- frequent denials and modifications for reasons that are inappropriate , often without written notice

The Autism Society of California would like to thank Beth Burt and Marcia Eichelberger for their leadership and development in this project, and Kristin Jacobson, Co-founder and President, Autism Deserves Equal Coverage (ADEC), for her technical assistance with this survey. We acknowledge with appreciation the participation of the families statewide in sharing their experiences in order to benefit the autism community at large.