

**SENATE SELECT COMMITTEE
On
AUTISM & RELATED DISORDERS**

Darrell Steinberg, Chair

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Capitol, Room 3191
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Informational Hearing:

***Health Insurance Coverage for Autism Spectrum Disorders (ASD):
Current Regulatory Oversight of Behavioral Intervention Therapy***

SENATOR DARRELL STEINBERG: Good morning. The Senate Select Committee on Autism & Related Disorders will come to order. I would like to welcome my colleagues: Senator DeSaulnier, Senator Emmerson, Senator Fuller, Senator Correa, Senator Liu, and Senator Price. I'm Darrell Steinberg, the President pro Tem of the Senate, but more importantly, the chair of this important select committee.

Let's digress for a moment. It is great to be gathered with colleagues talking about advancing an agenda instead of just talking about the state budget. And it's good to see democrats and republicans because this is an issue that certainly knows no partisan divisions. This is an issue that affects children and families in all of our communities.

We have a very important and interesting hearing today and let me sort of set the stage. It was a year or so ago when the Select Committee held its last hearing. And the subject of the hearing was the relationship between the health plans and ABA therapy, which most everyone agrees is the cutting edge, most effective way for the medical community to intervene and help children with autism and autism spectrum disorders early in life. And the controversy, of course, is whether or not this therapy should be covered—should be covered by the health plans.

I'm the author of Senate Bill 166 which would require that autism and behavioral intervention therapy, specifically, be a covered benefit. At the same time though, there are some parallel efforts to this legislation. The Department of Managed Health Care and the Department of Insurance are both, by virtue of their regulatory

authority, intimately involved in this issue. And last year when we met, I certainly came to the conclusion and I think the colleagues that participated came to the conclusion, that the question is not whether behavioral treatment is effective but rather who should be paying for it?

Last year I made it very clear that I wanted the Department of Insurance and the DMHC to work collaboratively with the advocates and health plans to ensure the following:

- That the families are treated fairly;
- That the State provide clarity and appropriate oversight;
- And that the health plans and insurance companies do their fair share, *do their fair share* to help pay for this cost-effective therapy.

Today's hearing will focus on what steps have been taken during the past year to ensure that we're on the right track to accomplish these important outcomes. I've asked that the first panel set the stage for this hearing by providing a very brief overview of the issues related to behavioral intervention treatment (another way of referring to ABA), including an update of what's happening at the federal level. And then we want to go into the meat of this.

Today's hearing: we're very pleased to have California's insurance commissioner, Dave Jones, who's taking a leading role in this effort, here to testify. We will have Dave Jones and his department representatives, as well as the DMHC representatives, to talk to this Committee about what they are doing to take all of the necessary steps to ensure that the health plans and insurance companies are in full compliance with California's Mental Health Parity Law.

A special thank you to the advocates, to the consumers, to the families, to Dr. Vismara, to Myesha Jackson of my staff, both of my staff, for your work.

We won't turn back. The question is how quickly can we get to where we all know we need to go?

Let me also welcome Senator Pavley, Senator Berryhill, invite any other member of the Committee to make a brief opening comment if you would like. If not, we can get right into the testimony.

Very good! Let's call up the first panel which is entitled, *Current Status of Behavioral Intervention Therapy*. I'd like to welcome Joshua D. Feder, M.D. and Robin Hansen, M.D. I'd like to also welcome to discuss the challenges faced by consumers

and families; Dr. Areva Martin, or Areva Martin, Esquire, I should say (it's still doctor as far as I'm concerned), who's been a leading advocate in this field, as well as Kristin Jacobson, another leading advocate. I'd like to also ask Lorri Unumb, J.D. to come on up here. And as well, Charles Bacchi, who represents the health plans. Come on up.

I'm sorry, Dr. Hansen's father is ill and so she won't be here. Robin Hansen will not be here.

But again, we want you to be extremely thorough and extremely brief.

I want to welcome Senator Mark Leno, as well, the chair of the Budget Committee. And I know Senator Rubio is presenting a bill and then he will be here as well.

I've got to tell you this last thing—the last editorial comment: select committees are great things in this Legislature. A lot of important work gets done. You don't see this many members at most select committee hearings. That speaks to the importance of this issue. So thank you. (applause)

Go right ahead.

DR. JOSHUA D. FEDER: Thank so much, Senator Steinberg. I'm Josh Feder. I'm a child psychiatrist from Solano Beach, California. I've been working in the field since 1980. And actually in 1990, had a son born with autism, so I've seen it from both sides. I'm here today to speak about medical treatment for autism spectrum disorders. And Robin Hansen was going to be presenting some of this information but as you said, she's unable to be here due to family circumstances.

As you may know, autism is a brain disorder with problems in structure and problems in how the brain functions. It creates severe impairments in communicating, relating, and thinking and often includes severe behavior problems such as head banging, self-biting, those sorts of things. There's a wide range of severity in autism with some people being very impaired, unable to speak, unable to take care of themselves, and others, who with help, can become productive citizens.

The brain problems in autism include trouble taking in information. So for instance: you might hear or see something either less or more than other people. Regular raindrops might sound like machine gun fire and be traumatizing. Or alternatively, while looking at your mom's face, something like that, it might not register as important to you and you may not really make any meaning of that. So in addition to this incoming information people often have trouble processing

information; making meaning of it, and so, they don't know to care about the things around them so that they can function well in society; figure out how to problem solve, things like that. And then finally, you know, so there's in-taking information, there's processing information, but then the output has problems as well. People are often stuck in pause. They don't know to do something about the situation that they're in, or they may be stuck in kind of a repeating kind of behavior, or be stuck on a certain topic and talk about it over and over and over again. I feel like, as a doctor who treats autism, I'm talking about the same topic over and over again but our patients and certainly our family members do that quite a bit. And so, they can't move forward with problem solving, with relating to people, with being able to do things like hold a job and get a promotion, that sort of thing. Or, even be able to function in everyday life.

The numbers are staggering. Back in 1990 or so we thought there were about four people with autism for 10,000 people in the population. But as you've probably heard, we're in the midst of an autism epidemic where now we believe that there are at least 1 in 110 of us who have an autism spectrum disorder. And by "disorder," I mean it's interfering with the person's ability to function and to move forward in their lives. Beyond that, among our military kids: we think about 1 in 88 military kids have an autism spectrum disorder. And while at the outset, unless you have questions, I'm not going to get into all kinds of thoughts and theories about what the causes are but we know that the numbers of diagnosis are rising. We know that we also have better recognition of the disorder as well. But we also know that medical treatment works. We can create positive changes in brain structure and function and that's a lot like other severe brain disorders: like depression, like bipolar disorder, like obsessive compulsive disorder. Medical treatment for all of these was already covered in California's Mental Health Parity Act of 1999, requiring insurance companies to cover treatment.

But I want to talk for a minute about, and give you the definition, really, of the behavioral intervention therapies which are really the best treatments we have for autism. Just as autism has this wide spectrum of symptoms among the people who have it, behavioral intervention therapies include a wide range of research supported and clinically proven treatments, including behavioral, developmental, and combination treatments. Still, all of these treatments have a common goal. They want

to help people relate better, communicate better, and think better, and also reduce problems behaviors such as self-injury. Because each person with autism is different, the treatments need to be fitted to the person and their family so that we can achieve the best result.

So what does treatment do? Well, some therapies focus more on building the relationships between the person and those around them so that the person cares about communicating and relating and problem solving. And recent research at UCLA does support this approach. Other therapies focus on specific skills and on curbing specific behaviors, so looking at what triggers a behavior and what the payoff is, what comes after it. And by doing that with that knowledge, there's plenty of research to show that we can change those behaviors in people with autism. Many people also respond to a combination of approaches as demonstrated by recent research at the MIND Institute here at UC Davis.

It's important to also understand the difference between medical treatment and educational assistance for persons with autism. Of course, learning disorders are brain disorders too, and the methods may look similar at times and I think this gets confusing so I'd like to give you an analogy. If you have a pencil, you can certainly use that to teach someone math, numbers, things like that but you could also use the same pencil to engage with someone around a drawing or around an idea. And the point is that you can use the same tool with an education goal or with a medical goal but they have different purposes. The educators want to help people learn facts and strategies for learning and the health professionals are looking for change in brain structure and function.

As I said, the research on treatment for autism is really very robust. It's easy to study and prove that behavioral approaches change the behavior of persons with autism. And again, there are lots of good studies. Of course, it's harder to study internal brain experience and changes but the great news, especially since Senator Steinberg was talking about recent changes since last year, the research is continuing to give us more information, including some upcoming robust research that's coming out showing that with the relationship-based interventions you have changes in brain structure towards normalization along with better function. So it's very much, again, like the studies with obsessive compulsive disorder where there's changes in brain structure as people get better, and the studies in major depressive disorder where you

see parts of the brain functioning better in brain imaging studies—functional brain imaging studies—as people get better. And again, every person is different and needs different combinations of treatment. And current scientific principles of evidence-based practice—it’s an important concept—from the American Academy of Sciences Institute of Medicine require that we offer families the best information, the best relevant research as well as our best clinical judgment on how to apply that research. Give that information to families so that they can make their best informed consent decisions based on their own family and culture on what’s going to fit them for their families.

So in conclusion, evidence-based practice using the behavioral intervention therapies leads to more effective, cost-effective care with better outcomes, better function, and lower long-term costs. These treatments are the best treatment we have for autism at this time, and as a medically necessary treatment, should be routinely covered as required by current law.

Thank you.

SENATOR STEINBERG: I’m going to next move to Ms. Unumb and Mr. Bacchi because one of the things that’s very important for the Committee and for the public is to understand, upfront, distinguishing between the controversy about ABA therapy as a covered benefit versus whether it’s medically necessary in a given case. Those are two separate but related concepts. And so, as we’re moving forward, I want to make sure that that frame is very clear. So Ms. Unumb is going to talk about the status of behavioral health treatment as an essential benefit and if you can briefly give us an overview of the law please.

MS. LORRI UNUMB: Thank you, Senator Steinberg and Members of the Committee. My name is Lorri Unumb. I’m an attorney and a parent of a ten year old son with autism. I’m vice-president for state government affairs at Autism Speaks, which is the world’s largest nonprofit advocacy and research organization for autism. And I also teach a law school class called “Autism and the Law” back in Washington, D.C. and have a textbook out by that same name.

So I’ve been asked to address the very narrow topic of federal health care reform and the Essential Benefits Package.

As you know, the Patient Protection and Affordable Care Act that passed in Congress last year, under this act, states setup exchanges—artificial marketplaces

through which some individuals and employees of small groups may purchase health insurance starting in 2014. Congress wanted to make sure that plans offered through these exchanges were meaningful and had a floor of essential benefits. So Congress put a list of ten essential benefits in the legislation that any plan offered through the exchange must include. When this bill was working its way through Congress in 2009, the essential benefits included these ten, and I know you can't read them right now but you don't need to.

The autism community looked at this list of ten essential benefits and said, "We're not sure that our treatments are covered in that list the way it's written. And we want to make sure that our treatments are deemed essential and in the Essential Benefits Package." So we went to a couple of members of Congress who had been friendly to the autism community and proposed an amendment and asked them to amend that list of essential benefits in the Affordable Care Act, or the predecessor to the Affordable Care Act. That amendment was introduced and so now the Essential Benefits Package includes language in the fifth bullet where it used to read, "Mental health and substance use disorder services," it now reads, "Mental health and substance use disorder services including behavioral health treatment." So that language was added to the Essential Benefits Package specifically to cover individuals with autism and their behavioral health needs. Now you may say, "Well, that's kind of an ambiguous term. What is behavioral health treatment?" I wish so much I could have shown you today a three or four minute C-Span clip where it is very clear the member of Congress who was introducing the amendment speaks about individuals with autism; speaks about ABA therapy; speaks about what behavioral health treatment is meant to include. And it is quite clear that the purpose for the amendment was to include in the Essential Benefits Package, exactly the type of treatment that your legislation is looking to mandate.

There's also a letter from Congressman Mike Doyle, one of the amendment authors, that says explicitly, writing to the head of the Institutes of Medicine, which is helping to define the Essential Benefits Package, and I quote, "It was the intent of Congress that ABA be included in the Essential Benefits Package." So while it is true that the Department of Health and Human Services has not yet defined with specificity exactly what each of the essential benefits is meant to include, it is clear that autism services were meant to be included under behavioral health treatment.

And you may know that 27 states have passed legislation similar to the bill that Senator Steinberg introduced. Of those 27 states, 13 have passed legislation—autism insurance legislation—since the passage of federal health care reform. So 13 other states have examined this issue and determined that autism treatments are in the Essential Benefits Package and it's okay for the State to pass this legislation.

SENATOR STEINBERG: Texas is one of them?

MS. UNUMB: Texas is one.

SENATOR STEINBERG: People like to compare California to Texas.

MS. UNUMB: Texas was actually one of the early adopters. People often think I'm from Texas. I'm from South Carolina, which passed this legislation in 2007, so you maybe should start to feel a little bit embarrassed when both South Carolina and Texas have preceded California in passing this type of legislation.

UNIDENTIFIED: We are.

MS. UNUMB: I can say that since it's my home state. Now why am I telling you about all this? What is the significance to autism insurance reform in California? I think you know that the PPACA, the federal health care bill, makes states on the hook for benefits that they mandate that are over and above the Essential Benefits Package, so states are understandably reticent to pass a new law if they're not sure that that benefit is in the Essential Benefits Package. But as I mentioned, 13 other states, including some intelligent states like New York and Massachusetts, have examined this issue, determined that they—they're satisfied that they autism treatments are in the Essential Benefits Package and so they have passed this mandate subsequent to the enactment of federal health care reform.

Just one more comment. Senator Steinberg, you talked a little bit about the parallel efforts that are ongoing in California. It is more complicated in California than in many of these other states because of your state Mental Health Parity Law that you passed a decade ago, and I commend you for being a leader on that. With regard to autism treatment specifically, though, families have waited long enough for a clear, unequivocal statement that these autism treatments must be covered, so I urge you to pass legislation specific to autism so that families will wait no longer.

And I thank you for your time. I'd be happy to entertain questions.

SENATOR STEINBERG: Thank you. Senator Leno has a question. Then we'll move to Mr. Bacchi. And then we'll hear from Ms. Jacobson and Ms. Martin.

SENATOR MARK LENO: Thank you, Mr. Chair. Just on that very point, Ms. Unumb: in your professional opinion, then, California, if we were to join the other 28 states, with your understanding ...

MS. UNUMB: Well, 27, soon to be 28, have enacted autism insurance legislation. Thirteen have done so since the passage of federal health care reform.

SENATOR LENO: Should we join the other 27 states? It is your professional opinion that given the amendment that you worked on with the autism advocacy community to amend the Affordable Care Act, that California would not be at any risk of any additional cost through this kind of mandate?

MS. UNUMB: I'd hate to say "not be at any risk," but not any significant risk. As a lawyer, I'm afraid to say "no risk," because you never know what the federal government might do. But it is ...

SENATOR LENO: I guess, let me rephrase the question for counsel. That we would not be going above and beyond the requirements of the Affordable Care Act?

MS. UNUMB: That's correct.

SENATOR LENO: Thank you very much.

SENATOR STEINBERG: Very good. Thank you. Mr. Bacchi.

MR. CHARLES BACCHI: Good morning, Chair and Members. Charles Bacchi, representing the California Association of Health Plans. Our member health plans, they number 39, provide medical insurance coverage—health care coverage—to over 21 million Californians. This is not the first time we've come before the Committee. Last year, we brought medical directors, attorneys from our health plans, to talk about what medical services we do provide, what services we don't provide, and the legal rationale for that decision.

But first I wanted to note that we as health plans understand that families caring for children with autism are trying to do the best that they can in a challenging situation. As a parent, I very much respect their passion and their commitment to get up every day fighting to make their children's lives better.

And there is some good news about California, in that we do have a system for dealing with children with autism and it has three basic legs. And I know that's not the subject of the Committee but I just want to remind folks of those.

1. We have regional centers which provide assessments and evaluations to kids;

2. We have the K-12 education system which is required by federal law to provide educational services to children with autism;
3. And then the third funding source is of course, health plans and insurers who provide coverage for medical services.

So what is it that we do cover? And I think it's important to note that we do cover medical services for children with autism every day. We're required to by the Mental Health Parity Act, both at the federal level and at the state level. We provide payments for early childhood screening, diagnosis of children with autism, assessment, medication, speech therapy, occupational therapy and physical therapies and, psychotherapy for the child and their family. However, we don't cover educational or social services and that's where the controversy is that we're here today to talk about; is behavioral intervention therapy or ABA a medical service? At this time our medical directors do not agree that it is. The American Academy of Pediatrics has labeled it an educational service. I know there is a lot of debate about this not only in California but in other states as well. And these services, unlike medical services, are usually provided by unlicensed providers in a home setting.

Now California's passed scores of benefit mandate bills. You've all been here for a while. You've seen them. You've voted on them. However, California has not passed a benefit mandate bill requiring coverage of ABA.

SENATOR STEINBERG: Yet.

MR. BACCHI: Yet. And it's important to note, because this is to Mr. Steinberg's point—Senator Steinberg's point (my apologies)—when you asked—I'm going to go off script a little bit about the coverage determination because it is really important—when health plans cover a service there's really two reasons why a service is covered:

1. It's either enumerated in law and we're required to cover it as a basic health care service under the Knox-Keene Act. Or;
2. It's a provision in the terms of our contract with our enrollees or purchasers, employers.

Those are the two general reasons why we cover something.

Once something is covered, so the first test for any service to be provided payment for by a health plan; is it a covered service; is it required by law; is it in our contract? And then secondly; is it medically necessary? And it's important to

remember that because there have been some cases that have gone to the IMR process that have been determined to be medically necessary. ABA has been determined to be medically necessary and we've heard testimony that there is evidence that it is effective. We're not here to dispute that. Where the conflict really is is on this first question of is ABA required under California law to be provided as a benefit? And we have a disagreement with the Department of Managed Health Care over this legal issue. We believe that they've exceeded their legal authority by trying to compel plans to pay for ABA; that we are not required to cover it under current law. So how do we resolve it?

The Chairman noted his bill that would mandate coverage of ABA is obviously under consideration by this Legislature. So California can pass a benefit mandate bill clearly outlining that health plans are required to cover ABA. Secondly, the federal government can list clearly and unequivocally that ABA is an essential health care benefit and California can amend its laws to conform with that.

Now to pass an ABA mandate in California does come with a price. An analysis of AB 171, which is Assemblymember Beall's bill, which is currently in the Assembly, estimates that requiring coverage of ABA would cost over \$200 million a year in increased premium costs. That same analysis acknowledges that there would be a shift of state payments for these services onto private insurers and we can't support that kind of shift at this time. It would increase premiums when many Californians are struggling to afford health insurance, and we are being criticized for our premium increases.

I will just echo the testimony earlier about the Essential Health Benefits question. It's really important that California know whether or not it's going to be on the hook. The Institute of Medicine and the federal HHS hopefully will have a list of essential health benefits clarified by the fall or the winter and that will clearly, I think, give us all a path to know that sort of decisions that we are making.

Once there is clarity in the law, health plans are going to implement it and we're going to comply with it. We're going to move to create networks of providers to provide this service if it's indeed required and we're going to move to ensure that children receive high quality care. And, we believe that, you know, there needs to be probably a licensure structure in California if you're going to do this. There's also a bill on that

pending in the Assembly as well. And, we'll bring our expertise in managed care to try and make this work once there is clarity to the question.

Today you're going to hear testimony from our regulators that they're taking steps to require plans to cover ABA right now under existing law. We take their efforts seriously and we value our relationship with our regulators. However, we believe until the Legislature requires coverage for ABA, it's not a required covered service and the power to change the law and mandate coverage, we believe, to compel us to pay for a medical or a non-medical service, appropriately resides with the Legislature.

SENATOR STEINBERG: Mr. Bachhi, let me ask you one question and then we'll move to our other panelists. One of the reasons, the obvious reason, that the health plans traditionally oppose mandates is for cost reasons; is that correct?

MR. BACCHI: That's correct.

SENATOR STEINBERG: ABA therapy has been around for decades as I understand it. Have the health plans done, and if not, why wouldn't you do a study that shows a relationship between ABA therapy and reduced costs for children as they get older, as they transition into adulthood? In other words, you're looking at the costs in, frankly, a most narrow fashion. Have you done such a study and if not, why not?

MR. BACCHI: We have not done such a study, Mr. Chair. We get this question a lot with benefit mandates, where legislators say, for example, let's mandate smoking cessation. And folks say, "Well, there's clearly a cost savings to society if people stop smoking, and it over time will reduce medical costs which would therefore be benefit to health plans." However, we have to take all of the mandates sort of unilaterally and say if it increases the premium to our consumers, we have to watch out for that. And we have seen reports, for example, on tobacco cessation that over the long-term, it could reduce medical cost. However, we still oppose those mandates. This is really no different.

I do agree with you though, that to the extent that society and the system that California has in place today or will have in place tomorrow to provide coverage for children with autism, should clearly be trying to get these children as highly functioning as possible. The debate is which funding source do these services come from?

SENATOR STEINBERG: Thank you. Very good! Ms. Martin.

MS. AREVA MARTIN: Thank you, Senator Steinberg. Good morning. My name is Areva Martin. And thanks to all of the esteemed Senators that have joined us this morning. I am the co-founder and president of Special Needs Network, a nonprofit agency that works on behalf of families in working class communities, particularly, underserved communities in the Los Angeles County area. Special Needs Network provides services, training, resources, and advocacy on behalf of thousands of families who have children with autism. In addition to my role as president of Special Needs Network, I'm also a disability rights attorney. I served as a member on the Blue Ribbon Commission on Autism and I'm the current chair of the South Los Angeles Regional Taskforce for the Senate Select Committee on Autism, or have the pleasure of working with the esteemed Senator Curren Price, who left the room for a moment, but I have an opportunity to work with him and appreciate the leadership that he's taking with respect to this issue. And perhaps most importantly, I'm Marty's mom. A twelve year old little boy who was diagnosed with autism at the age of two and who has never had one hour of intervention, ABA therapy, paid by my family's health care plan.

I'm here today to speak on behalf of my son and the thousands of families and consumers around the state who have children and/or adults with autism and who despite the Mental Health Parity Law, continue to struggle to access basic health care coverage for their children and loved ones.

And Senator Steinberg introduced me earlier as Dr. Martin, but I'm actually an attorney and as an attorney I just can't resist just making a couple of rebuttal points to the statements that were made with respect to ABA therapy and funding sources. The regional center and the K-12 system that's mandated by federal law to provide services for kids with special needs are not mandated either by the Lanterman Act or IDEA to provide medical services for children. So when we talk about ABA therapy, and we've heard from the psychologists and psychiatrists today, the psychiatrist that's a medical doctor, that this therapy is in fact a medical intervention. It is not appropriate to state that these services should be paid by a regional center or a school district because those entities are not charged to provide medical care for kids. And the Knox-Keene Act and the contract which provides for services for children cannot, *cannot* be considered without considering the Mental Health Parity Law in the state of California which mandates coverage for the types of services we're talking about for children with autism.

And to really understand the crux of this issue it's really important to look at the history of insurance reform discussions that have occurred over the last several years beginning as early as 2005. The Blue Ribbon Commission, which I had the pleasure of serving with Senator Steinberg, recognized from its exhaustive work that health care coverage for behavioral and psychotherapeutic services for those with autism was limited, inconsistent, or excluded altogether by private health plans. The blue Ribbon Commission Report of 2007 noted that there was a lack of consensus about the medical necessity of services for individuals with autism with respect to behavior intervention, leaving families across the state with inadequate or the complete lack of services. The Commission recommended in 2007 that the State enact legislation, regulations, and other policies to ensure that all health plans and insurers treated autism as a neurological medical condition and provide the same coverage as afforded to other medical conditions. That all health plans provide a full range of services including behavioral therapy. And most importantly, that all health plans and insurers not use a diagnosis of autism as an exclusionary clause to withhold coverage, benefits, services, and interventions. Despite these findings and clear recommendations of the Blue Ribbon Commission, families continue to struggle as many health plans and insurers use every conceivable tactic to deny families coverage and to blatantly discriminate against families, refusing to issue denials, to force families to pay out of pocket for services, failing to reimburse them because they allegedly chose out of network providers.

Fast forward to 2009. The Senate Select Committee is formed and again the health insurance coverage issue is identified as one of the key focus areas. The Committee forms eleven regional taskforces around the State and unanimously these groups report that families continue to experience tremendous challenges in their efforts to obtain coverage for basic behavioral therapies and interventions, including speech and occupational therapy. These sentiments were echoed again during the 2010 hearings held by this Committee.

Now we sit here on July 13, 2011, four years after the report of the Blue Ribbon Commission and the problems that families face are worse, not better. Carriers continue to discriminate and refuse to provide coverage by engaging in some of these actions:

- Terminating services and denying services, claiming they're not medically necessary when we know that issue has been established;
- Repeatedly changing the reasons for denial once issued;
- And once they lose an appeal, refusing to build or maintain provider networks;
- Inconsistently treating appeals made to the Department of Insurance and the Department of Managed Health Care;
- And as it relates to the Department of Health Care, imposing that providers of ABA services be licensed when there is no such legislation or statute in the state of California;
- Authorizing very short treatment plans then refusing to reauthorize treatment claiming the lack of progress;
- Requiring frequent and cumbersome reporting unlike that which is required for other conditions, a clear evidence of disparate treatment;
- And refusing, *refusing* to implement decisions by the Independent Medical Review Board.

And Senators, these are but few of the problems. The list is longer and growing and as that list grows, so does the frustration of parents who are quite simply buried by this current system. A system that is designed to require parents to take on the role of sophisticated advocates at best, and at worst, experience insurance lawyers.

Families who are already struggling to maintain the basics: employment, housing, transportation; who are paying thousands of dollars in insurance premiums, are being forced to draft extensive letters, hire advocates and attorneys, engage in protracted appeals, navigate a convoluted system involving two different regulatory agencies (DMHC and the California Department of Insurance), both of which have their own separate and contradictory approaches to how they handle appeals, and in the backdrop of this chaos, thousands of kids like my son, Marty, like Kristin's son, and like the thousands of kids that I represent at Special Needs Network, are going without much needed interventions that we all know as professionals and lawmakers, is critical to their development, progress and growth.

And as I end, I just want to leave you with this: My son Marty, who you've heard me make reference to, he didn't speak until he was four years old. Many professionals told my husband and I that he would never talk and because of some of

his very disruptive behaviors, that he would need institutional care and definitely the most restrictive educational setting possible. They said he couldn't possibly attend a public school. He couldn't spend time in the community. He couldn't make friends or enjoy the simple pleasures that all little boys dream of. Well, because I had the resources, the access, and most of all an unequivocal resolve, Marty received 40 hours of behavioral therapy from age two until the time he entered school. Those services continued once he was in elementary school. And today, at twelve years old, he still receives ABA therapy. As a result of this early and intensive intervention, I stand here before you today proud to report that Marty is a middle school student at our neighborhood public school. He not only talks, but he gave part of his 5th grade graduation speech. He loves to play basketball. He loves his iPad. He listens to hip-hop music. He loves to go to the mall with his sister and her friends. And as a result of behavior intervention ABA therapy, Marty has a life and a future.

Respectfully Senators, each one of you has an opportunity to make sure that every child in the state of California has the same opportunities for a life and a future that Marty has been given. And real, real, real insurance reform is the only way to give our children and their families a prospect for a better and brighter tomorrow and the hope that is each child's birth right.

Thank you.

SENATOR STEINBERG: Thank you, Ms. Martin. Compelling as always. Before Ms. Jacobson, I want to welcome Senator Wolk, Senator Alquist, and Senator Dutton, the Republican leader to the Committee. Thank you.

MS. KRISTIN JACOBSON: Senator Steinberg, Committee Members, thank you very much for giving me the opportunity to testify today. My name is Kristin Jacobson.

First off, I'm a parent who has struggled and fought my own battles. I have also turned around and helped many, many families try to navigate this system.

I've included lots material in the briefing binder so I'm not going to go in depth into it. But I am going to share just a couple of stories to put a face on this problem.

This is a picture of Alesandra. She is a five year old girl with autism. Every story I have has happened since the hearing last year. She was diagnosed in 2007 by Kaiser after repeated requests for an evaluation over five months that started when she was 18 months old but no treatment was provided or recommended. Kaiser

refused to authorize the ABA until 2011 after two DMHC overturns when she was five and a half. That is more than four years; three years after her diagnosis, 20 months after appealing to the Department of Managed Health Care and 8 months after the last insurance hearing. Nine months of that was trying to find a doctor to fill out the Autism Physician Questionnaire required by the DMHC, only for autism cases, stating that her care had to be covered by licensed provider.

This is Edward. He's a five and a half year old boy with autism. I spoke with you last year about his initial fight with Blue Shield which took 15 months and two DMHC overturns to resolve. Despite having resolved the coverage issue and the medical necessity issue since the hearing last June, his treatment has been interrupted twice for four new specious reasons. And this family has had to go to IMR two more times and the denial has been overturned two more times.

SENATOR STEINBERG: Independent Medical Review—IMR.

MS. JACOBSON: Because the coverage issue was already decided, and so the only thing left was a number of different various medical necessity denials. One was, "You've made some progress. You don't need care anymore." The other was, "It's educational." And actually, they went back to experimental and they said, "Well, let's try again with that one."

This is Paul. He's a three and a half year old boy. And Anthem did almost the same thing to Paul that Blue Shield did to Edward. And they refused to build a network that had a single provider who met their own licensing standards. And it didn't get resolved until his assembly member personally got involved with the DMHC.

This is Annie. The DMHC did find her care to be covered through a standard complaint September of 2010, but Blue Shield has refused to comply with this order for more than six months.

This is Macklin. He's my son. And I helped families full time and it took me more than seven months to even get a denial from Blue Shield that I could appeal to the DMHC. Then they changed the denial reason from "experimental," to "a coverage decision," so that it would not go to IMR and lawyers would decide instead of doctors. Blue Shield ordered the care to be covered—sorry; DMHC ordered the care to be covered but there was no network and Blue Shield refused to find a network or find a provider. They provided a false authorization which required the provider to attest that 100% of the hours would be provided by licensed provider, which is an

impossibility. And then they denied and misprocessed every claim despite the authorization.

This is a picture of the 10,000 kids who have not received any treatment for autism from their insurance. The denials are systematic. Areva has already gone through all of them. The State spends hundreds of millions of dollars on this. And when you talk about the three-legged stool with the regional center, the school districts, and the health plans, the stool has fallen over because there is no third leg at all provided by the health plans.

So I told you a story of five kids that through extraordinary effort were able to get coverage, but the 10,000 or 20,000 or 50,000 who can't, are the people that we need today. And I agree with Areva; we need significant, substantial insurance reform.

Thank you.

SENATOR STEINBERG: Thank you all very, very much. Let's take questions from Members of the Select Committee. Any questions? Senator Pavley.

SENATOR FRAN PAVLEY: I didn't have a question. But I just wanted to thank, especially, the parents of children that have autism for leading this battle and leading this fight. I appreciate that greatly.

Senate pro Tem Steinberg, your bill is critically important. It's the early intervention that would save California lots of money. The impact to our schools is unbelievable, affecting all children of all families. The impact of these kids growing up that haven't had early intervention is going to be a tremendous impact. As a parent with a young adult who's autistic, these services were not available. This is an epidemic that California is facing and the long-term impact of these kids growing up without all the services they need to becoming functioning members of society, is what we're here for.

So your bill is essential to moving this forward.

SENATOR STEINBERG: Thank you, Senator Pavley, as always. Senator Leno.

SENATOR LENO: Thank you, Senator Steinberg. I'm one of the fortunate dozen senators who's chaired one of the taskforces. The San Francisco Marin Autistic Regional Taskforce and we focused on the basic issues of access to housing, to employment, and, of course, to insurance. And your testimony has been very, very compelling, as Senator Steinberg has already said.

I wanted to just briefly return to something you had said, Dr. Feder, in your opening. You used the term “born with autism” and I know that’s not the focus of this particular hearing and I don’t want to digress too far, but one of the subsequent issues that we’re going to be dealing with as we reconvene the taskforce in the coming year is to look at potential, and I say “potential” because I’m not a doctor, I’m not a scientist, I’m not here to make any claims, but the potential of environmental factors. And given that you had used the term “born with autism,” I just wanted to get your take on, from your own experience both as a parent but also working in the advocacy community and representing so many families, if there is an understanding, this is something genetic and/or are environmental factors that may be impacting this explosion of cases of autism?

DR. FEDER: Thank you for that question. There is a recent paper you may have heard from the archives of general psychiatry that talked about environmental factors perhaps accounting for as much or more of the reason someone ends up with an autism spectrum disorder than genetic ones. And I think most of us accept the idea that there probably is genetic vulnerability in most if not all persons with autism. Some of that might be hereditary. I’d like you to meet my dad one day. And some of it probably is mutation from things that occur perhaps in utero and these environmental factors they were talking about in this paper talked about during pregnancy seem to be part of the case. I think it’s essential that we run down some of these potential culprits. I think we also have to be looking at the spread of diagnosis. There’s a couple of papers that are showing that based on current diagnostic standards, and not the ones when my son was diagnosed by the way back in 1992, but more broad ways of conceptualizing it. But if we look at people who are age 70 we can find a number of persons who may have disabilities that we didn’t previously recognize but we would now call them as having autism spectrum disorders. So it’s very confusing.

There’s a great paper that’s in press by Dr. Eric Courchesne down at UC San Diego, which is a federally recognized autism center of excellence where we do a lot of early intervention research as well, (I think Senator Pavley would be happy about that) that is looking at that same problem of mutations caused by environmental factors that then lead to these cases of autism. So you know, I’d stay tuned. I think we’re going to be learning a lot over the next few years, *short years*, about the various

factors. Probably my take, in utero factors, so during pregnancy kinds of issues that come up.

SENATOR LENO: I've been working along with Senator Pavley and others in the Legislature to look at serious effects of some of the toxic chemicals. We know there are tens of thousands of chemicals in every day products that have never been tested by the federal government or anybody else with regard to their safety and among them, and one that we're going to be looking at in the ongoing work of our taskforce, are brominate and chlorinate (fire retardants), which have been mandated by state law here in California to be included in some of the consumer products that children use most intimately that are in their pillows and their cribs and in their strollers that could be replaced in a nontoxic fashion. Again, there have been some papers written about this already. I certainly encourage those who do such research to continue but you've got to connect the dots at some point.

My bottom line, and I'll conclude with this, has been that if in just the past ten years—and you correct me if my numbers are off—I think it was one in 16,000 down to one in 1,600, down to one, I think, they used the term “88,” that something is happened and some of it may just be a clear ability to diagnose. But in any case, the numbers are growing very quickly. Something is, I think, in the environment and we need to learn more about this.

DR. FEDER: So to clarify; 4 in 10,000 was the estimate in 1990, and now about 1 in 110. There is a study out of Korea about two months ago; 1 in 35. So we'll see.

SENATOR LENO: And more prevalent in boys than girls.

DR. FEDER: More prevalent in boys than girls, for the more severely impacted people, generally speaking.

SENATOR LENO: Thank you, Doctor.

SENATOR STEINBERG: Thank you. Senator Fuller; and then Senator Berryhill; and then Senator Dutton.

SENATOR JEAN FULLER: An interest that you brought up in your comments today was that there seems to be on both sides a lack of way to index providers or have a network—a lack of providing a network of certified providers. And so, for me one of the questions that I'm really interested in pursuing is not only who pays for what but for what quality of treatment? In my experience, that's the place that

parents may have been able to find a way to—that there are existing networks that maybe the rest of us don't know about. So for me it's how hard—you may or may not be able to answer it now, but how hard is it from the insurance company's perspective to find certified treatment that has been documented that works? And on the other side of that question is so how did parents find things that they felt worked for them that gave them value? Because there's a huge array of services available and because of the customization requirements and the multiple handicapping conditions and disorders that often apply, that's the jungle that seems to me that we have to figure out in order to make it somewhat cost-effective and helpful to parents.

DR. FEDER: Thank you, Senator. From the perspective of the health plans and insurers, there are groups and services for children with autism that include ABA. There's a growing number of businesses that are being created across the State to provide ABA treatment for children. Those have traditionally had a relationship with the regional centers. And of course, with regional center funding being cut, it puts a strain on those ABA providers.

As far as the licensure and certification, we generally contract with physicians and hospitals and medical groups. So this is a different thing for us, which is why when I talk about the fact that we're not clear that it's covered, building a network for a service that we don't believe is a covered service wouldn't make a lot of sense. There is a bill, however, in the Assembly that does establish a California licensure process by Assemblymember Berryhill (that was held in the Assembly Appropriations) but would create a California licensure process. Right now, ABA providers are certificated by the—I'm forgetting the title—but ...

UNIDENTIFIED: Behavior Analyst Certification Board.

DR. FEDER: Yeah. Thank you. Which is, I believe, located back East. But it's a certification; it's not a state licensure under our Business and Professions Code.

MS. JACOBSON: Let me just add one comment. In most of the states that have enacted autism insurance bills where coverage is clear, where it is clear that ABA must be a covered benefit, those states, the insurers in those states pay based upon that national certification. Separate licensure is not required. Now we certainly don't object if California wants to create a license for behavior analysts—that's fine. And about a half a dozen states have done so. But in the other 20-something states where autism insurance coverage has passed, payment is based upon that national board

certification and that's been deemed an adequate credential for the establishment of networks.

DR. FEDER: If I might add. As a physician, I can have someone in my office who's helping with blood pressures and helping me with medical care and they don't have to be licensed by a board to do that. It's very similar. Certainly my experience with my son follows a little bit of the history. I mean back then, federal—I was in the military. I was a navy doctor and Champus didn't cover autism. They just denied care, so my kid didn't get anything. They told us to institutionalize him.

By the way, he just got his first patent. He's at Cal Poly Pomona. You know, he's doing pretty well right now.

But back then, it was a different story. I think we need federal leadership now. We need to follow federal leadership in having this coverage. But back to the point, what we found as a family, I think what a lot of my patient families find, is that they get people who certainly don't have certification but they find people who are good. They try to help find credentialed professionals for them to work under, under supervision. Right now we certainly need better training; we certainly need more trained people to do these therapies; and we certainly need national certification. However, right now, people's experience, it's catch as catch can. You find good people and do what you can with what you've got.

SENATOR STEINBERG: We're going to have to move through relatively quickly here because we have a whole other panel where we're going to get into where the law stands now. So I want to ask the panelists if you can keep the answers brief.

Senator Berryhill.

SENATOR BERRYHILL: I'll try to be brief. Obviously, in my district to the Central Valley, we've had a great increase in autism over the last ten years—a real problem.

Mr. Bacchi, you brought up really, who is ultimately responsible for the funding, and this is maybe for Ms. Martin too: in your case, when these kids are diagnosed early, is any state or federally funded system that helps these kids long, or is it all private? How does it work?

MS. MARTIN: Would you like me to answer first, Senator?

SENATOR BERRYHILL: Yes. Who's responsible?

MS. MARTIN: Essentially, there is the Lanterman Act that creates the system of regional care systems that we have. And if a child goes to a regional center and they're deemed eligible as having autism, they are entitled to certain early intervention services and they will receive services through the regional center. However, some regional centers require before parents can receive services, that they demonstrate that they've gotten or they've made every effort to receive services from their health insurance plans and that they've been denied services because the regional center in the Lanterman Act—the Lanterman Act says that they are provider of last resort. So they are not the first line provider; they're the provider after there are no other services. And then we do have the federal law which mandates that special education and related services be provided to children through their public school system. So if you're a three year old child you go to your public school, you can be assessed for free and you can receive certain educational and related services that will help you access your curriculum. School districts are not providing medical care. They're not in the business of diagnosing; making medical diagnoses or providing medical care. So, yes there are some services that can be provided through regional center and through the school district, but they are not the medical services that we are talking about here today.

SENATOR BERRYHILL: Okay. So you are arguing that there should be supplementation from the insurance companies?

MS. MARTIN: Absolutely! Absolutely! As demonstrated by the doctor, ABA therapy has been determined to be a medically necessary service. I don't think there's any dispute about that. I think the statement about whether they're medically necessary has been established by the medical community as a service that should be provided to improve the brain functioning of children with autism and it should be a covered benefit.

SENATOR BERRYHILL: Mr. Bacchi, I'll let you have the last word there.

MR. BACCHI: Well, I think I would just note that, you know, shifting those costs onto health plans, in our view, increases premiums for people purchasing insurance which, obviously, increases the ranks in the uninsured. And in our economic situation, it's extremely difficult.

I would just like to point out another area that I think is a real problem. I'm just sort of stepping back from my role as a health plan—representing the health

plans is that when these children, because of the budget cuts, once they reach age three, the regional centers, they have to prove substantial disability in order to continue to get coverage. And then technically, the K-12 system is supposed to pick up educational services from 3 onto 19. But in reality, a lot of three year olds don't have a school to go to. And I do think that another area that I think would value the State to look at is what to do with this gap that I see for these kids irregardless of whether insurance should be covering ABA or not. I do think it's a real problem how these three pairs overlap with each other.

SENATOR STEINBERG: Not to bring up a sore subject, but just the record; we cut almost \$600 million from the developmental disabilities budget this past year. That's context to your two.

Senator Dutton.

SENATOR BOB DUTTON: Just real quick; we're talking about the sudden, the drastic increase in cases. Are there any studies or information about emotional distress and having that become the trigger for, like, young people and so forth? I know asthma can also be that way. Asthma, you know, can be prone to it but it also sometimes the attacks or whatever are triggered due to emotional distress.

DR. FEDER: It's an excellent question because when we see kids who have been severely neglected or sometimes kids who have been severely traumatized or abused, many of their symptoms resemble some of the symptoms of autism. So there's certainly a lot of research about those kinds of situations. A lot of our kids in foster care end up with a number of diagnoses, including an autism spectrum disorder with post-traumatic stress disorder and it's hard to figure out. It's hard to tease out. It's a great question. It's a confusing topic. We do our best.

SENATOR DUTTON: Okay. Thank you.

SENATOR STEINBERG: Senator Alquist.

SENATOR ELAINE ALQUIST: Thank you. I'll be brief. I want to hear from everyone, as do my colleagues. I have been involved in this issue probably for about 25 years and have worked on this in Santa Clara County. Certainly, ABA therapy ought to be covered by insurance companies. That should be done because it would really allow children to grow into the potential that we all deserve. And it affects all of us. Research certainly needs to continue. I'll just mention one other comment and that is, it seems to me that in some other states that I understand that pediatricians

are giving some basic diagnostic tests to small children and then referring children to the autism spectrum disorder website. And I'm wondering, and if you've already covered this, I know I've been in other meetings, you can just say, "Senator Alquist, I've already answered that," but are we working on that here in California?

DR. FEDER: We are. Actually, a great paper just came out from UCSD, Karen Pierce and colleagues, looking at early screening with a screening tool called the CSBS. There a lot of screening tools around, but that's a great one. And the great thing about that program is that we were able to bring in a whole lot more pediatricians into that kind of a mode. Now the American Academy of Pediatrics does recommend screening a number of times in early childhood, but we can probably screen even earlier.

I'm co-chair of the South Counties Taskforce this year, but I was co-chair of the early intervention part of the South Counties Taskforce last year. And among all our different taskforces, we were all hoping that one of the pieces of legislation that might be created will be one that would mandate screening for developmental disorders—autism and related disorders—from really as early as we could make that occur. It's complicated because once you've screened someone then you've got to do something about it when they've been identified.

SENATOR ALQUIST: And there's the history here, where people who know there's a problem aren't doing anything about it and that's what we have to change.

DR. FEDER: And a history of reassuring parents that it will be okay. I bet! It happened to me a long time ago; it may have happened to all of you, "Oh, just wait a little bit. Maybe it will be okay." Unfortunately, we have to start earlier.

SENATOR ALQUIST: Thank you.

SENATOR STEINBERG: Right. Thank you.

SENATOR FULLER: Can I just ...

SENATOR STEINBERG: Briefly. We really have to move on. We've got a whole other ...

SENATOR FULLER: Then I won't ask another question. But just to finalize the thoughts here. Is there a cutoff age where we can sort of assess that those early intervention strategies are just absolutely critical to make the biggest difference as possible. Is it three and under? I mean, the diagnosis has to be early, or is it something that needs to continue for a long period of time?

DR. FEDER: Actually, it's zero to whenever. I've got adult patients who we've been able to implement treatment and they've benefited in their 60s. And now, instead of being institutionalized, they're camping, they're going on vacation.

SENATOR STEINBERG: The earlier the better, right?

DR. FEDER: The earlier the better.

SENATOR STEINBERG: Thank you all very, very much. Really! Thank you for getting us more than started here.

Let's now move to understanding the legal playing field here—the legal and regulatory playing field. As I said earlier, we've got a bill pending, 166, which would mandate coverage. But at the same time, the DMHC and the Department of Insurance are pursuing their own paths around this issue.

Before I welcome the panel, I see in the audience former assembly member and the author of the Mental Health Parity Act from 1999, Assemblymember Helen Thompson, Supervisor Helen Thompson, right there. Welcome Helen. (applause) Assemblymember Thompson has done more groundbreaking work in this area than just about anybody, so we're glad you're here.

We want to welcome our state insurance commissioner, Dave Jones. Thank you so much for being here and for your leadership. Why don't we have the rest of the panel introduce themselves? Maybe we'll start with the Insurance Commissioner and then we'll go around and introduce and get into the discussion. It's all yours.

INSURANCE COMMISSIONER DAVE JONES: Senate President pro Tem Steinberg, Minority Leader Dutton, Senators and Assemblymember Bell.

SENATOR STEINBERG: Let me welcome Jim Bell, as well, Assemblymember Bell. I'm glad you could join us.

COMMISSIONER JONES: It's a real privilege to get to join you today. And Senator Steinberg, thank you for your ongoing leadership on this critical issue which goes back to your time on the Sacramento City Council and even before then. You have been someone who's been a champion, authored incredibly important legislation, but also have been at the forefront of the founding of the MIND Institute here in Sacramento, one of the nation's foremost centers for learning and clinical work on this subject. I appreciate the opportunity to appear before you.

My comments today will be limited to those matters within the jurisdiction of the California Department of Insurance. As the Senators know well, we have a

bifurcated regulatory scheme here in California. I oversee health insurance. Our sister agency at the Department of Managed Health Care, from whom you'll hear later in this panel, oversees HMOs. My remarks will also focus on the preventative measures the Department of Insurance has taken to systematically address the barriers faced by families attempting to obtain behavioral therapy and ABA and increase their access to these transformative therapies.

The Department has embarked on a course of action to identify those barriers and create a strategic plan for surmounting them. The Department's purpose and goal is to ensure that insurance companies are in full compliance with California's Mental Health Parity Law and other laws in the Insurance Code.

I think it's important to note at this point, that it's the California Department of Insurance's view that ABA coverage is required under the Mental Health Parity Act as it relates to the Insurance Code. To this end; that is to the end of removing barriers and seeking to systematically address the challenges faced by those with autism and their families, we've taken three major steps to date to address the issue of coverage for ABA therapy.

First, notice to insurers. Our first step was to inform insurers of the status of our independent medical review decisions and remind them of their legal obligations pursuant to those decisions.

On May 17th, the California Department of Insurance sent a notice to all admitted insurers in the state of California, reminding them that the California Department of Insurance is committed to enforcing the provisions of the Insurance Code governing independent medical review of disputed health care services to ensure the full protection under law of policyholders under our regulatory authority. The notice also pointed out that the insurance commissioner's written decisions adopting the determinations made by independent medical review, are binding on the insurer. The notice specifically asked insurers to take note of nine separate instances in 2010 in which insurers' denials of ABA were overturned in the California Department of Insurance's independent medical review and specified, in addition, that in two of those instances the insurers' denials based on the contention that the therapy was experimental or investigational, were overturned because such treatment is now recognized as the standard of care for autism. The Department's notice further stated that in another seven instances, the independent medical review was overturned; the

insurers' denial finding the treatment was medically necessary for the insured. So our first step was putting insurers on notice with regard to these binding decisions of independent medical review.

The second step deals with network adequacy. The Department of Insurance initiated a comprehensive review and assessment of the adequacy of insurers' provider networks for ABA therapy. The Department's regulations establish provider network access requirements for mental health care services required by the Mental Health Parity Act in the definition of basic health services. Those regulations required insurers in arranging for provider network service to ensure that, and I quote, "There are mental health professionals with skills appropriate to care for the mental health needs of covered persons in the sufficient capacity to accept covered persons within 30 minutes or 15 miles of a covered person's residence or workplace." The Department sent a request for a geographical access report and provider network listing of behavioral intervention therapies to all 106 health insurers with covered lives in California. We refer to this as a "data call" and this data call was issued under the Department's provider network access standards for health insurance policies and agreements.

The purpose of this data call is to enable the Department to evaluate adequacy and accessibility of ABA therapy for the autistic insured population covered by each health insurer in California. Under this data call, insurers must submit reports to the Department showing the geographic distribution of behavioral intervention therapists and each insurer's network in relation to its members identifying all the network providers and the number of individuals with an organizational provider who are available under the provider network contract. The Department is requiring insurers to submit separate reports for individual, small group, and large group policies organized by county or geographic service areas. The only network providers to be included in the reports are behavioral intervention therapists who may be mental health professionals who are trained to provide behavioral intervention therapy. The insurer must also document that anyone listed is capable of providing medically necessary behavioral intervention therapy and has sufficient practice capacity to do so.

We are beginning to get responses from insurers to this request. We've not received all the responses. We are going through them. Those insurance companies

that have responded are asserting arguments that you heard earlier made by the California Association of Health Plans on behalf of HMOs, and those arguments fall under basically three categories.

First, the insurers are arguing that ABA therapy is not provided for at all in the applicable insurance contract so the Mental Health Parity Act does not require that it be covered for a severe mental illness. Insurers are analogizing to outpatient prescription drugs, claiming that a policy does not cover any outpatient prescription drugs and thus is not obligated to cover those drugs when medically necessary to treat a mental illness.

The second category of responses we've received so far is ABA is not listed as a covered service under the insurer's policies because there's no comparable service that is required for medical conditions.

And the third general category of responses that we're receiving is that ABA is almost always provided by individuals who are not licensed or certified by the state of California's health care providers and since it is a crime for someone to engage in the delivery of services to diagnose and treat a medical condition unless they're licensed to do so, ABA cannot be considered a health care or medical service. Suffice it to say, that it is the California Department of Insurance's view that we disagree with these responses made by the insurers to date. And as I set forth earlier, we believe that in fact ABA is a required covered service under the Mental Health Parity Act and that it's not necessary under our codes, this is the Insurance Code now, that individuals be licensed in order to be part of the provider network to meet network adequacy standards under the Insurance Code for the provision of this service.

The third category of actions by the Department is enforcement actions. The Department has filed and served an administrative enforcement action against a health insurer who until very recently, declined to follow two IMR decisions, overturning that health insurer's denial of ABA treatment for a policyholder. In these two particular cases, notwithstanding the IMR decision which is a binding decision on insurers, this insurance company continued, until recently, to decline to provide coverage. Having said that, I want to note that we believe that this is a practice prevalent across the industry and we are looking at the other insurers as well, both in terms of their responses to our data call and the responses to IMR decisions. The Department is concerned that there's a significant barrier to access posed to

consumers who are forced repeatedly to go through the IMR process when the broad weight of the IMR decisions indicates that ABA is medically necessary, not experimental, and covered under the Mental Health Parity Act.

With me today is my special counsel and deputy commissioner for policy planning, Pat Sturdevant, who I have tasked with the responsibility for coordinating the Department's response as it relates to autistic disorders, as well as Tony Cignarale, who is my deputy commissioner for the Consumer Services Branch which is the frontline element of the Department receiving complaints which oversees the IMR process. And we received specific written questions from the Committee that they are prepared to answer in more detail if the Chair is so interested, on this panel as well as the next panel.

SENATOR STEINBERG: Right. I think what I want to do given the fact that we started a little late because another hearing was going on, I'd like to kind of combine panels three and four because it's the same panelists. This panel is "Accessing Behavioral Intervention Therapy: Coverage & Medical Necessity," which you covered. The next panel is the licensing and certification issues. So maybe you can sort of combine the testimonies; I think that would be great and move us along. So you touched on it a little bit, Mr. Insurance Commissioner. What do I call you? Mr. Insurance Commissioner. I call you Dave, myself.

COMMISSIONER JONES: Dave is fine. Dave is really good.

SENATOR STEINBERG: Okay. Commish. So maybe your staff can touch on those issues as well. Go ahead.

MS. PARTICIA STURDEVANT: Thank you, Senator Steinberg, Members. I'm very pleased to be here today to supplement the Commissioner's testimony on this very important issue. First I'd like to describe some of the additional reasons why the Department of Insurance has concluded that ABA therapy is required under existing Mental Health Parity Law. We are informed by numerous decisions of our independent medical reviewers who have almost unanimously found that this therapy is medically necessary for children with autism. They cite and rely on voluminous scientific literature and they conclude that this treatment is efficacious, it's been well documented through five decades of research, and it's widely accepted as an effective treatment for children with autism. Those views are not at all unique. They are shared by a dozen governmental entities who we've listed in our submission to you,

including the surgeon general, the National Institutes of Health and scientific and advocacy organizations.

Implicit in the finding that ABA therapy is medically necessary is the conclusion that it is medical. It may be educational when used to help children learn geography or mathematics, but when it's used to address the core deficits of autism, it is medical treatment and it is almost always medically necessary in order to enable children to lead successful lives.

Our clinicians further note in comments that indicate that the experiences of Dr. Feder and Ms. Martin with their children, are not unusual but are typical and that address the long term cost that Senator Steinberg and Senator Pavley mentioned. That providing this essential treatment to children when they're young, enables them to learn in school, to succeed at work, and participate fully in family and community activities. It thereby provides a better quality of life for the patient and for the family so that they can lead productive lives instead of the future of institutionalization that's facing them absent this treatment. For these reasons, the Department has concluded that ABA therapy is encompassed in the scope of treatment mandated by Mental Health Parity. The Legislature mandated equal treatment a decade ago in passing AB 88 and it specifically did so in order that the taxpayers would not have to shoulder the burden that should be borne by the insurers.

In answer to other questions posed initially for this panel, next with regard to regulations, we think the statutory authority in the Mental Health Parity Act is clear and unambiguous, as is its legislative history. Consequently, since we've not declared any rule of general application that deviates in any way from the exact statutory text, we haven't found it necessary and don't think it would be appropriate to promulgate regulations. We think the Act provides us with sufficient authority to apply the statutory mandate for diagnosis and medically necessary treatment for autism. That is a sufficient basis; we don't need regulations.

Next, the Committee asked what happens if health plans fail to implement an IMR decision? As the Commissioner has pointed out, we take enforcement action. If they refuse—that's been an unusual, in fact, unique experience—but if they fail to implement the decisions we will take enforcement action. It's mandated. The decisions are binding on the plans and we will require compliance.

Would you like me to proceed to address the licensure issues now?

SENATOR STEINBERG: Yes, briefly if you would. And then, you touched a little bit on the lawsuit, or maybe you didn't. The lawsuit filed by the Department.

COMMISSIONER JONES: Yes. This is an administrative enforcement action.

SENATOR STEINBERG: Administrative enforcement. You did touch on it. It's not a lawsuit in state or federal court.

COMMISSIONER JONES: That's correct. We've initiated an administrative enforcement action which we're authorized to do under the Insurance Code against a health insurer, yes.

SENATOR STEINBERG: I just wanted to make sure. Go ahead on the licensing and certification briefly please.

MS. STURDEVANT: As the Commissioner indicated, we don't believe that licensure is required. There is nothing in the Insurance Code to require licensure and there is nothing in the Government Code which defines ABA therapy to provide for any licensure requirement. I think it's also important to note that the regional centers do not use licensed individuals. We have provided two letters to the Committee; one from the chief medical officer of the Orange County Regional Center, Dr. Peter Himber; the other from Dr. Daniel Shabani who is the incoming president of the California Association of ABA Providers. They both indicate that services are provided in the regional center and by the ABA providers with unlicensed individuals carrying out activities just as Dr. Feder described is typically the case for physical conditions under the supervision of a licensed individual.

SENATOR STEINBERG: And that's the key, right; as long as it's under the supervision of a licensed individual?

MS. STURDEVANT: Correct.

SENATOR STEINBERG: Okay. Good. Thank you. Sir?

MR. TONY CIGNARALE: Thank you, Chairman Steinberg and Members. Tony Cignarale, Deputy Commissioner of Consumer Services and Market Conduct. I'll add to some of the other questions that were asked by the Committee earlier.

The first question is how is coverage and medical necessity for ABA determined? In the Insurance Code we have expressed procedures in place that the Department of Insurance staff follows. We first look at whether there's any health services dispute. If we find there's any health services dispute we will send the case to IMR, regardless of whether the insurer may assert a coverage reason such as educational,

investigational, that sort of thing. So our process is if there's any health service dispute we will refer the case over to IMR. Since we've been doing this since about late 2008 early 2009, almost all of the cases referred to IMR have gone in favor of the insured; denials have been overturned by the IMR organization reviewer.

The Department, as mentioned earlier, is the final arbiter in kind of gray areas or disputes as to whether an issue is a medical necessity issue, which should go to IMR, or a coverage issue. And therefore, based on the facts of individual cases, the history of how these IMR decisions have been occurring, overturning them in favor of the insured and the medical information ...

SENATOR STEINBERG: Favor of the insured.

MR. CIGNARALE: In favor of the insured, yes.

SENATOR STEINBERG: Okay. It was a little unclear whether you said "insured" or "insurer."

MR. CIGNARALE: Yes, in favor of the insured.

SENATOR STEINBERG: A little difference.

MR. CIGNARALE: Correct. In virtually every case over the last—since 2009 there were 32 ABA treatment IMR cases denied by insurance companies, referred to the Department of Insurance for an IMR. All 32 of those cases went through the IMR process. Twenty-eight of those cases were overturned in favor of the policyholder and the family.

SENATOR STEINBERG: So here's a layperson's confusion here that maybe you can clarify or maybe you folks can clarify. But I understand that the IMR process and the medical necessity process is certainly fact based and case by case determinations are made. I get that. The insurance industry—Mr. Bacchi was up here testifying that as a whole, they don't believe that ABA is covered to even get to that determination, whether it's medical necessity, and yet a number of cases are getting to the medical necessity question. If the industry's position is that it's not covered, how are so many cases making it through the coverage threshold to get to medical necessity? Isn't that sort of an admission against interest? Maybe Mr. Bacchi should come back and answer that question.

MS. STURDEVANT: Senator Steinberg, the argument by insurers and health plans that this treatment is not medical is a new argument. Previously they have raised a number of other arguments in denying treatment. First that the treatment

was experimental, investigational, and it was only after a series of IMR decisions by DMHC and by the Department of Insurance found against the plans and insurers unanimously that they came up with a new argument.

SENATOR STEINBERG: I see.

MR. CIGNARALE: Senator, just to elaborate further; it's the Department of Insurance's view that ABA is a medical service and under the Department's administration of the IMR process, any dispute about a medical service is eligible for IMR. And so, we don't end the query where the insurers do it—the question of coverage. We believe it's a medical service. Therefore if there's a dispute about that medical service a policyholder has a right under the Insurance Code, to IMR in such a dispute. In addition, it's the Department's view that the Mental Health Parity Act requires this particular coverage as well. And so, as a result, the Department of Insurance, when there are disputes, when there are denials of coverage and those are brought to our attention, has afforded the IMR process. And in the vast majority of those cases, and I will note in the most recent year or so, the weight of those decisions has increasingly been decided on behalf of the policyholder, not the insurer, as there is more medical evidence and increasing findings in the academic literature and elsewhere with regard to the medical necessity of this particular coverage. But the vast weight of the IMR decisions which are binding on insurers is that these are—this is medically necessary treatment and the insurer's denials have been overturned.

SENATOR STEINBERG: I get that. I don't want to digress too much, but there are numerous instances, I assume, where the insurer does not dispute the coverage determination but disputes the medical necessity determination. And if what I just said is true—and maybe Mr. Bacchi, I know he walked back in. You thought you were done for the day. Come on up real quick because I would like to get an answer to this question.

COMMISSIONER JONES: And Senator, there is no question that there's a disagreement between the Department of Insurance and our regulated entities on this issue. Those are the three ...

SENATOR STEINBERG: I understand. No, I understand.

Mr. Bacchi, thank you for coming back. I framed the hearing here earlier as we wanted to distinguish between the coverage issue and the medical necessity issue and both appear to be barriers. And you've stated consistently, of course, the position of

the health plans and insurers that you don't believe ABA therapy is covered. And yet, is it my understanding that, in fact, a number of consumers get through the coverage hurdle and then are denied subsequently on the medical necessity issue; is that correct?

MR. BACCHI: Yeah. We've had a long running dispute with the Department of Managed Health Care over this. Coverage disputes actually go through a grievance process. So if a health plan denies a medical service on a coverage decision, it goes on a grievance process on a coverage dispute. If you deny on a medical necessity reason, it would go to an IMR. So if a plan makes a denial based on medical necessity, it would go to the IMR process. Plans have been generally denying based on coverage—that would go through the grievance process. So there was a moment in time in which there were a number of cases going—skipping through the coverage test and going straight to IMR. Even though plans were denying based on coverage, that's subject to our dispute with the Department of Managed Health Care and since were in litigation I wouldn't want to comment on that.

SENATOR STEINBERG: I understand. A slightly different question, though; are there plans that are essentially granting coverage and then denying based on medical necessity?

MR. BACCHI: You know it's hard for me to comment on that. There are some plans that provide ABA coverage through their contracts with employers in the large group market. I don't know. In those cases they do cover ABA as part of their contract. I guess those disputes potentially can go through IMR. I just don't know the details. My apologies, Senator.

SENATOR STEINBERG: Well, that's one we may want to ask for some response back. Because I'm just wondering whether, despite the industry's position, we've sort of crossed a threshold here in terms of some providers actually believing that in fact it is a covered benefit.

Why don't you introduce yourselves? Stay up here. We'll make this—introduce yourselves and weigh in please.

MS. MAUREEN MCKENNAN: Thank you. Good morning, Mr. Chair and Members of the Senate Select Committee on Autism. My name is Maureen McKennan. And I am the acting deputy director for Plan and Provider Relations for the Department of Managed Health Care. And joining me today, I have Kevin Donohue,

who is the assistant chief counsel for our department's help center, so he'd be happy to answer your questions about the Help Center; about the difference between coverage and medical necessity which his department or his division works with. And also with me, I have Drew Brereton, who's senior counsel in the Department's Office of Enforcement. And Ed Hidig(?), who's our interim director for the Department, very much wanted to be here and expresses his regrets. He's unable to be here due to a family commitment.

Autism spectrum disorder takes an incredible toll on the children and families involved and the needs of these children are of critical concern to our Department. We remain committed to ensuring that children with autism spectrum disorder receive the care they need and are entitled to under current laws and under health plan contracts.

Since last year's hearing, the Department has made great strides to make services more accessible to persons with autism. We have vastly improved the time it takes to analyze the complex legal questions posed under our current Knox-Keene Act law to determine coverage for many requested services. Since the last hearing, the average number of days that it has taken the Help Center to resolve autism related complaints was reduced by 42 days or 44%. We would be happy to show you. We brought some of our statistics for you and would be happy to talk to you about that. But we have dramatically improved our statistics and more quickly and accurately analyzing the complex ABA complaints.

SENATOR STEINBERG: Let me appreciate that. That's good. But I kind of want to ask the big question here, and maybe you'll have that sort of lead the testimony. Commissioner Jones and his staff here have said, I think, pretty clearly, that they view the law to require ABA therapy essentially as part of Mental Health Parity. They don't cover the HMO world. You cover the HMO world about 80% as I understand it, of the coverage. Last year, different administration, we sort of spent a couple of hours dancing around this ultimate question; whether or not DMHC believed and was prepared to promulgate regulations or simply just interpret the law to say that in fact ABA therapy is a covered benefit. Last year it was very murky. Is it any less murky as we sit here today, July 13, 2011? Does the Department have a policy on whether or not it is a covered benefit?

MS. MCKENNAN: What I can say is that in the last year we have found that 93% of the cases of our ABA complaints to be covered benefits.

SENATOR STEINBERG: That, respectfully, is not a satisfactory answer because we went through this. Now it's all coming back to me; the déjà vu here. It's all coming back to me because to just look at the success on appeal doesn't cover all the people who never get to that stage because they're too frustrated; they cannot manage the process. So what's the policy? Because policy determines how the stakeholders act. What you do on appeal is helpful, but unless you issue precedent decisions, regulations, policy directives that are firm and binding, we're still in the same place that we were at last year.

Do you want to add to that, Senator Alquist?

SENATOR ALQUIST: I do. I'd say ditto to what you said, Senator. And what I would like to ask DMHC is, Why haven't you promulgated regulations saying that ABA therapy is a covered benefit? Why haven't you done that? Why?

SENATOR STEINBERG: Maybe they're in the process. I don't know.

SENATOR ALQUIST: Well, what would you like to say?

MR. KEVIN DONOHUE: Kevin Donohue from the Help Center. I can tell you our approach at the Help Center. And it mirrors many of the comments that we've heard today and the many of the disagreements. And I think everyone agrees that ABA therapy is used in many settings, including the treatment of autism. And so, the Help Center approaches it from trying to analyze when a health plan says it is not a covered benefit because it's not a health care service, we analyze those cases to identify whether the provider who is treating the child has determined that the child's autism is of severity—sufficient severity—to need the treatment from the expertise of a licensed provider and in those cases it's a covered benefit. And over the past year, I would add the statistics to Maureen, is that actually through that complaint process, 95% of the time we found that the physician, who really is the person touching the child, analyzing his needs and prescribing what is necessary to effectively treat, we're relying on that opinion and that's a one by one case because each child is different and unique. But 95% of the time, the child's provider is making that determination so that the Department can move forward on the case.

SENATOR STEINBERG: But that's a medical necessity determination. You know as a layperson, you're the doctor then, okay, in this instance I don't prescribe

this therapy for X Y and Z reasons or I do. Then you may get into a dispute with the insurance company about medical necessity but that's different from the threshold coverage question.

MR. DONOHUE: Not exactly, Senator. And I would explain it this way. Our medical professionals treat you as a whole person. And we have situations in the medical field where a doctor—you have back problems; you have back strain—he may say it's so severe that I want to send you for physical therapy for a couple of weeks to strengthen your back. Well, that would be a covered benefit. On the other hand, he may say, "You need to get up out of your chair. And I know a good personal trainer that I would recommend that you go and see so that you can begin an exercising program that would, in fact, alleviate the discomfort and pain." In those situations, the Help Center would find that the doctor's determination that a physical therapist was necessary would trigger the covered benefit. But on the other hand, where he's suggesting that you go into an exercise program under a certified trainer, although that individual has expertise, it's not a health care service in the context of your health benefits.

SENATOR STEINBERG: I understand. Senator Leno, I know, had a question.

SENATOR LENO: I think we're peeling this back a little bit and making some progress. I'm glad you used an analogous situation with regard to physical health. But we heard from parents and professionals on the first panel that there is a disparity specific to autism spectrum disorder. Is there an analogy you can use with regard to some other mental health situation where it's covered sometimes and not covered other times?

MR. DONOHUE: Yes. I mean in substance abuse there's different—an organization and the like that you may benefit from and may actually help you to remain sober and the like. Those would not be covered benefits. But if it was an acute detox, those could be covered benefits. So there are situations ...

SENATOR LENO: How about short of addiction? I think addiction is potentially unique to mental health issues. But is there any other kind of mental health—I know I should be asking questions I know the answers to.

MS. MCKENNAN: If you look at your plan contract sometimes you'll see many of the health plans do not cover mental health counseling for marital counseling,

family, you know, disruptions and things of that nature. So if you're having those kinds of mental health issues ...

SENATOR LENO: I don't know if that's a mental health condition that you need counseling for a family situation. That's situational. We're talking about a medical diagnosis.

MR. DONOHUE: I think there are some that we've come across in the Help Center. They're not as frequent. But obesity is one where there is treatment for certain levels of obesity and the like, but there's also more social services. And we've had requests in the past for payment of camps and the like, where children who are having difficulties with controlling their weight have requested that because it is helpful in a group setting where similar children are experiencing similar problems to work through those. But those typically aren't found to be covered benefits although were very beneficial.

SENATOR LENO: Unless ...

SENATOR STEINBERG: Go ahead and then I want them to be able to finish their testimony.

SENATOR LENO: I'm just curious to know if Ms. Sturdevant or the Commissioner has any response to this with regards to my line of questions. Is autism spectrum disorder uniquely assessed in this way that Senator Steinberg has been suggesting? Or is this common with other kinds of mental illnesses?

MS. STURDEVANT: Thank you. In my experience it is unique. There are additional requirements imposed on autism that are not imposed on other parity diagnoses and I think that violates parity.

SENATOR STEINBERG: Let's continue. I know I interrupted. But you know, we're the appellate justices here. Not really. We're just legislators. (laughter)

SENATOR ALQUIST: Senator?

SENATOR STEINBERG: Go ahead, Senator Alquist.

SENATOR ALQUIST: Thank you. I never got an answer to my question. My question was, Why haven't you promulgated regulations so that ABA is a covered benefit? And just a clear answer. And you just really avoided answering it. So I want to know why it's not covered—why you haven't done the promulgation of the regulations? And if you are going to say you haven't done it and you don't plan to,

then tell us what does it take for you to do it? Because it almost sounds like you might be operating illegally.

MS. MCKENNAN: Thank you, Senator. No. The reason we have not done regulations on ABA and the reason that we haven't done regulations at this time is we feel it's premature, particularly in light of the Affordable Care Act and the Essential Health Benefits. And we need to wait until the federal government issues regulations or defines the scope of the behavioral treatment that is going to be covered under the Essential Health Benefits. Because if we have—if the State mandates or we mandate coverage for ABA or certain services that are going to exceed the Essential Health Benefits, then the State General Fund will be on the hook for those services that go beyond the Essential Health Benefits. So that's why we haven't done it at this time.

SENATOR ALQUIST: So you're willing to wait some years and have thousands of children who will not be afforded the benefit of getting this kind of therapy which could really improve their chances for life—for leading a quality life?

MS. MCKENNAN: Actually, I am glad that you asked that question. And one of the things I wanted to talk about today is that the Department has executed a written settlement agreement with Blue Shield, and we are in the process of finalizing a written settlement agreement with Anthem Blue Cross, in which these health plans are going to agree to provide ABA services to their enrollees through a network of qualified individuals who are either licensed or are supervised by licensed providers. So these agreements are intended to resolve the issues *now* by stopping the systemic denials of ABA based on the plans assertions that ABA is not health care, is not covered under the health plan contract, and it's also the settlement agreements are intended to expand access to ABA services by the plans' agreements to use either licensed providers or supervised licensed providers who will oversee the BCBA certified providers or others who have training and expertise in rendering ABA but are currently not recognized under our current California law as legislatively authorized to diagnose and/or treat health conditions.

SENATOR ALQUIST: Thank you.

SENATOR STEINBERG: Now you're making—you just made news.

SENATOR ALQUIST: Yes.

SENATOR STEINBERG: Because we had some inkling of this before the hearing but weren't sure whether or not you were prepared to make the

announcement publicly that you just made, but I think it's very significant. And of course, the devil is in the details. But what you're saying is that you've reached settlement with a number of the major HMOs ...

MS. MCKENNAN: Yes.

SENATOR STEINBERG: To require, *to require* that ABA therapy be provided to covered children.

MS. MCKENNAN: Yes.

SENATOR STEINBERG: Yes. No limitations?

MS. MCKENNAN: Let me talk just briefly. We have an executed written agreement with Blue Shield. We are finalizing a written agreement with Blue Cross. And in addition to that, we have been working with Kaiser Permanente on a similar agreement. So I'm just going to talk. I'll talk about five points of the settlement agreements which basically, really, the whole intention is to get patients the care that they need now, while these legal and policy debates continue. Because our lita ...

SENATOR STEINBERG: Good.

MS. MCKENNAN: As you know, we are in litigation and litigation can take years, so we want to do something now.

SENATOR STEINBERG: Undoubtedly will. Okay, so go ahead with the five points please.

MS. MCKENNAN: So these are my five points:

No more systemic denials based upon coverage. So in the agreement all denials other than if you're not a member or eligible under the health plan contract, so you're no longer an enrollee, have to be construed as medically necessary. So you're not going to be able to deny and say it's not a healthcare service; it's not a covered benefit; it's excluded because you're using an unlicensed provider.

SENATOR STEINBERG: No limitations on that?

MS. MCKENNAN: You can only deny for medical necessity. No more coverage denials.

SENATOR STEINBERG: I understand. Beautiful! Okay.

MS. MCKENNAN: So that would be the same as with the Department of Insurance—medical necessity.

SENATOR STEINBERG: Okay. Good. Number one.

MS. MCKENNAN: That's number one.

SENATOR STEINBERG: We're one for one here.

MS. MCKENNAN: Okay.

Number two: Broader access to ABA providers and networks. As you know, there's a lot of tension between the current law, our interpretation which we believe is correct of the current law, which is health care services are required to be rendered by licensed health care providers and the reality that ABA is often provided by unlicensed providers. And you know, I believe it was Dr. Feder who mentioned this morning sort of "catch as catch can" for providers, and that's a little worrisome to think about "catch as catch can" to have a provider who may not be licensed or supervised coming into your home to take care of an autistic child. And that has been one of the Department's concerns and that's been one of our concerns in our lawsuit, as you know.

Putting that aside, the plans are agreeing to expand their network and they are going to be doing letters of agreement or some sort of contracted terms with licensed providers or supervised licensed providers who are going to supervise these BCAB or other providers and there will be terms in those contracts for consumer protection.

That's two.

SENATOR STEINBERG: Okay, that's two.

MS. MCKENNAN: Two for two?

SENATOR STEINBERG: Two for two.

MS. MCKENNAN: Number 3: Stop interrupting care. So as you heard the consumers talk, they start the care, then they stop the care, and they do a medical necessity review which they're entitled to do under the law. What the settlement agreements are with Blue Shield, and we're anticipating with Blue Cross and Kaiser as well, is that the initial treatment has to be authorized for at least six months. You cannot do a medical necessity review during that time. You cannot deny. And it has to be authorized at the number of hours per week, per month that the licensed provider orders—so up to six months. If by chance the licensed provider, you know, has a shorter period of time, then we will go with the licensed provider's recommendation. But up to six months. Following that, the plans may do utilization management or medical necessity review no more often than every six months.

SENATOR STEINBERG: Every six months. Once every six months. Okay. Thank you. Number 4.

MS. MCKENNAN: Number 4: Reimbursement and payment issues or problems. So on a retrospective basis, as to—again, I’m only going to be speaking as to the Blue Shield agreement—as part of that settlement the plan will agree to reimburse for past ABA services paid for by those subject members for the dates of services between date the Help Center notified the coverage was to be authorized and the date the plan commenced service. And for those PPO members if they had to go out of network, they’ll be reimbursed at the in-network level of benefits, so in other words, the co-pays and deductibles.

SENATOR STEINBERG: So what does that mean practically? If five years ago one of the advocates out here had this struggle and had to pay for the treatment out of their own pocket, how far do you go back?

MS. MCKENNAN: I don’t know if I can give you an exact date. I could probably get that information for you. Again, in the case that we have with Blue Shield, it’s for the seven members that we’re talking about, so our seven cases. So I don’t have that detail for you—how far it goes back.

SENATOR STEINBERG: This would apply sort tantamount to a class action settlement where the others, other than the seven people named in the lawsuit, the other people would be able to seek recovery under the same rules?

MS. MCKENNAN: No. It’s just for those seven members. But I have good news.

SENATOR STEINBERG: Okay, but the first three criteria apply to everybody going forward?

MS. MCKENNAN: Absolutely.

SENATOR STEINBERG: Okay, so we’ve got an issue there with number 4. Three and a half out of four ...

MS. MCKENNAN: But going forward prospectively, these settlement agreements, because the plans are agreeing to do letters of agreement and contractual terms with these providers, this should either eliminate, and certainly reduce, any sort of payment problems.

SENATOR STEINBERG: Going forward?

MS. MCKENNAN: Absolutely. So going forward.

SENATOR STEINBERG: That’s good. That’s significant. Five.

MS. MCKENNAN: Five: Oversight of the settlement agreements to ensure implementation is working seamlessly for the consumers. And I think this is probably one of the most important aspects of this agreement, which is we are committed at our Department, particularly in our Help Center, to have a liaison who is going to work with the consumers and the health plans under these settlement agreements to ensure that this is working and solving these problems while we continue to debate these legal and policy issues. So we're very pleased to talk about this today.

SENATOR STEINBERG: Is there a time limit to this settlement going forward? Or is it ...

MS. MCKENNAN: It's the change in the law.

SENATOR STEINBERG: The settlement agreement rules unless there's a change, subsequent change, in the law?

MS. MCKENNAN: Yes.

SENATOR STEINBERG: Okay. Before I congratulate you, because it sounds very, very positive, I'd like to hear from Commissioner Jones, if you've had a chance to review. If you haven't, then I won't put you on the spot. But your opinion on the breadth of this, or maybe your staff I just think would be helpful to our understanding.

COMMISSIONER JONES: Certainly. I can start by providing the Department's initial views. We were only provided the settlement agreement yesterday. And as you've heard in the testimony today, there are some variances in views between the two departments with regard to the application of certain laws.

In our initial review, and we've reached out to DMHC and indicated it's our desire—and we've gotten a positive response from DMHC—to talk to them further about the proposed settlement agreements as it relates to other plans; that there may be some differences in views with regard to some of the provisions in the settlement agreement.

As you heard earlier, as the Department's personnel testified, it's the Department's view that licensed providers are not required—it appears that there may be a difference of view in that term of the settlement agreement.

SENATOR STEINBERG: I heard her say that you're talking about licensed providers overseeing, overseeing the treatment even if it is provided by an unlicensed.

COMMISSIONER JONES: As I said, we only just got the settlement agreement from an insurer yesterday and so there may be some, in our view, some ambiguity on this point, so we're happy to talk to DMHC further about that.

SENATOR STEINBERG: I understand. Okay. Fair enough.

COMMISSIONER JONES: But we do have a—the Department does have a view vis-à-vis licensed providers and utilization of unlicensed providers, as you heard earlier, and that's an issue that we want to have a conversation about.

SENATOR STEINBERG: Okay. Be clarified.

COMMISSIONER JONES: Yes. Second, again, this is an initial view of the settlement agreement and we've indicated DMHC, once we got it yesterday, we're happy to talk to them further about it and they've indicated a positive response to having that conversation.

Our understanding of the settlement agreement is that it provides the right to this benefit for a six-month period, so we have some concerns which we're, again, happy to talk about with DMHC about the limitation of the coverage requirement to a six-month period. So we're concerned about that. In addition ...

SENATOR STEINBERG: What I heard though, I just want to clarify, medical necessity determination every six months, not the coverage determination.

COMMISSIONER JONES: The coverage goes on forever but at six month periods they could ...

MS. MCKENNAN: No; more frequently.

COMMISSIONER JONES: They could question whether 25 hours or 20 hours or 15 hours was more appropriate for the child.

SENATOR STEINBERG: I got the distinction. Go ahead.

COMMISSIONER JONES: I think the question that it poses for us, and again, this is a conversation we want to have with DMHC, is in the Department of Insurance's view, is a limitation like that comparable to how one treats other mental health benefits or not? And so, that's the conversation we'd like to have with the Department.

And so, these are some of the issues. Again, we've just looked at it yesterday. And I think it is important to note as well that, again, the Department has initiated an enforcement action against an insurer on these issues and regardless of whether the HMO arm of that insurer has settled in this fashion, the Department will be

independently assessing the conduct of the insurance arm of that company under the Insurance Code as we described earlier.

SENATOR STEINBERG: Okay. So in a few minutes I'm going to ask Mr. Flannigan from Consumer Watchdog to come up. Not right now. But I want to ask a couple more—so look it, this sounds very positive so let me commend you, without having read it in detail myself, for making an advance here. The question that the Commissioner raises, that we'll all want to know, is how much of an advance is it really? And that leads to a couple of other process questions. Is the Department planning to sit down with the client networks and the advocates soon, to go over the details of this settlement so that they have a voice and can comment?

MS. MCKENNAN: Yes, we'd be happy to do so.

SENATOR STEINBERG: Okay. Can we arrange that—well, you'll arrange it. The Committee officially instructs you to reach out to the—okay, if you'd do that quickly that would be good. Because we want to get that feedback because it impacts, obviously, how the Commissioner views their further actions. It also impacts how fast we need to move the legislation clarifying the law in this instance.

Let me ask you another process. So among the—you named a bunch of companies—HMOs; Blue Shield.

MS. MCKENNAN: Blue Shield has a written executed agreement ...

SENATOR STEINBERG: They have a written but you're continuing to negotiate with who?

MS. MCKENNAN: Blue Cross is very near finalizing a written agreement.

SENATOR STEINBERG: Blue Cross. Okay. And Kaiser?

MS. MCKENNAN: We are in verbal communications with Kaiser and are confident that we will be able to work out a similar type of agreement.

SENATOR STEINBERG: So if you take those three, what percentage do they represent of the Knox-Keene plans in California?

MS. MCKENNAN: Probably over 90% of enrollees. I mean, Kaiser alone has 6.6 million enrollees.

SENATOR STEINBERG: Okay. So this is a very interesting development. And again, appreciate you coming forward and using this forum to announce this. I like to think—well, I credit the advocates and the Department for pressing, pressing, pressing, but we're going to want to listen very carefully to, obviously, the insurance

commissioner, the consumer watchdogs, but most importantly, to the advocates out here who—the only thing that matters in the end, is whether this makes it easy for parents in in another wise difficult situation, to be able to get the help they need. That’s the test, right? That is the test.

MS. MCKENNAN: That’s our goal.

SENATOR STEINBERG: Okay. Mr. Flannigan—aha, he walked out the door.

UNIDENTIFIED: _____

SENATOR STEINBERG: Well, that’s alright. If we can just make a seat for Mr. Flannigan, that would be good. You are all welcome to stay because other Committee Members, I’m sure ...

Mr. Flannigan from Consumer Watchdog, you have been intimately involved in this by virtue in filing a lawsuit attacking the DMHC—previous 2009 underground regulation. I want you to be brief, okay, but if you can just give us sort of the “30,000 foot view” on what you—if you’ve reviewed the settlement, just some things we ought to watch for. I’d be tentative in your—I don’t think we’re at a point where even you maybe want to state final conclusions here about it, but maybe you do.

MR. FLANNIGAN: I did have the opportunity to review it last night and this morning. Two points: One; existing law does mandate ABA coverage. And I was a little concerned in the beginning about there may be—there’s a question about that. I think the Insurance Commissioner deserves a lot of congratulations for standing up here to say that.

SENATOR STEINBERG: Well, absolutely! And he does, because he’s always taking the bull by the horns. We believe the same thing, at least a lot of us. That’s why we’re pushing the bill. But the fact that we’re here—it is the law but it is not being interpreted as the law, so any advance that we can make, whether it’s through settlement, whether it’s through legislation, whether it’s through the strong advocacy and action of the regulator, is all good. We’re not in a place where we want to be now.

MR. FLANNIGAN: I agree. So to be clear, we don’t necessarily have to wait for new legislation but really push the DMHC to enforce the law.

SENATOR STEINBERG: I get it. So what’s your ...

MR. FLANNIGAN: I have five points as well.

SENATOR STEINBERG: Quickly.

MR. FLANNIGAN: One; under the settlement the DMHC still says the license is required in order for a provider to provide ABA; that's the statement up front. Blue Shield also, this is in the findings, states that ABA is not a medical procedure. Number 3, there's a supervisory model on paper. So what the settlement says, though the DMHC does not believe—still believes that licensure is required for ABA to be covered, for purposes of the settlement, we're going to require Blue Shield to cover ABA under the supervisory model where there is a licensed provider.

A couple of problems with the way that system is set up.

One, there is no provision in there that a BCBA or someone has an ABA certification from a national organization actually knows how to perform these services can be the supervisor, and those are the folks that really understand how ABA must be provided. But most importantly, the essential problem here is that there is nothing in the settlement that requires Blue Shield to have an adequate network of providers. The findings, and this is the essence of it, the findings state the DMHC believes it's necessary that Blue Shield and other providers have an adequate network of medical professionals. But the meat of the settlement, the requirements on the insurer, does not strictly require an effective network of providers. And this is the problems currently. People are waiting a long time _____ .

SENATOR STEINBERG: I understand. There needs to be providers for it to work. I'm going to have Ms. McKennan and her team respond _____ .

MR. FLANNIGAN: And what the report says is that Blue Shield will (quote) "assist parents" and if parents can find a licensed provider, Blue Shield will pay. But if the parent cannot find a licensed provider, Blue Shield is off the hook.

SENATOR STEINBERG: I'm glad you're putting it out there on the record. We're going to hear response. And we're at number 4.

MR. FLANNIGAN: Number 4, the—that was maybe number 4.

SENATOR STEINBERG: Okay. Then number 5.

MR. FLANNIGAN: Number 5: if Blue Shield asserts there is a change in the law either through litigation or otherwise, they can opt out of the settlement and pursue other negotiations with the Department. So this settlement can terminate if Blue Shield can cite some (quote) "change in the law" then these negotiations will have to start all over again. This settlement should be binding and have a clear requirement on the plans.

SENATOR STEINBERG: I'm not carrying a bill to deny people ABA coverage.

MR. FLANNIGAN: No, I understand that.

SENATOR STEINBERG: I'm just saying, what change in the law are you—what change ...

MR. FLANNIGAN: That's a good question. It's necessarily not just legislation, it could be litigation. It's unclear what they're saying.

SENATOR STEINBERG: Okay. Good point. Are those the five?

MR. FLANNIGAN: For that report. I would also—there is one other issue. The issue of existing law requiring a mandate has been very clear. The Court of Appeals in California has found that to be the case. The DMHC, I believe with this report, is really trying to deflect attention today by attempting to say that we're handling a problem that they haven't handled. And I certainly hope that the Committee keeps scrutiny on the Department and keeps that follow-up.

Thank you.

SENATOR STEINBERG: Of course. That's why we're not throwing bouquets out here, right? We're recognizing this is a potential advance. This needs to be reviewed. It needs to be reviewed thoroughly by the Commissioner, by you, and most importantly by the advocates and then we'll come to a conclusion. But you know again, the only thing that matters is the law, is the law, is the law; are parents getting the help that they need? That's what we want to know. And if this helps, then it helps. It may not be the end but it may help.

So let's go through all five because I think these are important. Is licensing required? What about Blue Cross saying that it's not a medical procedure, what impact does that have on the actual provision? Is there an adequate network or is it all on the parents to find somebody? What about this opt-out provision?

MS. MCKENNAN: Okay. So the first provision, in the recitals basically what we are doing is we are setting forth our disputes. We know that our department does not agree with the health plans. The health plans do not agree with us. In order to do the settlement, that's what the recitals are. So that's all they are. And that's just to preserve our rights for the litigation that the Department is involved in, as well as the health plans. That's all it is.

SENATOR STEINBERG: Nobody admits fault, in other words. You just go ahead ...

MS. MCKENNAN: Correct.

SENATOR STEINBERG: As a recovering lawyer, I remember those provisions.

MS. MCKENNAN: Yes. So that's all those provisions are. The third one—oh, I think you asked about licensed provider. We acknowledge that the consumers and the advocates have indicated that ABA is not usually rendered by licensed providers. The Department's position in this litigation is that licensure is required under the Knox-Keene Act and it's a good idea for safety purposes. That said, in order for these kids to get services, the plans have agreed that they'll either use a licensed provider or they'll have a supervising licensed provider and those supervising licensed providers may oversee either the BCBAs, which there's probably not enough of them either, or other providers that have experience, that have ABA training and experience in serving children with ASD (autism spectrum disorder). And that's why we wanted to make the settlement agreement broad enough; because we heard the consumer advocates and their concerns that there weren't enough providers out there and that they wanted this to be a little broader, and so, the plans have agreed to do that. Or Blue Shield in its written agreement and hopefully in the subsequent other written agreements, will have a broader network. So that's where we are in the licensed provider ...

SENATOR STEINBERG: I'm going to want to hear, not necessarily today, but Ms. Martin and Ms. Jacobson and others about, again, what that means for the real family in the real community in California getting the service they need, okay?

MS. MCKENNAN: Hm-hm.

SENATOR STEINBERG: What about the opt-out?

MS. MCKENNAN: Opt-out, I mean, obviously, any settlement agreement, if the law changes, you're going to have to follow whatever the current law is. Basically what the opt-out agreement is; first of all, it has to be a final decision so again, we're involved in litigation. Some of this litigation could take, you know, several years. What it requires is that if Blue Shield or a health plan feels that there is a final court decision or some sort of legislation that supports their position, that ABA is not a health care service that is required to be covered under the Act or if Blue Shield says that they may lawfully deny coverage because you're not using a licensed provider, they have to give the Department 60 days notice, and then they can suspend it, and then we will meet. The agreement requires them to come and meet and confer with the Department to try to reach a further settlement. But what we really wanted to do,

Senator, is we understand this debate has gone on and could go on for several more years and we wanted to do something now.

SENATOR STEINBERG: I'll tell you what; maybe one of the things to do here, Mr. Vismara, Mr. Vice-Chair, Senator Leno, is maybe we schedule another hearing in several weeks. No? No?

MR. DONOHUE: What I would suggest, Senator ...

SENATOR STEINBERG: Specifically to review the settlement and actually flesh out, you know, some of these issues. Is that sensitive?

MR. DONOHUE: Well, the one thing—it's sensible but probably premature.

SENATOR STEINBERG: I said "sensitive."

MR. DONOHUE: Oh, okay. Well, that is sensitive too.

SENATOR STEINBERG: And I appreciate you saying "it's sensible."

MR. DONOHUE: What I think would help would be that if we give it a little bit of time, because we already talked about the liaison at the Help Center that's going to be working with the consumer groups to make sure the settlement—but what we want to do is make sure it actually works; where we're not getting the numbers of ABA denials in the Help Center. So probably it would take longer than a couple of weeks. If we did it you know, three to four months out, we would bring you statistics and probably, hopefully, show you that we have had a dramatic drop in the number of complaints that we're getting in.

SENATOR STEINBERG: Fair. I mean we'll think about it. You know, let's talk. We'll think about it.

Mr. Commissioner.

COMMISSIONER JONES: The Department of Insurance has asked, and DMHC has responded in the affirmative, that our senior staff have an opportunity to meet with theirs before they execute another settlement agreement. And so, we would like the opportunity—I appreciate DMHC's testimony with regard to road testing the Blue Shield settlement agreement, but we respectfully ask, and I believe DMHC has responded in the affirmative, that our two departments have an opportunity to meet at a senior level to discuss the issues that have been raised and potentially competing views to see if there might be some resolution related there to, before another settlement agreement is entered into. Certainly that is a call for the Department of Managed Health Care. It's up to them. Our understanding is that they are amenable

to having that meeting. We'd appreciate the chance to do so to see if, before another one is entered into, we can resolve any disagreements. And there may not be resolution, but our desire to see if there might be an opportunity to resolve disagreements that currently exist potentially vis-à-vis the departments' different views.

SENATOR STEINBERG: Sooner than later please.

COMMISSIONER JONES: We're making ourselves—we've communicated—once we saw the settlement agreement yesterday, we immediately communicated our desire to sit down and our understanding is the Department is willing to do that.

MS. MCKENNAN: Absolutely!

SENATOR STEINBERG: It is, I mean, not that we're dealing with government organization here, but it is odd that California has a system with two different parallel regulators dealing with the same topic. So I think it is important that the Department communicate with the elected commissioner on all these steps and try to come together where you can.

COMMISSIONER JONES: We've had a very good collaborative working relationship with the Department.

SENATOR STEINBERG: Okay. Good! Good! Good! Well, I want to thank everybody for coming. And this was very, very informative, instructive. And, I think, in fact I'm confident, to say that progress is being made. The question remains how much progress? But we thank you all for taking the lead, both the Commissioner and the Department, in trying to help families here.

Ms. Sturdevant, did you have one last comment?

MS. STURDEVANT: No.

SENATOR STEINBERG: Okay. Good! Thank you very much.

MS. MCKENNAN: Thank you very much.

SENATOR STEINBERG: Appreciate it. Thank you, Commissioner Jones, especially.

COMMISSIONER JONES: Senator, thank you for your leadership. You were far too modest a moment ago in describing where the credit lies for the progress that has been made today, and it lies with you and your colleagues on this committee, who held an incredibly important hearing a year ago and have held this hearing. And I know both departments want to thank you for your tremendous leadership and your

responsiveness to all of the concerns associated with this issue. Thank you very much, Senator.

SENATOR STEINBERG: Thank you. We do have now time on the agenda for public comment and it's an important part of the hearing. I don't think that we want to—we cannot hold a lengthy discourse right now on what we just heard.

SENATOR LENO: _____ a show of hands?

SENATOR STEINBERG: Yes. Do we have a show of hands of who wants to testify publicly? Okay. Come on up. I'm going to ask you to be brief. And again, there's going to have to be some exhaustive review and probably public hearing on what we just heard regarding the DMHC settlements. I don't want to litigate that here. Connie.

MS. CONNIE LAPIN: Members. This is impressive. I'm glad to be here. My name is Connie Lapin. You said you want to hear from advocates; well, I'm an old one. And I'm here because of my son but also because of what he went through. My son is forty-three. And I probably think I have the oldest kid here. I'm here because I don't want what happened to him, to happen to the other ones. And I'm here also to thank you guys, because when he was around there weren't legislators that were interested and that were willing to make a difference.

If you would time travel with me, you know, you would find out that my son was a victim of his times because there was no interventions. And it's a tragedy because he is severely impacted and he's severely expensive. I don't know if we use that word.

What do we know?

SENATOR STEINBERG: We get what you mean.

MS. LAPIN: Yes, I know. What do we know? And I will be brief. We still don't know what causes autism. I mean that was apparent from the testimony. We don't really know that there's a definite cure. If you meet one—and I'm sure you've heard this—you meet one person with autism, you've met one person. They're all very unique. Although autism is not a disease, the medical issues create neurological conditions that are profound, and I don't need to tell you what they are; you know what they are.

What's the good news: There's neuroplasticity of the brains.

And what's amazing here, no one, even with the controversy or the conflict; no one said early intervention is bad. We all know it's good and it's necessary.

We do know that—and this is just another thing I want to add—that there is a variety of evidence-based treatment and they must be dynamic, developmental, and evolutionary. We don't know what causes autism so we need to be open to that.

And I want to use other words, like “PRT,” “DIR,” “RDI.” I mean it's not only ABA.

Finally, I've coined the term—developmental disabilities is called “DD,” well I call it “denial by delay,” and I think we see it here. We see this. And as parents concerned about our kids, what are we supposed to do with that information?

There was an Emmy thirty-seven years ago called *The Minority of One.*” And I don't know if anyone's old enough to remember Lloyd Nolan, the actor, he came out and said, “I have a son with autism.” And at the end of the Emmy, I mean the movie, the documentary, he said, “You know what?” and this is the bottom line here; “Our kids are going to grow up in one way or another trained or not.”

So in this house of laws, thankfully to you, Senator Steinberg and Assemblyman Bell, we want this piece of legislation passed. We need it. I don't want to be here next year and I know you don't want to be here next year. So thank you.

SENATOR STEINBERG: Thank you, Connie. Appreciate it always very much. Let's go through again if we can, relatively briefly because we're running over.

MS. LISA COOLEY: Good afternoon, Assemblyman—Senator Steinberg and Members.

SENATOR STEINBERG: I used to be an assemblyman; it's okay.

MS. COOLEY: My name is Lisa Cooley. I represent the California State Council on Developmental Disabilities. Like Ms. Lapin a minute ago, I am here because I am able to be with you this afternoon because I have adequate medical coverage that covers my disability, which is cerebral palsy. I want the same thing for future generations of children that have autism and other related disorders on the spectrum.

Thank you.

SENATOR STEINBERG: Thank you very much.

MS. FEDA ALMALITI: Hello. My name is Feda Almaliti. I have a six and a half year old son named Mohammed, with autism. I want to just bring up one specific

point because I know everybody is going to go through the line here. But part of the settlement agreement says that they are going to pay retroactively from the time that the Department sends out a statement that ABA is covered. The problem with that is, is that it could take up to six months for them to issue that statement, so there's no timeline that's in the settlement agreement of how fast they're going to issue that statement. So if they are going to do retroactive funding, it should be from the time of the grievance.

Thank you.

SENATOR STEINBERG: Very good. A very good point. That's something we'll follow up on—absolutely!

MR. JIM LANTRY: Jim Lantry with the DIR Floortime Coalition of California. I'm also the South Counties Autism Taskforce co-chair. I'd like to thank you for your leadership on this issue. It's a fantastic thing that we heard this morning; that the Department of Managed Health Care and the settlement agreement. But I want to talk about semantics for just a second. I mean we shouldn't have to be here. This question was asked and answered twelve years ago when this legislature adopted the Mental Health Parity Act. It's pretty clear that autism was covered. And the only question is what is the semantics to define what autism treatment is? The problem is that that was not clearly answered at that time. And now today, as I look at it and I can follow-up on what Ms. Lapin said, we're looking at another semantic problem. We're looking at when we talk about behavioral intervention therapy we use the word "ABA." ABA is a behavioral intervention therapy; it is by far from the only behavioral intervention therapy. And if we continue to say "ABA" and we use it like we use Kleenex to describe tissues, it becomes so synonymous that when you write the regulations, these other evidence-based treatments become excluded. I don't think that was the intent. We could listen to the testimony this morning from the first panel that talked about how it is very important that these treatments be tailored and it's important that the semantics be corrected that we're talking about behavioral intervention therapy, not simply ABA, although, ABA is a very strong important part and very necessary.

SENATOR STEINBERG: Well, that's something that—I haven't looked at the language, but I assume it says "evidence-based behavioral therapy" and not ABA specifically in the settlement. I hope so.

MR. LANTRY: Well, I don't know. I can only say what they testified today.

SENATOR STEINBERG: We'll check it out. Thank you.

MR. LANTRY: Thank you.

MR. GUILLERMO ARCE: Good afternoon. My name is Guillermo Arce. I am the father of Andrew Arce. When people speak about what's going on in court, it's all about my little Andy. We went all the way up to the California Supreme Court trying to uphold our right to have a class action lawsuit specifically against Kaiser Permanente.

My son was—when I noticed that he was sick he was about thirteen months old. Kaiser delayed his diagnosis and treatment for fourteen months. Kaiser got fined for \$75,000 by the DMHC. After that, they refused to provide him treatment. He had been receiving that treatment from Kaiser for the last three years. From a child that didn't want to hug anybody, he now hugs and kisses, so that's very important to me.

There are a lot of things being said you know, like the other gentleman that was here who said we shouldn't be here.

And one of the things that when I started the whole thing way back then in 2008, was I smell a rat.

And again, I caution the Legislature that before you enter into any kind of settlement, you know, make sure you smell that rat because that's how the whole thing started way back in 2008.

So I just wanted to make sure that, again, there is some kind of cohesive coverage issues addressed. And that's pretty much it.

SENATOR STEINBERG: Another way of saying it is the Legislature will maintain a vigorous oversight rule to make sure any settlements or laws are for the people.

MR. ARCE: Yes. Because you know what? I smell a rat.

SENATOR STEINBERG: Well, there may not be one but we will—and it sounds to me like a real advance.

MR. ARCE: Yes, indeed.

SENATOR STEINBERG: But we will look at it very carefully and improve upon it.

MR. ARCE: Thank you.

SENATOR STEINBERG: Go ahead.

MS. KAREN FESSEL: Hi. My name is Karen Fessel. I'm a parent of a sixteen year old with Asperger's. And I founded a nonprofit called the Autism Health Insurance Project. And I help families advocate for insurance coverage. They have coverage; I help them get interventions.

One of the things that I did was I asked the Department of Managed Health Care for—they made me go through a public records request. And I wanted to know how many families requesting ABA that were sent through standard review, that they weren't IMRs, they were deemed legal coverage issues; how many of the families weren't properly filling out these questionnaires that there were requiring? And they have this questionnaire that they're requiring and it basically requires a licensed provider to say that the child needs care to be delivered by a licensed provider due to the severity of the case. And I'm wondering if, 1) is that going to still be required? Are they still going to make families go through that? For families in certain HMOs, they have to pay out of pocket; they won't get anyone in the HMO to write the letter—to basically fill out the questionnaire.

And then also, I have some data from the public records request, which was that last year ABA, they were, let's see, okay, 51 cases of ABA disputes processed as standard complaints. The Department determined that ABA services were covered in 51 cases and not covered in 6 cases. The Department closed 16 ABA disputes processed as standard complaints because it did not receive the required information. So what that means is that they were not filling out the forms in the way that—the licensed providers were not filling out the forms in such a way that they would hear as a standard complaint and that's a problem.

SENATOR STEINBERG: So let us—these are good questions between our legislative staff and Ms. Sturdevant and others, I think the question of whether or not—under the settlement the HMO will pay for the doctor to fill out the ...

MS. FESSEL: No, it's not that, it's that are they going to continue to require that the doctors fill out this form?

SENATOR STEINBERG: Oh, it's the requirement itself. Okay.

MS. FESSEL: Yeah. The DMHC imposed. The CDI does not impose this. It's a questionnaire making them state that the client needs the care—due to the severity of their condition they need a licensed provider to administer the care.

UNIDENTIFIED: That's in the settlement agreement; it's still required.

MS. FESSEL: Oh, okay, it was in the settlement ...

SENATOR STEINBERG: There was some ambiguity the way it was described and that needs to be understood, I think, better before we reach a conclusion, okay?

MS. FESSEL: Okay. Thank you.

SENATOR STEINBERG: Thank you.

MS. SALLY BRAMMELL: I'm Sally Brammell. I'm a mother of ten year old Jonah Fox, severely affected by autism. We're constituents of Senator Leno. Walking around the Castro with our child every day. My child's case typifies every issue that's come up here. We have a PPO. I, myself, am a recovering lawyer. I made it my business that when the regional center recommended that I put my child in a residential placement because he was a danger to himself with running into traffic, a danger to his sister, I'm going to get this through my PPO. One year later: It took one year. We got a coverage denial. We got a denial that it was educational. We appealed that. We went to the DMHC on the coverage issue. We had to get our doctor and I had to, line by line, tell him how to fill out that questionnaire, with help from others who had been through it that said you have to say "it has to be a licensed provider." My BCBA had to go out and hire a licensed provider to provide Jonah's care although BCBA's are, as you know, trained to do this intervention. That's the intervention he needed.

SENATOR STEINBERG: BCBA; define that.

MS. BRAMMELL: Board certified behavior analyst.

SENATOR STEINBERG: Okay.

MS. BRAMMELL: She went out and hired a LMFT to provide Jonah's care.

SENATOR STEINBERG: LMFT?

MS. BRAMMELL: Licensed Marriage and Family Therapist. And then that licensed marriage and family therapist has honestly, honestly, got to be supervised by the BCBA, because although she does have some autism experience, the BCBA's are those who know how to deal with the behaviors of my child running into the street to go play basketball. It's a farce. The whole licensing requirement is a farce. But we got through that farce. You know, we hired the person. The BCBA helped supervise that person. My child had surmounted that hurdle and we got a coverage decision from the DMHC. When I got the coverage decision, I raised the issue with DMHC, "I'm now concerned. You know we're going on months now of my child—of having to go out

of pocket to try to cover my child. I'm worried they're going to say it's not medically necessary."

"Oh, that never happens."

Mr. Bacchi said, "I'm not aware of that happening. I don't know." I can tell you, it happens. They got the coverage decision.

I called Anthem. I was elated. I was, like, "You know, 20 hours a week Jonah needs this."

They said, "Well, we'll get back to you." Two weeks later, "It's not medically necessary. Your child is eight and, oops, the literature says ABA doesn't work after seven." This is not what the literature says, I can assure you. "And your child has epilepsy and he can't benefit from the treatment." So we went through IMR.

So I had initially filed with Blue Cross in July. It was February when we finally got this sent to IMR. In May, we got a decision from IMR that, "Yes, it was medically necessary. Yes the literature was out there. This will help older children. This helps children regardless of their cognitive status." In May, we got that decision.

I get a useless authorization that says, "You have chosen to go out of network. You will be responsible for all charges above reasonable and customary."

So I call in and say, "What is reasonable and customary? This is thousands of dollars and you're requiring that it be done by a licensed provider, not supervised by but done by. So you're talking about hundreds of dollars per hour, you know, for many hours. I can't do this without your treating this as an in-network provider."

"Sorry. We don't have any network providers."

And I'm a lucky person. I found a provider who could do it. If you don't have of the resources, if you don't speak English, if you don't understand the difference between licensed and unlicensed, you're not even going to get to finding yourself that licensed provider. It is just empty to say that you can have this therapy if you find a licensed provider and if you are, you know, informed enough to tell your pediatrician how to write it to say that you have to have a licensed provider doing it. We finally got it but we got it because I have those resources. And it took a year to get it, I can tell you that—one solid year.

Can I say another thing that has to be fixed? Are the specious and bad faith medical necessity denials that go on. So they were told, "Your child has epilepsy. That doesn't negate his ability to learn. He has cognitive issues. He can still learn."

Our authorization expired. We get a medical necessity denial; “your child can’t learn. He has an anoxic brain damage and severe dementia.”

I call up and I say, “Where did you find these medical records?”

“There are no medical records that say that. Our apologies.”

I still have to go through IMR.

Enforcement actions need to be taken when medical necessity denials are made speciously. Networks have to be built. I shouldn’t have to go out and define my network.

SENATOR STEINBERG: Correct.

MS. BRAMMELL: I mean this is what—the settlement agreement doesn’t address that. It doesn’t require the plans to build networks. They need to build networks and those networks need to be experienced providers and available.

SENATOR STEINBERG: Okay. You know it’s hard to cut somebody off who has such a compelling story. And they’re all so compelling. But I mean I think the point is is that as we evaluate this settlement, as we look at the legislation, my 166, it needs to be analyzed through this frame, right? It needs to be analyzed through this frame and this story and the similar stories that we’ve heard, to see whether or not good faith efforts and good faith work are actually making it better than what we just heard.

Okay, let’s go through the last four witnesses briefly please.

MS. TARA DELANEY: Okay. I’ll make it quick.

SENATOR STEINBERG: Please.

MS. DELANEY: My name is Tara Delaney. I’m an occupational therapist. I come here as a representative of the California Occupational Therapy Association who represents more than 14,000 practitioners in the state of California. I also am executive director of Baby Steps Therapy. We provide occupational therapy, speech therapy, psychological services to children in northern California. We’re a not-for-profit agency.

And I just want to sort of reiterate what we’ve heard today. We take insurance. And we are a not-for-profit because we take insurance. And I take one dollar every two weeks off that clinic because we have to have so much expertise dedicated to fighting insurance companies. If you even mention autism you can assure a denial. Our therapists, who are speech pathologists, psychologists, and occupational

therapists, all licensed, so I want to reiterate that—licensed—and we’re getting denied. We are trained in behavioral methods such as discreet trial, pivotal response training, and now one of the best documented methods, the Denver Early Start Model right here at the MIND Institute, which is a combination of floor time and pivotal response or discreet trial training.

We don’t mention autism. We don’t mention behavior. We have to make it medically relevant but even then we are denied. And we fight for families.

It has to stop. I understand, you know, overseeing when you’re handing out money, but we can’t have it where medical providers are going under.

We have Kaiser right here. Kaiser tells families, “Sorry, we don’t have those providers. You can’t get the services.” Families have to come us and pay cash. We collect monies to give scholarships to families.

So anyway ...

SENATOR STEINBERG: Provider networks—easily accessible provider networks. Next.

MS. DELANEY: Speech and OT as well.

SENATOR STEINBERG: Speech and OT as well.

MS. GINA GREEN: It happens to be a great segue. Thank you. I’m Gina Green. And I’m a California resident and voter, autism researcher, and practitioner, and I’m also the executive director of the Association of Professional Behavior Analyst, which is a national professional organization—international really. And I just want to pick up on some points that were made about providers. Both I’ve been hearing people say, “Well, it’s got to be catch as catch can for consumers to find people who are qualified to provide ABA services, and then I’m hearing on the other side now, those providers have to be supervised by someone who holds a license.

I’ve worked on autism insurance mandates. In most of the states they have those mandates. And I will reinforce what Lorri Unumb said earlier; in most of those states, health plans are accepting the board certified behavior analyst credential in lieu of licensure. The reason for that is that credential, which is issued by an accredited national credentialing body, reflects the requirements that our profession have identified; the training that’s necessary to practice applied behavior analysis. This has been developed over the course of ten years.

The credentialing program is accredited by the National Commission on Certifying Agencies of the Something for Credentialing Excellence. I always forget all of the agencies. This is a valid respected accepted credential.

The issue that Mr. Flannigan raised and this woman has raised about having people who have licenses in something else oversee the practice of ABA is problematic, obviously, for our practitioners. It's going to be problematic for consumers as well. There will be the problem of people who have a license in something else. Behavior analysis is a distinct discipline. It's not marriage and family therapy. It's not clinical psychology. It's not developmental psychology. It's a distinct discipline. If you have people have a license in some other discipline trying to oversee a treatment in which they're not trained and qualified, I shouldn't have to explain why that's problematic. The other thing, is that it will actually decrease consumers' access to these services and it will drive the costs up even more if they have to go find somebody who's licensed absent licensure for behavior analysts, for people who actually are qualified in behavior analysis.

SENATOR STEINBERG: We're hearing it all. I mean, you know, there's access on paper and there's access in reality and we have to focus on both.

DR. LINDA COPELAND: Hi. Really quickly, I'm Dr. Linda Copeland. I'm a board certified developmental pediatrician. I'm also a board certified behavior analyst; I'm a BCBA. And I want to verify that the process of becoming a board certified behavior analyst is a very rigorous scientific professional process. And I totally want to endorse Dr. Gina Green's comments and your comments.

One other issue, and I'm speaking as an individual physician, that I've been licensed as a physician for 32 years, is that there's a possibility of training in medical education about behavior analysis as a science and that should be addressed, I think, by separate legislation, especially if doctors within health plans are going to be making issues of medical necessity on a distinctive discipline that they have no training in.

I'm one of those rare cross-trained individuals. Thank you.

SENATOR STEINBERG: It's nice to see you again.

DR. COPELAND: It's nice to see you.

SENATOR STEINBERG: Last but not least.

BRIANNA LIERMAN HINTZE: Good afternoon. My name is Brianna Lierman Hintze. I'm here on behalf of the California Association for Behavior Analysis that is,

as the name would indicate, the provider pool of behavior analysts. This is your provider pool. We are happy to be here and we are engaged and we are available to you and your staff as a resource.

Clearly, there's momentum building in getting coverage for autism, whether it's by—as a function of state legislation, or as Ms. Unumb said, the fairly clear mandate of the Essential Health Benefits Package, we are going there. And we as your California provider pool are here for you and want to work together.

I want to make two other points. Licensure; it is obviously a hot topic and clearly there's debate. There have been court cases that have ruled that licensure is not required for it to be a covered benefit and for the provider to be paid for the services. We agree with that, of course. That being said, we were the sponsors of a licensure bill just this year. It stalled in the house of origin. We sponsored that bill because of this hurdle that is constantly being raised for services being available to the children and to the parents.

SENATOR STEINBERG: Whose bill was it that got stalled?

MS. LIERMAN HINTZE: Berryhill.

SENATOR STEINBERG: Bill Berryhill.

MS. LIERMAN HINTZE: AB 1205.

SENATOR STEINBERG: Okay. So that's one we're going to look at.

MS. LIERMAN HINTZE: Right. So that's the status of the licensure bill.

I want to also correct something about the status of providers in regional centers. Regional centers do not require licensure; they require certification. So a BCBA can provide the services through a regional center. I just want to clarify that, that currently in this state that BCBAs are able to provide services through the regional centers. They do not have to be licensed.

SENATOR STEINBERG: That's the certification.

MS. LIERMAN HINTZE: Or supervised by a licensed ...

SENATOR STEINBERG: Or supervised by a ...

UNIDENTIFIED: There's an independent vendor category for a board certified _____ regs.

SENATOR STEINBERG: You know this hearing, which really started out as a hearing on coverage versus medical necessity, has evolved into that plus this issue of

licensure and certification and really about access to providers, is really what it is. So we thank you. We thank you very much for coming.

MS. LIERMAN HINTZE: May I make one final comment on the settlement agreement?

SENATOR STEINBERG: Yes.

MS. LIERMAN HINTZE: You're looking for reactions. The initial reaction is it progress? The initial reaction is no! The key in there is that the providers have to be licensed. You see the circles we're going in.

UNIDENTIFIED: And you have to find your network provider.

MS. LIERMAN HINTZE: Right. We would argue that your most qualified providers of these services are behavior analysts. They are not licensed, so the catch there is that the parents have to find a licensed provider. Those providers aren't licensed.

SENATOR STEINBERG: We've got to conclude. Thank you. Thank you very, very much. We appreciate it. (applause) Hold on! Hold on! _____ because Senator Dutton and Senator Leno may have some closing remarks, or not.

SENATOR DUTTON: I found this very informative and I think you're right. I think there's some other issues that are going to come out of all this. I would also like to suggest that we come back. We're going to be going—there will be a brief break we'll have. Certainly, I would think in 30 days from now or whatever, we might want to come back together to see if there's been any new information before we finish the legislative year and that would be my only suggestion. I'll leave that up to your judgment, Mr. Chair.

SENATOR STEINBERG: Thank you. We'll work together and figure out the best time.

Senator Leno.

SENATOR LENO: Thank you, Senator Steinberg and all of the professionals, families, advocates, who have been a part of this process. I think we're making significant progress on the broad scope of that which was agendized today. As I mentioned earlier, through the San Francisco Marin Taskforce we're going to hold hearings and I hope that I can further engage folks, that we can further engage folks, in looking at preventing future generations from having to deal with all that we are dealing with currently, and that would be looking further at the environmental

potential factors that are causing this explosion of new cases and asking the question rhetorically right now, when do we focus more on a precautionary principle? Is it when it's 1 in 80; 1 in 50; 1 in 125? If there are alternatives to chemicals that are currently used in consumer products shouldn't we be allowing for those alternatives to be accessible to consumers? because something is going on here. We don't know what it is yet. We've got all of these issues. If we can potentially save future generations from having to deal with this, we're making further progress.

SENATOR STEINBERG: Thank you, Senators and all the Senators who attended; the staff, of course, and the panels, and all the people who came here—the advocates—on behalf of your own children and California's children here.

You know, there are so many challenges here but one of them, of course, is that we're trying to make up for lost time. And so, moving quickly is imperative. And yet, what we heard today is that we are in fact making some progress. My bill for example: I don't believe my bill deals with the issue of licensure; it deals with the issue of behavioral therapy, intensive behavioral therapy being a covered benefit. Well just maybe, *maybe*, after we review this settlement here, there's some advance on that end. But there needs to be greater advances here, whether it's the bill so that it's a uniform state law, but as importantly, we talk a lot about the health care workforce in this legislature and we have challenges and shortages across the board and we cannot unduly restrict access by limiting who can provide the service. And we will tackle that and we'll tackle it right away.

I thank you all. The Committee will stand in adjournment.

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