

**Select Committee on
Autism and Related Disorders**

Darrell Steinberg, Chair

***An Overview on the Implementation of
California's Autism Insurance Mandate Coverage Legislation***

**Tuesday, March 4, 2014
State Capitol, Room 4203**

SENATOR DARRELL STEINBERG: Good afternoon, everyone. The Senate Select Committee on Autism and Related Disorders will come to order. Since this is a select committee and it's an informational hearing, we don't have to call a formal roll but I want to thank Senators Vidak, Huff, Leno, and I know that there will be others who will be coming as we all have a lot of work to do. But for some reason—and I think I know the reason—this issue of autism and related disorders is a very compelling topic to members because it affects many families and many children in all of our districts. It knows no artificial boundaries; it knows no political boundaries; it knows no socioeconomic boundaries; it has no regional boundaries.

Just to bring us up to date here as to why we are here, first, let me emphasize, apparently there was a little bit of a mix up in the agenda. Apparently the old agenda was distributed publicly. There's an updated agenda but it's not much different from the old agenda so we'll improvise and go forward.

I want to thank Lou Vismara and Jackie Wong, my fine staff, for helping to put this hearing together.

Members, it was some years ago back in '05 when I chaired the California Legislative Blue Ribbon Commission on Autism. Over the years, we've had a number of high-profile hearings on this issue. And one of the hearings, post-2005—and welcome Jim Beall as well—post-2005—was on the issue of insurance coverage for ABA therapy, which is the coin of the realm, if you will. The studies have all shown that children who get the benefit of this behavioral therapy early have better outcomes—educationally, socially, behaviorally—in all parts of life. And yet for many years, the law was not that insurance companies had to cover this therapy, and so that hearing now several years ago led to the opportunity for me to author Senate Bill 946. In 2011, Governor Brown signed it into law in his first year which requires coverage of ABA therapy.

Since then, there have been, I think, more ups than downs, but some ups and downs, namely, the budget decision last year, difficult and controversial, to prohibit the development centers from paying for the regional centers—excuse me—the regional centers for paying for the deductibles on ABA therapy, though they still have the authority to pay the copays, and there was a significant outcry from the community around that issue and we've heard it. And as the budget season begins, under Senator Leno's leadership, it's an issue that, among others, that we're going to want to look at very closely. But

today is a check in, call it a litmus-test hearing, on how 946 and its interaction with the regional centers and our budget action last year is working.

Are more children and families, despite the deductible controversy last year, accessing the service? And if so, through the regional centers or through the private insurance or a combination of both? Has one gone up and one gone down? And if so, why? Is 946 increasing access and the actual service in the way that we hoped it would? And, of course, for those seeking 946 coverage—whether associated with the regional center or not—what practical barriers do they continue to experience in terms of families being able to get covered and then assure their child gets the service? So we want to cover all these things today in about an hour and a half to two hours and really get a check in here as we begin the budget season as to what our direction ought to be. I

I don't know if any other member would like to make an opening but you'd be welcome to. Ready to go? So that is the hearing.

Okay. Let us begin then with Panel 1 which is just a little refresher and an overview of SB 946. Let me ask the new director of the Department of Managed Health Care, Ms. Shelley Rouillard, as well as Robert Herrell from the California Department of Insurance. Both entities, as you know, have authority over this, and I want to thank both of you. I want to thank Commissioner Jones who I know can't be here. There's litigation in this area, also helped a great deal spur the 946 movement. So here we are. I would like to hear briefly from you as to what actions have been taken to implement 946, a little bit about the network of providers, an overview of the DMHC's task force

and recommendation, what you're doing to monitor and oversight and, you know, all this in, like, five or ten minutes, okay?

Who wants to go first?

MS. SHELLEY ROUILLARD: I will.

SENATOR STEINBERG: Go ahead.

MS. ROUILLARD: No problem. (Laughter)

SENATOR STEINBERG: Okay. Thank you.

MS. ROUILLARD: Thank you, Senator Steinberg, Committee Members. My name is Shelley Rouillard. I'm the director of the Department of Managed Health Care as of December 2.

I'm happy to be here to talk a little bit about SB 946 and the implementation activities that the department has undertaken. Basically I'm going to cover the plan's compliance with SB 946, the regulations that the department adopted, the Autism Advisory Task Force, and some of the consumer assistance activities that the department has been undertaking.

So starting with the licensing process, after SB 946 was signed by the governor in October of 2011, our division of licensing developed a checklist of compliance documents and filings that health plans needed to submit to us. Those were all submitted—they were due March 15 of 2012. And by July 1 of 2012, the plans were to have a Qualified Autism Service Provider network, a QASP network. By July 1, all the plans had at least a minimal network of providers. Some had more robust networks. And over the next nine months or

so, we worked closely with the plans to make sure that they had an adequate provider network to serve all of the individuals that needed the services.

The department adopted emergency regulations on September 6 of 2012. In that regulation, the department required that the plans have an adequate provider network by December 31 of 2012. The formal rulemaking process began in October of 2012 and the final regulations were adopted in April of 2013. So that was sort of getting the whole structure set for implementation of SB 946.

As you know, as part of the bill, the department, in conjunction with the Department of Insurance, was tasked to convene an Autism Advisory Task Force. We did that, and the purpose of the task force was to develop recommendations regarding behavioral health treatment that's medically necessary for the treatment of individuals with autism or Pervasive Developmental Disorder or PDD. The task force—and you're going to hear from some of the members from the task force today—convened from February 2012 through October of 2012. And in February of 2013, the department submitted the Autism Advisory Task Force report to the governor and the legislature. As directed by SB 946, the task force recommendations addressed medically necessary behavioral health treatment or individuals with autism or PDD, the qualifications, training, and supervision for providers of such treatment, and requirements that unlicensed individuals providing behavioral health treatment should meet in order to obtain licensure from the state.

We had a very diverse group of task force members representing parents, providers, health plans. And I have to say that they did a remarkable job in coming to consensus on 54 out of 55 recommendations that the task force developed, truly remarkable, and I do credit a lot to our facilitator, LRI, for managing that process and really helping the task force focus to reach consensus. In addition to the specific requirements of SB 946, the task force also made recommendations regarding care coordination, parent participation, health plan policies, consumer safety, and practice guidelines.

I'm going to talk a little bit about the help center and some of the changes and issues that folks who are trying to get access to these services experienced. Our help center, as you all know, provides individual consumer assistance to people who are having trouble navigating the healthcare system. So what we found is that prior to 946, health plans were routinely denying coverage for behavioral health treatment, either because it was not medically necessary or, in many cases, it was not a covered benefit. It was actually, some of these services were specifically excluded. However, after SB 946, the health plans no longer routinely denied services on the basis of coverage. The types of issues or complaints that come to the help center typically involve requests for access to out-of-network providers, denials based on medical necessity, and delays in accessing care.

Over the time from, let's say, 2010-11 to the present, the standard complaints that the department's received around access to these services has dropped significantly. For example, in 2010-11, we had 94 standard

complaints related to, you know, not being able to access services. So far this fiscal year, we've had 12. Similarly, denials of care have been significantly reduced from 65 in 2011-12 to only 15 so far this year. So this really demonstrates, you know, at least from our experience with the help center, that the plans are implementing the law. And while there are still some problems, the number of issues have dropped significantly.

I would also add that plan reversals, which is where, after a consumer submits a complaint and our department starts to investigate it, the plan withdraws its denial. That happens many times. And so in the last 18 months, we've seen a significant overturn rate or reversal rate by the plans, as well as through the Independent Medical Review process.

So just in conclusion, you know, in the last year and a half since this bill took effect, health plans have built provider networks to include behavioral health treatment providers; as a result, access to appropriate services has improved for many children and families that have children with autism and PDD.

SENATOR STEINBERG: Do you keep track, Director Rouillard, of the number of people accessing 946 services through the private insurance market?

MS. ROUILLARD: We don't track the number of people who receive it through their plans. What we track is when we get complaints.

SENATOR STEINBERG: Just—it's the complaints? Okay.

MS. ROUILLARD: Yeah, it's sort of on the back end, when there are problems.

SENATOR STEINBERG: I've got it. Thank you.

MS. ROUILLARD: That's how we identify them.

SENATOR STEINBERG: Mr. Herrell.

MR. ROBERT HERRELL: Thank you. Good afternoon, Senator Steinberg, other members of the committee. I appreciate the opportunity to speak in front of you this afternoon and, as you mentioned, Mr. Chairman, Commissioner Jones was unable to attend this afternoon so he sends his regrets.

I'll try not to be redundant to what the director covered in her five minutes. I know you have a lengthy agenda and lots of folks that you'd rather hear from than us, so I'll be brief.

We did emergency regulations pursuant to SB 946 as well. Those became effective in March 2013. We are in the process of finalizing the permanent regs that'll go into the Office of Administrative Law by the end of this week.

SENATOR STEINBERG: If I may—excuse me. Just for clarity, what do you cover that DMHC doesn't? I know the answer but I'm not sure that—I think it's important to clarify that. What are your separate jurisdictions when it comes to this issue?

MS. ROUILLARD: Are you speaking about the types of plans...

SENATOR STEINBERG: Yes.

MS. ROUILLARD: ...that each department—yeah, so the Department of Managed Health Care regulates all the HMOs in California and some PPOs.

MR. HERRELL: And we cover some PPOs and the individual market.

SENATOR STEINBERG: Got it.

MR. HERRELL: Grossly oversimplified but, yeah.

SENATOR STEINBERG: Good.

MR. HERRELL: So finalizing the permanent regulations, we train the department's staff as to the specific provisions of the legislation to increase awareness, including the Independent Medical Review, or IMR panel process, which is very important, which Director Rouillard has mentioned as well.

I'd like to touch in a little more detail about establishing a network of providers because I think that's important to what you're going to be hearing a lot about today. We did—even just a little bit prior to SB 946 becoming law, we had reached out through a data call to begin this process to provide information, get information, from the insurers regarding the geographic distribution of behavioral intervention therapists, including both ABA therapists certified by the Behavior Analyst Certification Board, as well as non-BACB, Certified Mental Health Professionals if they were properly trained, et cetera.

We asked insurers to provide a listing of all in-network behavioral intervention therapy providers at that time that began this process. We required health insurers to demonstrate compliance with this provider-access regulation, including for Qualified Autism Service Providers. These standards

applied to other specialists within the network as well, so we began to try to apply that as this was coming together.

The insurers need to demonstrate by way of a detailed report that sufficient capacity exists in the network to accept covered individuals within specified travel time or distance rules. During this review, insurers may also be asked to submit complete rosters of their qualified autism providers. More recently, as part of the implementation of SB 946 and as part of our approval of revised policy forums for compliance with the Affordable Care Act 2014, Affordable Care Act requirements, the Department of Insurance is requiring the insurers submit updated network adequacy reports that include detailed information regarding autism providers so that we can properly track this.

I would note that network adequacy in general is an issue of paramount importance to the commissioner, both as it pertains to this area and beyond, and that's one of the things—I know recently we've reopened network adequacy regs to take a fresh look at, in this new ACA world, what network adequacy regs should look like so that's been an open process that began recently. Director Rouillard did a good job of overseeing the task force that DMHC headed. We participated in that. I won't be redundant.

I'd like to focus a little bit on monitoring and oversight. Our Consumer Services Bureau, which has a 1-800 hotline, we get about, overall, 170,000, 180,000 calls a year. So it's extensive and expansive and covers a wide range of things, including folks who are with products that are appropriately regulated DMHC and other places as well. This experience with the

implementation of the autism provider and network requirements is used by our Health Policy Approval Bureau to refine its review of networks as we get these calls and complaints and things like that.

We also conduct Market Conduct Exams where we look in more detail at insurers. Sometimes that happens on a regular cycle; sometimes it happens prompted by complaints or trends or a series of complaints that we're beginning to see. The department examines these regulated entities. We fully incorporated the requirements of SB 946 into those Market Conduct Exams to make sure that insurers are fully complying with the law. That includes information governing procedures, operations with mental health claims in general, including the Mental Health Parity Act, which I know is of paramount importance to many of the members of this panel beyond just autism and autism-related disorders.

If I could just finish up a little bit about the grievances and appeals, for calendar—we've got a little bit of data that may be useful. For calendar years 2011 through 2013, inclusive, we received 129 autism complaints that was for both ABA and non-ABA treatments. Of these 129 cases, 102 or 80 percent were resolved in favor of the insured consumer, either through the formal Independent Medical Review process, IMR process, or by direct intervention on the part of the department. There is a handful of cases still pending that go back to 2013 origination, so that 80 percent number could well go up a little bit more. Similar to what Director Rouillard said, the trends that we are seeing

are that you're seeing fewer denials on the front end as the effect of 946 is beginning to take hold so the trend line there is good.

And then finally, Mr. Chairman, following up on a note that you made as you began the hearing, Commissioner Jones wanted to make clear to the committee and interested stakeholders, both in attendance and watching, that the department supports efforts, most likely pursuant to a follow up budget trailer bill or subcommittee action through the budget process, to provide that regional centers pay for relevant deductibles and copays connected with autism-related services for families that have coverage, and I know you'll be hearing more about this as the hearing continues but you have our full support and efforts that you undertake this year to try to fix that. Thank you very much.

SENATOR STEINBERG: Thank you both very much for excellent overviews.

Do members have any questions of the two regulators before we give them their leave? Senator Leno?

SENATOR MARK LENO: Thank you, Mr. Chair, and for the convening of the hearing. There are so many questions to be asked. I know we were all elated when we first passed and then saw the governor sign 946. But how it actually works in the real world, of course, is of utmost importance.

So my question is motivated by just some anecdotal information I have so I don't know that in fact it is pervasive or all that accurate. So the legislation required the provision of treatment paid for by health insurers or

denied the prohibition. Did the legislation get into, I would imagine, some sort of terminology as to adequate compensation for providers? Because what I'm hearing is that some folks are having their providers drop them because the insurers are paying so little, and I know you don't have certain control over the industry. But is this an actual problem and is it something that we need to address?

MS. ROUILLARD: I'll take the first stab at that.

So our department does not get into provider contracting issues. We don't get involved in what a plan is going to pay a provider for a particular type of service. I personally am not aware of complaints that have come in on that particular issue, but it's something I'll check back with our help center about. But at this point, the department doesn't really get involved in those kinds of contractual negotiations.

SENATOR LENO: Let's just say hypothetically we were able to identify some of these actual cases. Where would one turn? And is there any recourse if an industry just wanted to continue to buck what we're trying to get them to do by going around us or saying, okay, you can require that we provide this service but we're going to pay so little for this service, no one's going to actually fight it?

MS. ROUILLARD: Well, the way that the department would get at that is through the network adequacy evaluations that we do and whether there are enough providers that are available to serve the population of people who need

the services. So if providers start to drop out because they are not getting adequate reimbursement...

SENATOR LENO: Then we don't have the adequacy...

MS. ROUILLARD: ...we would take a look at why that was happening and work with the plans to figure out how they can rebuild their networks or build them up.

SENATOR STEINBERG: Mr. Herrell.

MR. HERRELL: Senator, thank you for the question. It's similar to what the director said. We may have gotten some—I'll check on the data—may have gotten some calls that come in. As you know, we get a lot of calls to our 1-800 number. Some then develop into formal complaints. Some are then matriculated over to the proper entity, but we would access some of this information by network adequacy. We also may come across it in the course of market conduct exams where we look in more detail at an insurer. Sometimes the two are related; and that if, for example, we were to see a troubling trend coming from some complaints, that could lead to a deeper dive into a part of a market conduct exam or one that's narrowly focused on just these issues if we were concerned about that.

SENATOR LENO: And I would imagine that the same response would be out of concern that copays or deductibles, for that matter, rates were so excessive that there would again be a concern for adequacy, network adequacy?

MR. HERRELL: Indeed. To the extent that it impacts network adequacy and we monitor that...

SENATOR LENO: That's our recourse?

MR. HERRELL: Yes. That's one of it. And then also what I indicated, which is potentially, as you go into your, your sub-chairs go into their work and then it goes up to the full budget committee looking at this sort of fix of the fix of last year to see what may be done there. We'd be very supportive of trying to address it through that manner as well.

SENATOR LENO: Thank you.

SENATOR STEINBERG: Are you seeing any trend or even instances of plans turning a site coverage because they deem ABA to be experimental?

MS. ROUILLARD: Well, we're not finding that to be the case. Typically the denials are based on medical necessity; and often, once the consumer files for Independent Medical Review, the plan will reverse its decision so that happens probably about 20 percent of the time. But overall, I would say that similar to what the Department of Insurance is seeing, you know, somewhere between 60 and 80 percent of denials that come to the department get either overturned by the IMR organization or are reversed by the plan before it goes to IMR.

SENATOR STEINBERG: Very good. Okay. Thank you both very much.

MS. ROUILLARD: Thank you.

SENATOR STEINBERG: If there are no other questions...

MR. HERRELL: Thank you.

SENATOR STEINBERG: ...really appreciate it.

Very good. We now move to the next portion of our hearing, which is Agenda Item 3, and this is the impact of 946 on the Regional Center System, and we want to ask Rashi Kesarwani and Shawn Martin, please, to come forward. And, again, I kind of want to frame this, just for a second, because there may be a lot to talk about but I know what I've been hearing from the advocacy community and from others.

Prior to 946, a lot of clients at the regional centers were getting ABA therapy essentially for free, correct? Now 946 comes into play. And, of course, when you talk about insurance, you talk about copays and you talk about deductibles and that sort of thing. And there has been some concern raised, real concern, especially in light of the trailer bill language last year that prohibited the regional centers to pay the deductible—they can still pay the copay—that somehow 946 has actually decreased in a way the amount of access inadvertently. And I'm not necessarily going to ask you about this, unless you are already familiar with it, but I do want the other witnesses who are coming up to be prepared to address what is contained under Item 4 of the agenda, namely—or Tab 4, I should say—which is the Autism Society of California Executive Summary that is a survey which apparently has been updated that speaks to many of these—that speaks to any...

MR. HERRELL: That would be on the website.

SENATOR STEINBERG: ..and it's on the website as well. That will speak to many of these issues because, as we get into a lot of detail, which I

want to in the individual circumstances, I also want to know whether overall this law, in combination with some of the unfortunate budget decisions made last year has still been a net improvement and to what degree and where, and, of course, where it isn't. Okay, so the big picture here. That's sort of what we need to know.

Our experts. Go ahead.

MS. RASHI KESARWANI: Good afternoon, Mr. Chair, Members of the Committee. My name is Rashi Kesarwani with the Legislative Analyst Office.

I will be providing a data and information overview on the Autism Insurance Mandate, and I can touch on, to sort of a degree that I'm prepared to, on the co-pay and coinsurance issue and I think the department is probably in a better position to speak more fully to that issue. So there's a handout that I hope that was made available to all of you that I'll be speaking from.

I'd like to start with a cost estimate of the Autism Insurance Mandate conducted by the California Health Benefits Review Program, or, as it's known by its acronym, CHBRP, which was established in 2002 to conduct analyses of health insurance benefit mandates.

So what CHBRP did in 2013 was estimate the annual cost of behavioral health treatment provided by private health insurance plans. The way that CHBRP did this was to first estimate that consumers with private health insurance plans receive behavioral health treatment on average for a total of 600 hours annually and that estimate is based on academic literature and expert opinion. CHBRP also estimated that behavioral health treatment cost

on average, \$90 per hour, which is based on health insurance plan data from 2008 provided by an actuarial firm. So taken together, the 600 hours annually and the \$90 per hour enabled CHBRP to estimate that the average annual cost of behavioral health treatment provided through private health insurance plans was \$54,000 per child in 2013.

Now I'd like to transition to discussing the relevant data currently tracked by the Department of Developmental Services as it relates to SB 946. And on page 2 of our handout, we provide a table which shows that the department does track the number of regional center consumers with autism receiving behavioral health treatment purchased by regional centers. And if you look at this table, you can see, that after a period of caseload growth, the number of consumers with autism receiving behavioral health treatment purchased by regional centers fell by 684 consumers in 2012-13, which is when the mandate went into effect. And this reduction does appear to be related to the autism insurance mandate.

We know that several factors cause consumers who may be receiving behavioral health treatment from a private health insurance plan to remain in this count provided by the department as receiving behavioral health treatment from regional centers—for instance, if a consumer receives another behavioral service not covered by the health insurance plan from the regional center, that individual would remain in this count. So for that reason, the figure of 684 consumers who are no longer receiving services from the RC for behavioral health treatment, that figure could be understated.

We also note that the department tracks regional center expenditures to assist consumers with out-of-pocket costs, so this would be the copays and coinsurance associated with receiving behavioral health treatment from private health insurance plans. And the department, which is next on the agenda, will go into these expenditures in greater detail.

SENATOR STEINBERG: Do we know, if you take that 684 number again, which may be understated, do we know how many of those people, those children, are receiving the behavioral therapy through 946 coverage?

MS. KESARWANI: So I'd have to work with the department to drill down on that number, so I can't say for sure at this time exactly how many children comprise the 684 consumers.

SENATOR STEINBERG: Maybe that's a wrong assumption. I'm assuming most of the people receiving behavioral therapy are minors.

MS. KESARWANI: That's correct. The vast majority are likely children, likely children under the age of three.

SENATOR STEINBERG: My point is, Do we know whether those folks who are no longer receiving the services through the regional center are still receiving them but through private insurance?

MS. KESARWANI: Yes. That is the reasonable expectation, that they were receiving these services from the regional center. And as a result of the autism insurance mandate, which went into effect in 2012-13, they're now able to receive the services from their private health insurance plans.

SENATOR STEINBERG: So then where—I'm sorry to belabor it—but this is sort of the heart of the hearing here, I think...

MS. KESARWANI: Why is there a bigger drop?

SENATOR STEINBERG: Well, so what about the folks we hear about who had fallen through the cracks, those who can't afford a deductible on the private insurance side or the high copays? If all or most of the 684 people are accounted for, in terms of receiving the coverage, where are the people then who are going without because of, because of the shift between from the regional center to 946?

MS. KESARWANI: Because, as you have said, those people are slipping through the cracks, it's difficult to know exactly how many individuals who may be able to receive behavioral health treatment through private health insurance are making the decision not to access those services because of cost considerations related to the deductible.

SENATOR STEINBERG: We don't know that, but we do know a universe, 684, who are receiving full, free regional center services, no longer free, and your assumption is that the majority of them are now getting the services; they're just getting it through a different method?

MS. KESARWANI: That's correct.

SENATOR STEINBERG: Okay. Keep going. Thank you.

MS. KESARWANI: Okay. Finally, on our last page here, I'd like to cover the additional data collection that could assist with future SB 946 impact analysis.

In our conversations with the California Health Benefits Review Program, we learned that more health plan data will become available, the longer the autism insurance mandate is in effect. Therefore in the future, once more recent data is fully available through an actuarial firm, which is the entity that CHBRP uses to extract its data, CHBRP could conduct estimates of the utilization of behavioral health treatment provided by health insurance plans and the average annual cost of this benefit. Unlike prior estimates that relied on academic literature and expert opinion, future estimates could be based on plan's actual experience with the mandate.

SENATOR STEINBERG: Thank you very much, Ms. Kesarwani. We really appreciate it. We may have some more questions for you, but let's hear from Mr. Martin from the Department of Finance.

MR. SHAWN MARTIN: I was just hear in case there are some additional questions of an historical nature but I don't have anything to add.

SENATOR STEINBERG: Right, from the Leg. Analyst's Office, so we don't have someone here from Finance, and they're the ones that should be here because they're the ones who insisted on the deductible issue. But, hey, here we go.

MS. KESARWANI: Exactly.

Jim—Senator Beall.

SENATOR JIM BEALL: To get to your \$54,000 number, you said that entailed 600 hours a year?

MS. KESARWANI: Yes.

SENATOR BEALL: Okay. So \$600 at \$90 an hour, and that's just the total cost, right?

MS. KESARWANI: Yes. That represents the total cost, so obviously the family that is paying the deductible on the copay and the co-insurance, they wouldn't be paying that full cost but that does represent the full cost that the health insurance plan incurs.

SENATOR BEALL: So when I take—sorry, are these, like, three hour-sessions?

MS. KESARWANI: So various individuals, depending on their need, receive a range.

SENATOR BEALL: ...days, right?

MS. KESARWANI: So on average, on a weekly basis, typically, it can be 25 hours.

SENATOR BEALL: Per week?

MS. KESARWANI: Per week.

SENATOR BEALL: Twenty-five hours per week?

Okay. Then the other question I had, Are these children—what age groups are we talking about?

MS. KESARWANI: So CHBRP used sort of academic literature and expert opinion to arrive at an assumption of utilization across age groups, but it's primarily very young children, typically children under the age of three.

SENATOR BEALL: So you have, like, infants, that do a three-hour session a day?—an infant—you're saying that's what's the case, three hours, three-hour sessions, an infant?

MS. KESARWANI: It would be children and it would be 25 hours per week. I'm not certain as to how many...

SENATOR BEALL: You said under three; you said under three, right?

MS. KESARWANI: Typically young children receive these services.

SENATOR BEALL: All right. I'd like to know what the medical professions think of a six-month-old baby having a three-hour session a week, five days a week, see what they think.

Do you have—when they come up with an estimate, do they have offsets? Are there any, like, a certain percentage of these children have behavioral—correct?—problems, correct? Is that true?

MS. KESARWANI: Yes.

SENATOR BEALL: Okay. Is that considered in this number of \$54,000?

MS. KESARWANI: Do you mean, sort of additional services that might be provided?

SENATOR BEALL: Yeah. They go to additional services.

MS. KESARWANI: No. So this just covers that behavioral health treatment, so the assumption is 25 hours per week for about 40 weeks a year.

SENATOR BEALL: So it does include any other medical or behavioral appointments that a child might have?

MS. KESARWANI: No, it does not. So those would be in addition to this figure.

SENATOR BEALL: Okay. So 25 hours a week of this, plus other appointments beyond this, correct?

MS. KESARWANI: Yes, that could be possible for some individuals.

SENATOR BEALL: Okay. And none of this behavioral health therapy would offset those appointments? In other words, they cover the behavioral issues as well; is that true?

MS. KESARWANI: I think it's difficult for me to comment on that because I think a lot of this can depend on an individual's particular needs as to what types of services they may need.

SENATOR BEALL: But did they examine what kind of needs they have?

MS. KESARWANI: Right.

SENATOR BEALL: Had they examined medical doctors, psychologists, other kinds of medical care?

MS. KESARWANI: Yes.

SENATOR BEALL: Did they examine that?

MS. KESARWANI: Yes.

SENATOR BEALL: How many hours a week does that entail?

MS. KESARWANI: You know, it's difficult for me to speak in general terms for all private health insurance plans.

SENATOR BEALL: All right. I'm interested in what other people have to say about, you know, a six-month-old child or one-year-old child having 25 hours of therapy a week.

SENATOR STEINBERG: That's not—we don't think that's the case here.

SENATOR BEALL: Right. It's not necessarily all very young children. They can be school-age children as well.

SENATOR STEINBERG: Right.

MS. KESARWANI: But predominantly, it is sort of younger kids who are receiving services.

SENATOR BEALL: Okay. I'm interested—you know, this is a hearing to discuss what it costs and whether or not this is a worthwhile program, but I want to make sure that there's an accurate kind of assumption in the beginning of what is actually occurring with these children.

SENATOR STEINBERG: Sure. It is to look at costs but also it just as important here is to look at access and whether or not 946 in an unintended way, an unintended way, has increased access on the one hand but has reduced it on the other and that's the thing I want to get at, this sort of definitively, with as much data as we can. And you've answered one question. I think you had a very fine presentation. But to answer it, I think, the key question for me, which is that you've identified a number of those who were in the regional center system, getting the services who are no longer getting it from the regional center system, but your conclusion, at least tentative conclusion, is that most of those people, children, received the services through

insurance. And then Mr. Vismara here points out to me—he hands me notes, you know, and I read them—that, of course, we’re not dealing with a stable population here. We’re dealing with the increasing number so there still may be that whole population of that increased number cohort who aren’t being able to access the services but we’ll explore—we’ll explore that with other witnesses, okay?

SENATOR BEALL: Well, Mr. Chairman, the reason, I’m asking those questions is I’m trying to figure out what indeed, how many—what’s the total costs overall, what’s the number of children that are affected. And then once you figure that out, you can figure out how many people are needed in the profession...

SENATOR STEINBERG: Sure.

SENATOR BEALL: ...to then treat an expected number of children. And I think, if you do that, you have to come up with some accurate numbers.

SENATOR STEINBERG: I got it.

SENATOR BEALL: And I’m kind of hesitant to say this is an acceptable number at this point. That’s why I’m saying it.

SENATOR STEINBERG: I’ve got it. Well noted and there’s need for—you know, and the more data we have, I think the easier it will be to provide the level of specificity that Senator Beall rightfully calls upon.

Go ahead, Senator Leno.

SENATOR LENO: Thank you, Senator. My colleague here has given me some information from California Healthline.

MS. KESARWANI: My spokesman.

SENATOR LENO: And this actually relates to the question I'd asked earlier with regard to adequacy and network capacity. This California Healthline Reports, as according to a survey that they had done, almost 20 percent of families receiving autism therapy treatment at regional centers have cancelled the health insurance policies of their children in large part because they can't afford the copays and deductibles. I'm not sure if you would have the answer to this or if we need to go back to Director Rouillard. But at what point, if it's not 20 percent, when do we bump into network adequacy? Is it 30 percent, 40 percent? And what do we do with all those who are impacted up until we hit that threshold?

MS. KESARWANI: Senator Leno, I'm not familiar with that particular survey. I haven't had a chance to look at it, and I think you're probably right. In terms of answering questions about what is appropriate for network adequacy, those questions would be better addressed to the Department of Managed Health Care.

SENATOR LENO: All right. Thank you.

SENATOR STEINBERG: Okay? Any other questions? Thank you both very, very much. We appreciate it—succinct and helpful. We also recognize that there's more data and information to be had here.

All right. Let's move on here. I want to invite two representatives, managers, from the Department of Developmental Services, Ms. Nancy Bargmann and Mr. Jim Knight, as well as Mr. Rick Rollens, representing the

Regional Centers for the Association of Regional Center Agencies—and Santi Rogers as well.

Okay. Welcome. Go down the line here.

MR. SANTI ROGERS: Senator and Senators, good afternoon. Thank you very much for welcoming me here. This is my first day of work as Director of the Department of Developmental Services.

SENATOR STEINBERG: Mr. Rogers, welcome, and a good way to start your tenure here with your friends from the legislature. (Laughter)

MR. ROGERS: Absolutely, the close and dearest friends.

SENATOR STEINBERG: Absolutely.

MR. ROGERS: Years and years. As well, I'm here to support our staff. I'm here to support our staff and maybe address issues as they come up through the discussion. Thank you very much. Happy to be here to serve the governor again. Thank you.

SENATOR STEINBERG: Thank you. Go ahead.

MS. NANCY BARGMANN: Good afternoon, Senator Steinberg and Members. We appreciate the opportunity to join you today and being a part of this hearing and being a part of identifying important information that we need and moving forward and being a part of that process.

Today, we've been asked to provide an overview of our role in the implementation of 946—copayments, coinsurance, and accessing federal funding. So DDS provides services to approximately 260,000 individuals who have a developmental disability. Of the 260,000 individuals who have a

developmental disability, there's approximately 68,000 who have a diagnosis of autism. Of the 68,000 individuals who have a diagnosis of autism, it is estimated, that from July 1 to December 31, 2013, that regional centers provided funding for behavior services as well as for copays, coinsurance to approximately 11,000 individuals.

SENATOR STEINBERG: Say that again—11,000 regionals...

MS. BARGMANN: Right. So of the 68,000 individuals, there's 11,000 that received services, behavior services, that may not have been funded at all by insurance as well as for copays or coinsurance, and this is from July 1, 2013, to December 31, 2013, so it's a short...

SENATOR STEINBERG: So they're not 946 clients, I assume?

MS. BARGMANN: So some of them might be, because of the copays and coinsurance, but it also included in that 11,000 member, includes those individuals who may not or do not have insurance.

SENATOR STEINBERG: Got it. Okay.

MS. BARGMANN: So regional center services are delivered, as all of you may or may not know, in accordance to the Lanterman Act. The Lanterman Act established the 21 regional centers who are contracted with the Department of Developmental Services to ensure that services are provided in accordance to their individual program plan. By law, the regional centers are required to use generic services and resources to include private insurance. The generic resources, if those are not available, the regional centers may purchase the service.

As discussed, that the enactment of Senate Bill 946 has moved funding sources for some consumers from the regional centers to healthcare plans. Effective July 1, 2013, as Senator Steinberg has also indicated, is that that was the time when trailer bill language was effective to allow the regional centers to pay for copayments and coinsurance. Also at that time, statute is prohibiting the regional centers from funding health insurance deductibles. There is, however, provision in the law, that under extraordinary circumstances, if a family is above the threshold, as outlined in statute of federal poverty level of 400 percent, that would make them eligible to receive funding for copayments or coinsurance, if they are in that threshold, whether the families or the consumers. But if there is an extraordinary circumstance, the regional centers may fund for that copayment or coinsurance.

SENATOR STEINBERG: How many have been granted exemptions out of that 11,000 number?

MS. BARGMANN: I'm sorry. I don't know that.

SENATOR STEINBERG: That's an important number to know.

MS. BARGMANN: Okay.

SENATOR STEINBERG: And how many of the 11,000 have insurance, if you will, and thus are subject to the copay and deductible? Do we know that?

MS. BARGMANN: We can split that out.

SENATOR STEINBERG: Those are important distinctions, okay?

MS. BARGMANN: Great. Thank you.

SENATOR STEINBERG: Thank you.

DDS is responsible for promoting uniformity and cost-effectiveness and insurance compliance with the laws and regulations governing our system. To that end, effective July 1, 2013, DDS, we established a uniform service sub-code as a means to be able to identify regional center services that are funding copayments and coinsurance. Prior to that date, there was not a specific statute that gave authority to do so. And so to be able to compare year over year, we don't have that information available. We do have, however, information from July 1, 2013, to December 31, 2013, regarding the cost and expenditures that regional centers had funded by—that's been identified through tracking the sub-codes. So based on all services—now the statute, the trailer bill language that allows for copayments and coinsurance is not just only for behavior treatment services. It includes all health-related services. So a part of that, regional centers funded approximately \$1.9 million in copayments and coinsurance for all health-related services. This includes physical therapy, occupational therapy, as some examples.

Of the \$1.9 million, approximately \$240,000 appears to be related to copayments for behavioral health treatment for individuals with autism.

SENATOR STEINBERG: How about coinsurance?

MS. BARGMANN: I apologize. Coinsurance as well. It's both of them—copayments and coinsurance.

SENATOR STEINBERG: So wait a minute. It would cost \$240,000 to fill the gap...

MS. BARGMANN: No.

SENATOR STEINBERG: ...for these families?

MS. BARGMANN: So let me—can I continue for a second?

SENATOR STEINBERG: Well, sure. I'm just trying to...

MS. BARGMANN: Because I might be able to answer a little bit of your question and then let me follow up to any question that you may, if that's okay.

SENATOR STEINBERG: Go, go, go. Of course.

MS. BARGMANN: Okay. So we understand—by taking a look at the information that is available to us, the data that is available to us today, because of a couple of, we believe, factors that are involved—one is that the sub-codes and the instructions to the regional centers to utilize these sub-codes was only made available as of July 1, 2013. That's not that long ago.

In addition to that, it's only been effective July 1, 2013, that copayments and coinsurance was outlined in statute but that the regional centers can fund for that. That said, we really do only have a very small window of where we're gathering data to be able to report on. So we also do not believe, that because of these two factors and potentially some other variables that we're not aware of, that we do not have reflective information that is really all conclusive.

SENATOR STEINBERG: Okay. But the \$240,000 number again, does that cover a time period, July 1, 2013, to six months?

MS. BARGMANN: It's six months' worth but does not include—based on our assessment, it does not include all of the funding that the regional centers have made for copays and coinsurance. We believe there's additional funding

that's been funded by the regional centers for copayments and coinsurance. It is not captured in our data.

SENATOR STEINBERG: Any estimate of how much?

MS. BARGMANN: I don't have that—I'm sorry—but we are tracking that.

SENATOR STEINBERG: Let's say, for the sake of argument, it's five times as much. Boy, that would be big. That's a little over a million bucks. That's six months. For a year, that's 2 million bucks. I mean, want to know, we want to come out of this hearing knowing—and this Department of Finance is not here—and, you know—this is all preparatory for the budget—but they will be when it comes to the budget subcommittees. If your data—and again, I know you're not—you don't have a definitive number but I'm just framing it here—if your data shows that it's a couple of million dollars to cover this gap for families, then this ought not to be a dispute in the budget. We ought to just do it for the families because this number, 240(000) extrapolated—again, and I multiply it by five. Multiply it by ten. That's \$2.4 million over six months. Okay, less than \$5 million to close this gap. What are we doing here? We round numbers much smaller than that and these are families.

MS. BARGMANN: If I may, can I just see if maybe there's a point of clarification here?

SENATOR STEINBERG: Please.

MS. BARGMANN: This is not referencing anything to do with deductibles.

SENATOR STEINBERG: You said copays and...

MS. BARGMANN: Copays and coinsurance.

SENATOR STEINBERG: Oh, which is separate from deductibles.

MS. BARGMANN: Separate from deductibles.

SENATOR STEINBERG: When you used *coinsurance*, I thought you were using that synonymously with *deductibles*. So the deductibles is a separate...

MS. BARGMANN: It's a separate...

SENATOR STEINBERG: ...issue.

MS. BARGMANN: Correct, right.

SENATOR STEINBERG: Do you have a number on that?

MS. BARGMANN: We don't because statute prohibits the funding of deductibles.

SENATOR STEINBERG: Aha. Well, that may be part of the answer here. Okay.

Yes, Assemblymember Frazier, you're welcome to sit up on the dais with us.

ASSEMBLYMEMBER JIM FRAZIER: Well, thank you, sir. No tie.

SENATOR STEINBERG: Come on up anyways. We're, you know, we're the formal informal setting. It's all right. (Laughter) Anybody in the audience want to loan him a tie? (Laughter) Okay. Here we go. You're welcome to join us. Thank you.

MS. BARGMANN: So lastly, just really kind of in summary, that we really are very committed to ensuring that we're monitoring all of the necessary

data presently and going forward and identifying what's going to be helpful moving forward. We also, as consistent with statute, that with the copayments and the coinsurance, that we will also make this information available on an annual basis to the public certainly at any point but it's going to be posted on our website every December. Then that's going to be effective this coming December. But again, we look forward to working with everyone to ensure that we're able to be a partner in establishing the data that's available and helpful to us.

SENATOR STEINBERG: Got it. Thank you so much.

MS. BARGMANN: So Jim will go ahead and do a review regarding federal programs.

SENATOR STEINBERG: Mr. Knight.

MR. JIM KNIGHT: Thank you, Senator, Mr. Chairman, Committee Members. Jim Knight with the Department of Developmental Services. I want to talk about federal funding and accessing federal funding for payments and copayment and coinsurance obviously. The receipt of federal funding is very important for our programs.

We do receive funding through Medicaid through a variety of programs, most notably, the Medicaid waiver in a 1959 ?? State Plan Amendment. Behavioral services are among the many services that are eligible for federal funding under those programs. And in order for the department to receive federal funding, the payment from the regional center must identify the type of service. So if it's for behavioral service, if the regional center identifies that,

then it becomes eligible for federal funding. Any payments made by the regional center, whether they're for copayment or for the entire amount, if it's a service, if it identifies a type of provider or the type of service that's provided, then we are able to access federal funding for that.

I know that Nancy kind of touched on a little bit of the issues with our data at this point. But while the implementation of these new policies may take some time to transition, the department's going to continue to work, in collaboration with the regional centers, to make sure we continue to ensure to maximizing the federal funding.

SENATOR STEINBERG: Okay. We heard the LAO earlier say that some 600 folks who are in the regional center system, a little over now, are not in the system getting these services. I don't know if I'm doing apples to apples here, but I just want to see if we can understand some of these numbers because, Ms. Bargmann, you talked about 11,000, 11,000 people we're talking about here. How does that compare—and that's a 2013 number?

MS. BARGMANN: That's a six month...

SENATOR STEINBERG: Six months. July 1, 2013...

MS. BARGMANN: Correct.

SENATOR STEINBERG: ...to January 1 or December 31, 2013? Okay.

MS. BARGMANN: Yeah, and it's inclusive of all behavioral services for individuals who don't have health insurance as well as...

SENATOR STEINBERG: ...those who do?

MS. BARGMANN: ...for those funding for copays and coinsurance, yeah.

SENATOR STEINBERG: I understand that.

How does that 11,000 number compare to the same data a year earlier or six months earlier? In other words, is that 11,000 number a decrease or is it staying steady? Is it an increase?

MS. BARGMANN: It's an excellent question but I believe that that's information that we don't have readily available at this time.

SENATOR STEINBERG: Why not?

MS. BARGMANN: Part of that is because it is inclusive of also the copays; and so being able to measure year over year, we didn't have a mechanism that we split that out prior year to compare it to current year.

SENATOR STEINBERG: Okay. Okay. Well, let's see where this hearing goes because somebody else may be able to—because again, we're just the policymakers here who want to know the impact of our policies and budget actions. Are more people getting service, less people? Are people falling out because of the interaction of the law, 946 in the budget, or not, and to what degree?

Mr. Rollens, you might have an opinion on this question.

MR. RICK ROLLENS: Thank you, sir.

Rick Rollens, representing the Association of Regional Center Agencies. And before I get into my testimony, I'd like to respond a little bit to Senator Beall's question about who gets ABA. Keep in mind that children diagnosed on the autism spectrum get diagnosed at all different ages, generally younger. The

more severe case of autism you have, so to speak, the earlier the child is recognizable as having autism.

I can tell you as a parent of a 23-year-old son with autism who has been receiving ABA services since the age of 18 months old, he at 23 years old, is still continuing to receive ABA services so it's a broad spectrum. One of the beauties, quite frankly, of SB 946 is that there is no age limit. There's no age-limit requirements or denials based on age and also no cost cap on how much health plans can pay for this service.

And, of course, the third thing I want to mention as well that hasn't been talked about is the access to this service for non-regional center clients. Keep in mind, our system in the regional centers is an eligibility-based system and we do not serve every person in this state—far from it—with autism or autism spectrum disorders. We serve, in my opinion, the more severe cases of autism, but there are thousands of children and others out in California who are not part of the regional center system who now have access through the good auspices of SB 946.

SENATOR STEINBERG: And that's the key question as well—right?—the balance, how many non-regional center children are getting 946 services.

Somebody, somebody—Ms. Jacobson is going to answer that when she comes up in a few minutes, okay? Good.

MR. ROLLENS: All right. Well, thank you for having me. I appreciate the opportunity to testify today. I've been asked to address four different areas on behalf of the regional centers. The first has to do with the role of regional

centers in accessing SB 946 funding. The regional centers through ARCA, its trade association, has worked with the Department of Managed Health Care and California Association of Health Plans to streamline the insurance referral process and to identify single points of contact within regional centers and health plans. They train staff to access insurance funding and to help families with the complaint and IMR process of the regional centers who worked to transition individuals to insurance funding and work to ensure the continuity of those services.

The second area of question that you asked us to respond to has to do with operational challenges and opportunities in the implementation of SB 946. Implementing SB 946 requires a significant amount of work on the part of regional centers and their staffs, both in coordinating care and administering the guidelines related to insurance and coinsurance and copayments. The regional centers did not receive any additional funds to offset this rather major increase in workload to administer this program. The biggest challenge is supporting families that were happy with their current ABA provider and turned out not to be in their insurer's network.

Another challenge was the time it took for many health plans to establish an adequate network to meet the demand for services. As a result of the implementation, many regional centers are now more comfortable accessing insurance-funded services and appealing those services when they are being denied.

The third area you asked us to address is the impact of the emergency regulations issued by DMHC and CDI. The emergency regulations by DMHC made it clear that Healthy Family Plans and some CalPERS plans are now responsible for funding needed behavioral health treatment. Emergency regulations put into place by the Department of Insurance clarified that services that must be provided include speech and occupational therapy and also limited funding delays and denials. The California Department of Insurance has recently proposed permanent regulations that clarify that regional center service funding does not change the responsibility of the insurer to fund these services. This all a good thing, very supportive, and thankful for the work of DMHC and the Department of Insurance in these areas.

The last area you asked for our comment on is an update of copays, coinsurance, and deductibles. Requiring many of our families to pay copayments or coinsurance for related behavioral health services has been a serious and most of the time a catastrophic obstacle to services that should be eliminated, particularly because those services were once paid in full by regional centers without any costs to the families. Even if regional centers paid all the associated copayments and coinsurance costs, the state would still realize significant cost savings from the implementation of SB 946. The total prohibition on regional centers to fund deductibles has posed a significant barrier to many families. ARCA strongly supports the repeal of the trailer bill

language and urges the state to fully fund copays, coinsurance, and that portion of the deductible that is related to the cost of the ABA service.

SENATOR STEINBERG: And your argument, of course—first of all, I agree with you, and you’ve been very vocal. But we need to understand how to make the most effective argument here. That’s the purpose of the hearing. So the argument is, of course, that folks who have this deductible requirement will drop their insurance.

MR. ROLLENS: And they are.

SENATOR STEINBERG: And they are, and then the regional center will pick it up at a full cost without the insurance company.

MR. ROLLENS: That’s correct.

SENATOR STEINBERG: Do we know how many families are doing that?

MR. ROLLENS: We don’t have that data for you. I think some of the advocacy groups will be able to respond, I think generally, to that question. We do know that families are in a very difficult situation—*Sophie’s Choice* kind of situation—in deciding, Can they afford to pay a copay or coinsurance, can’t meet their deductible, and therefore, who suffers? It’s the child.

SENATOR STEINBERG: We understand. But it’s important to know, or at least to have a means to know, how many children we’re talking about here, because we’ve heard this number, 11,000, that include no insurance but also insurance within the regional center system. We’re not talking about the non-regional center clients here and we still want to know what that number is. We’ll get that later. For the regional center clients, 11,000. How many—

they're all affected, if you have to pay something you didn't have to pay before. But how many have been affected in one of two ways? Either cancelling their insurance, period, so that the state then pays 100 percent instead of the insurance company; and number two, how many have just thrown up their hands and given up and whose kids are not getting the service that they need? Those are the two things we must know if we're going pursue this successfully over the next couple of months. Do you know, Rick?

MR. ROLLENS: I don't have those numbers.

SENATOR STEINBERG: Okay.

MR. ROLLENS: I will pledge to you, Senator, that we will do all that we can on the regional center side to try to get that information.

SENATOR STEINBERG: Okay. You're going to come up in a minute. We'll get you. We'll get you in a second, because Mr. Rollens has been very vocal about this and was last year after the budget. And so, you know, each panel, we want to understand and frame the argument here.

Okay. Question from members? Senate Beall?

SENATOR BEALL: I just want to take this time to just thank Santi Rogers for his service to the people in my community as the regional director in the San Andreas Regional Center representing Santa Clara. Let me get this right—San Benito, Monterey, and Santa Cruz Counties?

MR. ROGERS: That's right.

SENATOR BEALL: And I wanted to thank you for your service to our community for the several decades of work you did there as well as—I believe

you're one of the few people that served a former governor who is the current governor...

MR. ROGERS: That's also correct. We were both very younger.

SENATOR BEALL: ...as the director of our Portobello Hospital; is that correct?

MR. ROGERS: That's correct.

SENATOR BEALL: So I wanted to thank you for your service and I'm really pleased that you're serving us in Sacramento now. Thank you.]

MR. ROGERS: Thank you very much, Senator, appreciate that.

SENATOR STEINBERG: Thank you, and welcome.

MR. ROGERS: Thank you.

SENATOR STEINBERG: We hope the first day goes well.

MR. ROGERS: Thank you very much. I'm kind of a talkative guy and they were all sitting there saying a rosary in the background so thank you.

SENATOR STEINBERG: Good deal. We're really glad you're here too.

MR. ROLLENS: Senator Steinberg, if I may beg your indulgence, on behalf of the autism community and the entire developmental disability community, I want to thank you for your service in this area. You've been the leader on this committee. You've established a wonderful legacy with legislation impacting people with developmental disabilities, and particularly autism. And on behalf of my son and all the kids out there, thank you so much.

SENATOR STEINBERG: Thank you. Thank you very much, Mr. Rollens. (Applause) No, no, no, no. Thank you, thank you. Ain't done yet either, by the way. Thank you. One more budget cycle and we aim to get some good things done for people but I appreciate it very, very much, all of you.

All right. Let's hear from the consumers and their families here. We have two well-known advocates—Marcia Eichelberger, the president of the Autism Society of California, representing the Regional Center Consumers; and Kristin Jacobson, we know very well, from the Alliance, the head of the Alliance of California Autism Organizations, representing the non-regional center consumers.

And where's Beth? In the back here? Okay. Beth Burt? Welcome to you.

So you've had the benefit of hearing some of the prior panels and some of the questions here and, of course, I want you to present your testimony and I hope you'll hit on this Autism Society of California summary which I'm going to want to question you about as well. But in terms of the specific numbers that help us understand the context here, we look forward to your testimony. Go right ahead.

MS. MARCIA EICHELBERGER: Good afternoon, Chairman Steinberg, Members of the Committee.

SENATOR STEINBERG: You need to turn on the...

SENATOR BEALL: It's on; it's on.

SENATOR STEINBERG: It's on. There we go.

MS. EICHELBERGER: I'm just not close. Okay.

Good afternoon, Chairman Steinberg, Members of the Committee, and Distinguished Staff. My name is Marcia Eichelberger and I'm here today to testify as a parent of a 21-year-old son with autism who receives regional center services and is the president of the Autism Society of California. I have with me today Beth Burt who is vice-president of the Autism Society. She's here to provide answers to any questions you may have about the data and to provide technical support regarding the document.

Thank you, Senator Steinberg, for your leadership around this very important issue we're discussing today. The implementation of the autism insurance mandate has been a very big change within our autism community. I'll be sharing highlights with you today from the Autism Society of California's 2014 survey entitled *Impact of California's Autism Insurance Legislation*. We've provided you with a summary, as well as a copy of the full report, which we just distributed.

My comments will be from the regional center side of the house and we'll be addressing access, funding, awareness, quality of life, and the issues with the transition our families have faced since the mandate took effect on July 1, 2012. I'll be reviewing graphs and data, starting on page 17, in the report that we've given to you. You may turn there now, if you wish to follow along, while I continue with my introduction.

The Autism Society of California is comprised of nine affiliates throughout the state who provide support, education, advocacy, and awareness

to individuals with autism, their families, and the professionals who serve them. We estimate that there are over 85,000 individuals living in California who fall somewhere on the autism spectrum. In an effort to capture the impact and issues surrounding the autism health insurance mandate and the subsequent trailer bill language that directly affects the bill, we developed an online survey which was distributed through our affiliates and to over 50 California autism organizations. The survey was open for a 24-day period from January 15 through February 5 of this year, so the information is hot off the press.

Just over 1,600 individuals with autism, parents and family members, participated in the survey. There were respondents from each of the 21 regional centers and 44 of the 58 counties in California. As with any survey, there are limitations to our data reporting, including the number of respondents. The number of responses gathered represents just under 2 percent of the projected California autism population. Our survey respondents were primarily from English-speaking families. They tended to be of higher socioeconomic status than is representative of California as a whole, and more regional center than non-regional center families participated. Due to the fact that the survey was available only online, we are aware that families and individuals without access to the internet or those of lower socioeconomic status may have been excluded. We continue to investigate effective ways of reaching this population.

I'd like to start by sharing some of the positive highlights that have emerged from the survey.

First, I'll discuss access. The survey indicates that more regional center families are accessing behavioral treatment than before the mandate. This is really good news.

SENATOR STEINBERG: We can end the hearing now. (Laughter) Just kidding.

MS. EICHELBERGER: If you refer to page 17 of the report, you can see the graph on the right-hand side of the page that illustrates our finding. Prior to the mandate, approximately half or 51 percent of the regional center families were accessing behavior treatment. This was reported to increase to more than 62 percent with another 4 percent in the process of applying for treatment. This is a significant increase in access, and it has already been life changing for some individuals. You've been asking a lot of questions about the ages of the children that are accessing behavioral therapy. If you turn to page 18, you can see the survey results broken down by age for regional center clients.

Regarding the shift in funding, if you turn back to page 17, you can see how the survey projects the shift in funding across funding sources. The largest shift for regional center families was from regional-center-funded treatment to insurance-funded treatment. Insurance funding of behavior treatment has increased from 9 percent as of July 2012 to 38 percent as of last month. Conversely, regional center funding of behavior treatment has fallen from 39 percent to 24 percent over the same period. You can also see that

there was a decrease in those families who were paying privately from 3 percent down to almost none. These are good examples of what the mandate was intended to do.

Moving onto awareness, if you turn to page 19, another positive outcome that this survey shows is an increase in awareness. Eighty-two percent of regional center families, and 71 percent of non-regional center families, are aware of the mandate. This is an increase from our 2012 survey where only 56 percent of the families were aware of the mandate. Although this indicates a market improvement for both groups, the Autism Society suggests a requirement that California-regulated insurance companies notify policyholders that this benefit exists so that all families are aware of the benefit.

Quality of life is an area where we've seen some positive change as well. Page 22 shows the data on quality of life. I'm happy to say, that on the whole, more regional center families reported an improvement in their quality of life since the passage of the mandate. Forty-two percent of regional center families stated that their life has improved. This is for families with all types of insurance—those who are receiving behavioral treatment and those who aren't. The chart at the bottom right-hand corner shows the more detailed breakdown of regional center families by type of insurance. Not surprisingly, those families who have California regulated insurance—and would have been affected by the mandate—have self-reported a better quality of life than those who weren't covered under the mandate.

I feel that I'd be remiss if I didn't also point out an issue that is impacting the effectiveness of the mandate. If you look back at the top of page 22, while there were clearly more families that rated themselves as better off, twice as many regional center families felt they were worse off than non-regional center families—and that was 18 percent versus 9 percent. If you turn back to page 20, you can see a chart that illustrates the numerous issues that have affected regional center families with the transition from regional center funding behavior treatment to insurance company's funding the treatment. On June 27, 2013, trailer bill language was signed into law which prohibits regional centers from paying any health insurance policy deductibles and requires means testing for regional centers to pay copay/coinsurance for any services.

This has become a financial hardship for some of our families. Fourteen percent of the families that were receiving behavior treatment discontinued the treatment. The number one reason for this is that families could simply not afford the copays and/or deductibles. In fact, 75 percent of regional center families feel that paying the copays and deductibles poses a financial hardship for their family. This has resulted in having to terminate or reduce behavior treatment, discontinue other types of therapy in order to be able to pay for behavioral treatment, and in the most extreme cases, actually dropping the individual from a health insurance plan entirely. My colleague, Kristin Jacobson, will discuss this in more detail in a minute.

In closing, we want to stress there have been many positive outcomes for our regional center families because of the mandate. However, we believe the

trailer bill language has unfortunately negatively impacted some of the families with the restrictions it has put in place. Because of the trailer bill language that was passed after the mandate went into effect, unintended consequences have occurred by placing these costs on families in addition to insurance companies. Therefore, the Autism Society of California is calling for the 2013 trailer bill language to be amended to read: Regional Centers shall pay copays and deductibles for IPP and IFSP services with no means testing.

Amending the trailer bill as we've proposed would undo the significant damage to families that has occurred since its passage and saved the state significant funds. It would return the mandate to your original intent.

Once again, the Autism Society would like to thank you, Senator Steinberg, for your vision and leadership in authoring this groundbreaking legislation. We very much appreciate everything you continue to do to support individuals with autism and their families.

SENATOR STEINBERG: It's all my colleagues here, really. Can't do a thing without the support and prioritization by a lot of good people here and I thank you very much.

MS. EICHELBERGER: Yes.

SENATOR STEINBERG: Can you help me? I want to reconcile two numbers because—and maybe they're easily reconcilable but this is the part I'm having a hard time with, okay?

MS. EICHELBERGER: I'm sure Ms. Burt can help you. (Laughter)

SENATOR STEINBERG: We've heard about a base number of, like 11,000 people, and we don't know whether that's gone up or down or has remained stable. On the one hand then, looking at the survey, on page 17, the regional center families, some base, looking at their status before and after the insurance mandate, the rate of access of behavioral therapy has gone up from 51 percent to 62 percent. Good news.

On the other hand, 14 percent of some base—I assume it's the same base—were forced to discontinue therapy, looking at page 20. Those two don't seem to reconcile to me.

MS. BETH BURT: Well, it's actually not the same base because...

SENATOR STEINBERG: Okay.

MS. BURT: ...because of the awareness of the mandate, we had quite a few new families that were able to access the service that weren't accessing the service previously. So if you look at it as a sum total of all families out there in regional center, there was, according to our survey, an 11 percent increase, so we had quite a few families that weren't receiving this.

SENATOR STEINBERG: Okay. And the 14 percent then represents what number? Do we have any idea?

MS. BURT: The 14 percent, they were receiving behavior therapy.

SENATOR STEINBERG: Who have discontinued.

MS. BURT: Uh-huh, as of July 1.

SENATOR STEINBERG: What's that number in terms of whole number of families?

MS. BURT: That, I don't know.

SENATOR STEINBERG: A key number.

MS. BURT: Yes, exactly.

SENATOR STEINBERG: Because in part it informs the Department of Finance and the LAO and the legislature's estimate of what it would cost then to restore the deductible.

MS. BURT: Right.

SENATOR STEINBERG: Lou points out to me that that's a July 1, 2012—that's the date that the law...

MS. BURT: Mandate started.

SENATOR STEINBERG: ...went into effect.

MS. BURT: Yes.

SENATOR STEINBERG: So as of that date, they decided to discontinue those families?

MS. BURT: Yes. So as of the last 18 months, they have decided to discontinue.

MS. EICHELBERGER: So they had services on that date; and since then they've discontinued. It's the subset of people...

SENATOR STEINBERG: I see.

MS. EICHELBERGER: ...who had services that we looked at, yes.

SENATOR STEINBERG: Okay. Ms. Jacobson.

MS. KRISTIN JACOBSON: Senator Steinberg, task force members, and staff, thank you very much for the opportunity to present to you today. My

name is Kristin Jacobson. I'm president of Autism Deserves Equal Coverage, and I was a member of the SB 946 Task Force that Ms. Rouillard mentioned.

I am a parent of a child receiving behavioral treatment through insurance. While all my children went through Early Start in the regional center, none of my children any longer require regional center services and are not regional center clients. So therefore, I'm primarily going to be talking about the impact of the autism insurance mandate on the non-regional center families.

I will also then talk about some successes and barriers in accessing behavioral health treatment through insurance. But first, I'm going to continue where Marcia left off and talk about the regional center families who were forced to drop health insurance because of the exorbitant cost of the copays and deductibles and hopefully answer some of the questions you've been posing.

SENATOR STEINBERG: Good.

MS. JACOBSON: If you turn to page 33 and 34—we can start with page 33—one in ten families had to drop an individual with autism insurance from their health insurance, 19 percent of regional center families. There was another earlier of 15 percent. They're slightly different ends but it's between 15 and 19 percent had to drop a family member in order to keep their behavioral health treatment.

If you turn to page 24, I'm hoping that this will answer some of your questions about who is better off. Twenty-four on the bottom right-hand

corner—it's a graph called *Comparison of Families* as of February 2014. As Marcia has pointed out, the red is regional center and the blue is non-regional center. The first two bars Marcia has already talked about, they show that regional center families are accessing more in behavioral therapy through insurance and overall. So I would expect that they would feel better off than the non-regional center families because they have more behavioral treatment and yet they self-rated about the same. They feel that the same percent is better off. But then as Marcia pointed out, the 18 percent on the regional center clients have reported that they feel worse off and that percent correlates almost identically with the 19 percent who had to drop their insurance. So our hypothesis is that the families who had to drop their insurance are the ones that are feeling worse off.

You had also asked a question about just what were the costs of deductibles. And if you look on page 29, there is a detailed breakdown of the cost of deductibles and you will see that actually half of families have zero deductibles. So when you're looking at a finance, LAO cost, the cost to the regional center for those half is zero for the deductible piece. And then the average for the rest is about \$2,400, so \$1,200, on average, deductible per family.

So I did a little math and I was going to give you an example of two scenarios.

One, the regional center is paying the copay and the deductible. So they're paying \$1,200 on average and then the insurance company pays the

rest. The other scenario is the scenario where the family had to drop the health insurance in which case the regional center is paying the full cost. The LAO says it's \$54,000. I think that's probably high. They were using—CHBRP used 100 percent license, so I'll give them your 50 percent haircut. So say it's only \$27,000, then they're paying the \$27,000 and then Medi-Cal, because most of regional center families actually do have secondary Medi-Cal because of institutional deeming, Medi-Cal actually then has to pay the rest of their medical costs and private insurance pays nothing. So if you just do quick math, which I did in the audience, so I can't promise that it's been proofed or checked, \$1,200 for deductible—let's just assume you have to pay it for every single one of those 11,000 people. That's \$13 million.

Now of the 11,000, if 20 percent of them drop insurance, that's 2,200. If you have to pay half of what the LAO says, that's \$60 million. So you can choose to affirmatively pay the 13, plus the 2 that you came up with before for the copays or \$59 million in actual behavior costs if they drop it.

SENATOR STEINBERG: But you're saying it would cost us, the state, about \$15 million to fully cover, to fully pay, the copay and deductible for the regional center clients who take advantage of private insurance, who have private insurance, about \$15 million?

MS. JACOBSON: If you assume 100 percent of them ask you for it.

SENATOR STEINBERG: Okay. Now I remember in last year's budget debate that the estimated cost was significantly higher, was it not? So once

again, I mean, Senator Leno, as you tackle this and as the Budget Subcommittee tackles this, that difference is pretty stark.

MS. JACOBSON: Right. I mean, that's paying 100 percent.

SENATOR STEINBERG: And if it's \$15 million, which sounds like that's overstated a little bit, because 100 percent, it begs that question: Why don't we just do this and provide the aid and comfort to the families who need it? But, so it's set up for the budget process here to be able to really reconcile that.

MS. JACOBSON: Yes.

SENATOR STEINBERG: Okay.

MS. JACOBSON: Because we believe that the attempt by the governor to save funds has actually cost significantly more funds and is putting families at extreme hardship.

SENATOR STEINBERG: So the other question: Of the 19 percent that we're using to drop insurance or—excuse me—who had to drop, who left the regional center system or...

MS. JACOBSON: They dropped insurance. They dropped their private insurance so the regional center now has to pay the whole cost.

SENATOR STEINBERG: That's the 19 percent.

MS. JACOBSON: That's the 19 percent.

SENATOR STEINBERG: They all dropped insurance?

MS. JACOBSON: They dropped insurance, for some reason. They didn't all drop it because of copay and deductible but that was the primary reason.

SENATOR STEINBERG: Okay. Of those 19 percent, though, how many actually continue to get the services on the full dime of the regional center?

MS. JACOBSON: We would have to go back and look at that but we could. I don't have...

SENATOR STEINBERG: Please do that because that's another human factor here, right, who...

MS. JACOBSON: And then I think you brought up the other critical point as, How many dropped, you know, had to discontinue ABA?

SENATOR STEINBERG: Go ahead Jim. Thank you very much, Senator Beall.

You know, Finance, I guess, estimated that it was 40 million bucks to fully fund the deductible and the copay. It sounds like we have a little debate going here.

MS. JACOBSON: Right.

SENATOR STEINBERG: And it isn't even June yet. (Laughter)

MS. JACOBSON: And we doubled our numbers. We just, for the sake of it, doubled our numbers.

UNIDENTIFIED SPEAKER: _____.

SENATOR STEINBERG: Yeah, got it, and the deductible is even broader than ABA, right, because it's for other health conditions as well.

Okay. So what about—let's shift to the non-regional. So we know enough to be...

MS. JACOBSON: Right. We know about...

SENATOR STEINBERG: ...confused on the regional center side but we know where we need to go.

Now on the non-regional center side, because this is the highlight of the hearing...

MS. JACOBSON: Right.

SENATOR STEINBERG: ...and the other is the challenge and the difficulty of what we need to do. This is now the good stuff. This is the dessert, if you will. How many folks outside the regional center system are getting services who weren't, before 946, and now getting it as a result of 946?

MS. JACOBSON: Okay. If you turn to page 4, the chart at the bottom of the page, on page 4, shows increased access for non-regional center families. So previously, 30 percent had access to behavioral health treatment before and now 38 percent do.

SENATOR STEINBERG: What is that?

MS. JACOBSON: It's a 27 percent increase. That's very significant. It doesn't maybe look like a huge jump, but a third more people have access to behavioral health treatment. That is a life-changing event for a third more people.

SENATOR STEINBERG: Can you translate those percentages into actual numbers in any sort of estimated way?

MS. JACOBSON: Marcia, estimate.

SENATOR STEINBERG: Regional centers, Dr. Vismara says, provide 20 percent of the services to 11,000. So if you do the other, you're talking about 50,000, about 50,000 non-regional center...

MS. JACOBSON: ...families.

SENATOR STEINBERG: families.

MS. JACOBSON: Times eight percentage points.

SENATOR STEINBERG: It's an additional 4,000 families.

MS. JACOBSON: Four thousand, 5,000 families.

SENATOR STEINBERG: An additional 4,000 or 5,000 families.

Okay. Again, I think it's important that we get that data more specific...

MS. JACOBSON: Yeah, we did not translate it into number of families, but we can do that because the survey just looked at percentages.

SENATOR STEINBERG: Got it.

MS. JACOBSON: But I would guess it's about...

SENATOR STEINBERG: Four to 5,000 families on the non-regional center side.

MS. JACOBSON: And that's life changing treatment for those families. I've talked to those families and...

SENATOR STEINBERG: Plus an increase on the regional center side, albeit that's because more people are accessing the regional services, but folks, at a minimum, having to drop their insurance, and even worse than that, having to drop the service altogether potentially.

MS. JACOBSON: And so for the non-regional center clients, while they still have significant access and much improved access to behavioral health treatment, it's still quite a bit less than regional center families. And one thing that it led us to question is, it appears that the regional center, being a member of the regional center, has actually helped families figure out how to access their insurance, whereas the non-regional center families don't have the assistance. So when we started non-regional center families, we're getting more from insurance. And now regional center families have passed them and they're getting more from insurance. So I think there's something to be said where, if we can give some training and assistance to non-regional center families, you can see that access improve even more.

SENATOR STEINBERG: Got it.

MS. JACOBSON: Obviously also, the shift in funding that's shown on that same chart...

SENATOR STEINBERG: What chart?

MS. JACOBSON: Page 4. You can see private pay decreased from 7 percent down to 2 percent, so that's actually a lot of families who are no longer paying the full cost of behavioral treatment. That's a lot of money for those families to be saving. And even the regional center saved a little money on this group because some of these kids were in Early Start. So even though they're not in regional centers now, regional center through Early Start was funding 5 percent before and now just 1 percent because somebody new applied and was able to get regional center. So families and regional centers both saved

significant money, even when access increased. So it's really a win-win story—more access and cost savings.

If you switch to page 27, you will see information on non-regional center families' quality of life. And as Marcia pointed out, 42 percent feel that they are better off and only 9 percent feel that they're worse off—so four times more families feel better off than worse off and that's really significant. And then I think we've already talked about that only two times regional center families feel more better than worse, and that is probably because there are more of those families impacted by the copay deductible but we've, you know, hit on that plenty.

UNIDENTIFIED SPEAKER: Do access.

MS. JACOBSON: Do access? Which one's that?

MS. BURT ??: Timely access?

MS. JACOBSON: Oh, I'm not—yeah, that's coming.

Now I'm going to talk about what happened when people actually applied for insurance. So if you switch to page 25 and 26, you will see on the chart on page 26, 27 percent of families who were non-regional center applied through their insurance. So about a third of families applied through their insurance. And then if you switch to page—I think it's maybe the page before—yes, page 25—you'll see that 57 percent, if you look at the red line, that's the one that really matters because the red bars are California regulated—57 percent of people who applied were approved the first time. That is a significant

improvement for families compared to what it was like before when 100 percent of requests were denied.

Now there's still room to go because, really based on the literature, it should probably be closer to 90 percent are approved the first time. However, we've made a huge stride in the insurance companies' approving treatment, and I want to make sure to acknowledge that from them. And even though I will be talking about some challenges, overall, insurance companies have really moved forward in improving access.

SENATOR STEINBERG: There's another piece of this chart on page 26, though, that really strikes me that speaks to our continued work in this area, and that is, if I'm reading this correctly, 57 percent of eligible families outside of the regional center system who were eligible to apply for behavioral therapy did not. It's over half.

MS. JACOBSON: Yeah.

SENATOR STEINBERG: We've got to spread the word here.

MS. JACOBSON: Yes. That's why we are hoping that we can maybe ask insurance companies to inform people that this is available. Many people still are under the impression that it's not covered because they maybe asked years ago so we need to tell families, and the best way to access it is have every insurance company tell their families this is a service that we offer now—this is a covered benefit and you can apply.

SENATOR STEINBERG: Got it. Okay. Anything else?

MS. JACOBSON: Now I will touch a little bit on some of the challenges that people have been facing. If you turn to *Timely Access*, it's on page—I apologize...

MS. BURT ??: Thirty-five.

MS. JACOBSON: Twenty-five?

MS. BURT: Thirty-five.

MS. JACOBSON: If you turn to page 35, you will see, while 57 percent were approved, the timely access regulations require an approval or denial decision within five days. Only 34 percent of families actually received their approval or the denial in these statutory—in the statutorily required timeframe and several took 15, 30, 60, more than 90 days. So we do have some work on speed of access.

And then the second chart below that says how many people—how long did it take once you got an approval? And so once you got an approval, you went—it still took only—48 percent got it within the required ten days and many took longer, so some of these families are taking two and three months to get treatment.

The last, page 36, part of the reason that it might be taking so long is that the insurance companies are requesting a lot of documentation. All that SB 946 says you need is a diagnosis, a treatment plan with measurable goals, and insurance companies are requesting quite a bit more information which takes more time.

Then the last point I'd make is on page 37. Of the denials, you're still seeing denials for advanced age, even though there's no age limit on SB 946. It's considered experimental, even though that's been disproven—too low or high IQ, location of service, or not a covered benefit. So for those who are getting denials, the reasons are still not appropriate. And it sounds like, when someone appeals to the Health Department, the insurance company reverses itself but the problem is, 90 percent of people don't appeal to the Health Department and so they remain without treatment.

I would just like to thank you for the opportunity to have presented this information to you and to thank you again and again for how much you have done for our families and continue to do. You are just an incredible champion. Thank you.

SENATOR STEINBERG: Thank you. Thank you very much, Kristin, all of you, very, very much.

Senators, Assemblymember, questions?

SENATOR LENO: Thank you. A lot of information. It's going to take a while to digest. Remind us what the penalty is. What recourse do we have for these inappropriate and disallowed denials of service that you have on page 37? So what disincentive is there for an insurance company not to do this?

MS. JACOBSON: There's not a lot of disincentive and that's the problem. There could be a disincentive but 90 percent of families don't appeal. So they get away with it and just avoid the treatment for those. For the ones that do appeal, a lot of times, the insurance company just says, fine, I'm going

to reverse myself. And then they just avoided paying for treatment for whatever period of time that took.

SENATOR LENO: So there is no penalty whatsoever?

MS. JACOBSON: There could be. If they're overturned in an IMR, if it goes that far and they don't provide it, there's a penalty or the Health Department or the Department of Insurance could take an enforcement action but there are relatively limited penalties, but it takes many steps before you get there.

SENATOR LENO: I understand. It's all stacked against the family.

MS. JACOBSON: It is.

SENATOR LENO: A family, I'm sure, would need to engage an attorney?

MS. JACOBSON: Attorney or advocate. There are some health insurance advocates.

SENATOR LENO: But that would cost money too?

MS. JACOBSON: That would cost money too and it's very hard to do by yourself.

SENATOR LENO: If we're looking at amending 946 in some ways, updating it, that we would minimally want out-of-pocket costs and appeals that are overturned to be covered by the insurance companies. So that's a little bit of disincentive there and maybe we put some sort of timeframe, that if they drag this out, then they deny and then they see an attorney coming after them, rather than to have them have the option to reverse course quickly, that if they've already crossed a time deadline, they're going to pay some penalty.

MS. JACOBSON: If you look at the IMR statute, if it goes that far, and if they have an IMR decision and then they don't enforce it or they don't implement it right away, they're charged \$5,000 a day. So once the IMR comes out, they implement it right away because there is a disincentive. If that \$5,000-a-day fine started from the day you asked, boy, would they have an incentive to actually approve it and not drag their feet, because there's precedent for a \$5,000-a-day fine.

SENATOR LENO: Looking at your survey, it would seem that we need to do something.

MS. JACOBSON: We would agree.

SENATOR STEINBERG: Very good, Senator. Maybe we need to talk about it.

Mr. Bacchi's coming up in a few minutes. We can ask him about that as well.

Assemblymember?

ASSEMBLYMEMBER FRAZIER: So it's my understanding last year in the budget process that there was a small component in the ABA through the Medi-Cal that we did not fund.

SENATOR STEINBERG: This was the deductible issue that...

ASSEMBLYMEMBER FRAZIER: Right. And so is there a federal match that we overlooked, that when we fund that component, that the fed actually comes through? Are we stepping over a dollar to pick up a dime in any form or fashion of that?

MS. JACOBSON: When you do fund behavioral health treatment, you do get a match. I think you'd have to talk to the DDS about what the match is. Medi-Cal would also have a match. So I don't know if I can completely answer that right now but there is a federal match.

SENATOR STEINBERG: I can help here. I think that you may be referring to—there's another issue here, which isn't a subject to today's hearing but it might be right for a second hearing, and certainly in the budget committee—and that is, extending ABA therapy to kids whose families who are on Medi-Cal and that has been a longtime passion of the community here. And, you know, it's equal protection, right? If it's good for some kids, why isn't it good for all kids? And the answer and response is, it's a state budget issue. And, you know, we have had some wrangling back and forth about the costs. There is one—it's an issue that we intend to take up during the budget. It's harder than the deductible issue, frankly, because it's of greater magnitude but it's compelling and it ought to be one of our priorities this year, okay?

MS. JACOBSON: And there is some information about those families in the survey, if you want to read it.

SENATOR STEINBERG: Good. Thank you for all your great, great advocacy, and the survey is terrific because it isn't all, all the information that we need or you need, but it does give us a real early snapshot. It tells us where we're doing really well and where we have our challenges. Appreciate it.

MS. BURT: Thank you. Thank you everybody.

MS. JACOBSON: Thank you.

SENATOR STEINBERG: Appreciate you, all of you.

Okay. Last panel. We have Doreen Granpeesheh for the Center for Autism and Related Disorders, as well as Mr. Charles Bacchi, the California Association of Health Plans.

Ms. Granpeesheh is representing the providers here and Mr. Bacchi is representing the health plans, and we want to talk a little bit about the non-contracting issue, the network of providers, other important findings, how the insurance industry is monitoring the impact of 946, and maybe to answer some of the concerns that Senator Leno raised a moment ago in terms of denial of access and care. We welcome you and thank you. Please.

DR. DORIAN GRANPEESHEH: Thank you very much, Senator. I will also start by thanking you, Senator Steinberg, for everything you've done in this field. It has really made a huge difference in so many lives...

SENATOR STEINBERG: Thank you.

DR. GRANPEESHEH: ...so we appreciate it.

And thank you very much, Committee Members. It is an honor for me to present here. I do have a pretty large company in California. I have 14 of my 28 clinics are in California. So any given month, we're providing over 50,000 hours of ABA services. But in order to make sure this is kind of a fair representation of all of the providers in California, the information that I'm going to talk about was also collected from the California Association for Behavior Analysis, CalABA, as well as Autism Speaks and California Psychcare, Autism Deserves Equal Coverage, and the Southern California Consortium for

Behavior Analysts, so I'm hoping this is pretty representative of what's going on, on the provider's side.

So I'm just going to—a lot of what I was going to present has already been covered. And in order to honor your respect to try to get out of here in time, I'm going to just add to some of these issues that have been pretty important. I will say—and all of my material is also in the binders and you will see that—of course, we've had a tremendous growth in the number of children who are now receiving coverage for behavioral interventions. It's very difficult when you ask the questions about the difference between regional center and non-regional center because they transfer. So if a child is a regional center client but they have insurance coverage, they won't anymore access regional center. They'll become now an insurance client, so that is an ongoing process, and the switchover is difficult to estimate when that would happen. But, however, the issues that providers are having has really to do with implementation of the bill and so I'd like to talk about that a little bit.

The number one issue is, of course, what we've been referring to, which is the copay and the deductibles and all of that sort of thing. We do have data on our children, obviously. We're not representative of the whole state, but there are quite a number of families that will refuse all of their funding, simply because they cannot afford the copay, coinsurance, or deductible. And for me, I am a pretty big company and I am, just in the ten months of 2013—I was just calculating as you were speaking—we're carrying approximately \$250,000 of copay that people still owe us, so a quarter of a million dollars we're carrying,

the company is carrying, because it's difficult for families to make these payments. It's very, very difficult. But smaller providers, obviously, would not be able to do that and that would be very difficult for all of the providers.

So one of the big issues with ABA is that, in the younger population, it has to be pretty intensive. And because it's intensive, that means, you know, let's say five days a week, that has a lot of copay—so five times a week copays. So as these families start to not be able to afford it, what do they do? They'll possibly reduce services, not just deny but reduce services. And if they're reducing services, then their intervention becomes ineffective because, of course, by nature, ABA has to be for a certain age range quite intensive. And so once it becomes ineffective, then the effect is, the insurance company comes back and says, oh, this wasn't working. We're going to deny continued treatment, which happens quite a bit now. And that brings me to one of the most important points which is, slow progress is actually quite a big determinant in terms of discontinuation of services for insurance companies. We have a lot of data on this.

SENATOR STEINBERG: Can you repeat that again?

DR. GRANPEESHEH: Sure. You know, the Autism Advisory Task Force had said that rates of progress shouldn't be included in something that determines medical necessity. It is. It is being considered. A lot of the children are being denied access or treatment plans are not being renewed due to things such as slow progress, aging out. There is a lot of delay happening in terms of testing, wanted testing, cognitive testing, which shouldn't really have

anything to do with it either, as well as developmental testing, and which a lot of the insurance plans aren't very clear about the type of testing they want and so we end up doing a lot of different types of tests and this ends up being months and months of delay for the family because they won't get authorized.

The process of authorization is, you get authorized for an assessment first. We then as the provider provide all of that and then you have to resubmit for treatment authorization, and that process really does take quite a bit of time because of the assessments that are being required for each family.

So I also want to add that there were three separate sections that the mandate approved. They were the distinct roles. They were provider treatment, qualified ___ on service provider, qualified—the professional and the paraprofessional, okay? And this was very important because this three-tiered model reflects really what is the best considered treatment protocol offered by the BACB, the Behavior Analysis Certification Board, our board. But at this time, most of the health plans are not authorizing. In fact, I don't know any that are authorizing the midlevel, which is the professional level. And this, of course, makes it quite difficult because you now only have to have the higher qualification in order to be able to provide these services. It does go to an access-of-care issue. It reduces our ability to provide services.

Another issue that was raised was there is some confusion with health plans in terms of funding services that occur in school. So if the child is receiving educational services in school, some of those are of an educational nature in which case, of course it shouldn't be necessarily their responsibility.

However, a lot of what ABA does in the school setting is to provide access, allow the child to attend and be able to behave and go to class, and those types of things are medically necessary. However, insurance plans generally will exclude any services provided during the school hours or on school grounds. So this is pretty much a very important issue because it restricts what's appropriate for the child.

SENATOR STEINBERG: Don't they—well, we'll hear from Mr. Bacchi—but don't they think that the schools should pick it up through the IEP? Is that the issue?

DR. GRANPEESHEH: The schools won't pick it up because they feel...

SENATOR STEINBERG: I understand.

DR. GRANPEESHEH: ...it's medically necessary. Right, right.

And then another issue that has come up, a lot of providers have been calling in, I think, to CalABA and talking about this issue which is that they've encountered some issues with the use of third-party administrators. For instance, one of the insurance companies—I think it's Health Net—provides only Autism Services Group and there are not a lot of providers that are in network with Autism Services Group. I, myself, have actually been trying to get a network with Autism Services Group but they deny me. I'm probably the oldest provider, by the way, in California, so it's kind of interesting that we keep getting denied. So it's sort of a strange situation because there are families who have reached out to us who need help from these particular regions, but they're not allowed access to all providers. They're only allowed

access to very specific providers. And the reason for denial, by the way, is not credentials or anything like that. They've specifically told us that they want to keep it within a very small group of providers.

SENATOR STEINBERG: Okay. If you can wrap it up, please.

DR. GRANPEESHEH: Yes, certainly.

Finally, and this is kind of a big issue for us, is that a lot of families don't appeal their decisions when they are denied. And if they do appeal the decisions, the IMRs, or the Independent Medical Review boards, consist of individuals who have absolutely no knowledge of what ABA is, or Behavioral Health is, whatsoever. I haven't dealt with a single IMR that has had a behavior analyst or a licensed psychologist who knows behavior analysis on the IMR. So that's why the families are actually being rejected quite often because there's really no answer to their needs there. But having said all that—and I do look forward to the next speaker's comments—and I apologize because I don't want the comments to be all negative towards health insurance, but I really do want to be able to help fix some of the issues we're having with implementation. Thank you again.

SENATOR STEINBERG: Thank you. And we did hear from the regulators that the rates of denial have gone down and that there are positive things so, you know, we take it all—the positive and the negative—we're just trying to draw the information here in this hearing.

DR. GRANPEESHEH: Absolutely.

SENATOR STEINBERG: Okay? Cross-examination? I'm just kidding.

MR. CHARLES BACCHI: Thank you. Mr. Chairman, Charles Bacchi for the California Association of Health Plans representing 40 member health plans providing health care coverage to over 21 million Californians. Thank you for inviting us to participate on this discussion. As you're aware—and we've been saying we've been providing coverage for medical services for children with ASD for many years. With the passage of your law, now we're providing behavioral services to children as well, and these families are receiving valuable financial support in paying for what is a very expensive treatment.

We committed to you upon the passage of your law that we would do the best that we could in implementing it thoughtfully and in posthaste and doing a good job and bringing all of the tenets of managed care into ensuring that people are receiving effective care and it's a cost-effective price. Moving a system that's not used to managed care into managed care can have its growing pains, and I think a lot of what you're hearing from folks is just that. It's a system of organized care that uses evidence-based medicine and sometimes that isn't the way that providers are used to providing these types of services necessarily in the past.

So I wanted to start off with just noting that every health plan has a different story and it's the reason we didn't send one health plan up here to talk to you. But each one has handled this law differently in how they built their networks and how they went about contracting with providers in providing the services. And of course that was some of the first work we did,

was creating our networks. For example, one plan reports that since the passage of SB 946, they've hired or contracted with over 2,000 ABA providers, 120 additional speech therapy providers, 100 occupational therapy providers, and 34 physical therapy providers in order to deal with the increased demand within their service area. Another health plan reports that their networks of providers capable of providing behavioral health treatments has tripled since the passage of your law. But this explosive growth in networks isn't exactly the whole story because we and our contracted agents continue to contract with providers in areas where we find there is a shortage of providers. And so if we recognize a problem area, we're going to hire more providers in order to ensure that enrollees have the care that they need.

The question does present itself. What are we doing to make sure that people in these areas with these networks of providers are receiving timely access to care? We have not heard the anecdotal stories or seen the study, obviously, that was presented earlier. But I can share with you what plan is doing, which is that they created special positions in their plan. They're called autism care managers. They provided training to their subcontracted entities on—and to their network providers to ensure that treatment plans are developed, that those plans are followed, that authorization requests for service are handled quickly and accurately and efficiently. They're in constant communication with providers to identify areas where families are not receiving services in a timely access way. They've conducted provider training on timely access standards to make sure that our contractors know what we're expecting

from them. They require bimonthly timely access reports from their providers. And every six months, at a minimum, they review service utilization to make sure that services are being provided in an appropriate manner. Of course, there are areas where there are challenges to getting service. For example, one plan reports there's a three-month wait list for UCLA providers. Families who have health care coverage can choose to wait for a facility, if that's what they want to do, but there's other providers available to them within the plan network that they can certainly avail themselves.

The important thing that we wanted to remind the committee, is that in measuring whether or not people are getting timely access, it's not a measurement of how many providers are in a county or how many providers are in a zip code, it's really how many—whether or not the enrollees are getting in to see a provider in a timely fashion. And if there is evidence that we are not, the health plans will move quickly to fix that. It should be brought to the attention of the regulators. And in plans, we want to avoid corrective-action plans; we want to avoid enforcement penalties; and we certainly will work with anyone who says that we are having problems in meeting access in any specific area.

On provider licensure, we appreciate the guidelines that were created in SB 946 setting forth the parameters for our contracted provider networks; and we're following those requirements and they're a good first step. However, we believe that the state does still need to examine those standards and adopt an actual licensure framework. We know this is difficult and it is controversial

but we believe that parents, providers, plans, and most especially, children, should be confident that those who are providing services are doing so in a safe and effective way.

Contrary to the previous testimony, one of the issues the plans wanted me to bring to your attention is that we are having trouble in developing our network providers in one area, and that is, for qualified autism service professionals. The plans note, that as they are building out networks in areas, one of the requirements of SB 946 is that QAS professionals are vendorized by the regional centers. And what's happening is, that as we are hiring up providers who are newly certified or newly qualified as professionals, they're applying to be vendorized by the regional centers. The regional centers have a lot on their plates, so this isn't a criticism of them. It's not in their mission statement to approve professionals as vendors so we can then hire them, but that's the way the law works. And so that's an issue that we've sort of identified as an ongoing problem.

SENATOR STEINBERG: Okay.

MR. BACCHI: Again, grievances are down; complaints are down. We think that's a good sign.

While I cannot address the questions that the Committee had about the number of people receiving coverage exactly in California, I did ask the plans if the \$54,000-a-year estimate for ABA services was accurate in their experience. The responses I received back from the plans was that it is either accurate or it's a little low. So we think—from what we have seen, it seems to be a

relatively decent ballpark number for how much private insurance is spending annually per child with autism for just their behavioral health treatment so it doesn't count OT, PT, ST, and any other medical services that were provided for ...

SENATOR STEINBERG: Give an estimate on the numbers, if you know them.

MR. BACCHI: Well, so the CHBRP analysis estimated that there would be around 12,000 to 700 children with private insurance receiving coverage. That was just their using math, looking at the population. I had less than half of the plans respond to my survey and I got to half of that number. So I think it's fair to say, looking at the population of the covered lives out there, it could be accurate. If that's the case, we're spending between 600 and 700 million dollars a year in services under private health care coverage for children with autism.

So while the floodgates of private health insurance funding have opened, we do want to leave the committee with a couple of thoughts.

One, that we do believe the schools continue to play an important role in providing services. We're concerned—our plans are concerned—over the fact that the K-12 system, because of funding cuts, is perhaps feeling the pressure on developing and following through with their IEP plans. We note some anecdotal issues that they're not being followed in the school. So we support funding, the K-12 system, adequately enough that they can play their role in what is a continuum of care for children with these services.

And finally, we also support increased state funding for regional centers for children with autism—the regional centers continue to play an important role—and we caution policymakers against assuming this is private insurance—and you’re not one of them doing this at all today—that just because private insurance is now covering ABA services, that we can just forget about the regional centers. We do need to fund them and you’re right on point here today.

So in summary, we’ve rapidly built and are still building our networks. We’re monitoring our compliance of timely access law. We’re spending considerable amounts of funding on providing these services. Complaints and disputes are down but there’s still more to do. And I think looking at the provider licensure system, having a dialog over whether the professional standards need to be tweaked, and ensuring that we’re fully funded in the K-12 and regional centers are important, and we’ll continue to work with our regulators and stakeholders to make sure that this law is implemented correctly.

So with that, I’ll take any questions, if there are any.

SENATOR STEINBERG: Thank you. Senator Leno.

SENATOR LENO: Mr. Chairman, I thank you for a great hearing. I have to get to my office for another meeting...

SENATOR STEINBERG: I understand.

SENATOR LENO: ...so I’m going to go funnel all my questions telepathically to you. (Laughter)

MR. BACCHI: And I'm pleased that my testimony was as long as it was then. Thank you, Sir. (Laughter)

SENATOR LENO: Well done. Thank you.

SENATOR STEINBERG: Thank you for sitting through the entire hearing, Mark. Really. You're just great. And Senator Leno is going to be in the driver's seat on a lot of this—from the Senate side—as we begin looking at these budget issues, and has been—as much as you compliment me, which I appreciate, he deserves the same amount because he spearheaded us through this most difficult budget period and has been key on this issue as well, so thank you.

SENATOR LENO: And I've got the \$10 million in my pocket.

SENATOR STEINBERG: Yes, there we go.

DR. GRANPEESHEH: Thank you.

SENATOR STEINBERG: Well, what about the independent review issue, having qualified providers as members of the IMR, Mr. Bacchi?

DR. GRANPEESHEH: And could I also just quickly qualify that? You're absolutely right, that some of the care providers, some of the insurance companies, are unbelievably good with everything. In fact, we are providing training to Magellan. I think you're referring to Magellan. My company is the one that's training them. And the fact of the matter is, there's quite a bit of difference between the insurance carriers so that has to be said.

SENATOR STEINBERG: Yeah. Very good. Okay. Go ahead on the IMR issue.

MR. BACCHI: Well, Senator, this has been an ongoing issue since I started working on health care policy, you know, almost a decade ago, and that is, that providers always want the IMR reviewer to have the exact same qualifications as the medical service that's being provided and is in dispute and that's just not the way the IMR system was statutorily set up, or is the contract between the contract between the Department of Managed Health Care and their vendor to conduct the IMRs. It would be expensive to do that and it would be difficult to do because it's hard to find panels of qualified providers who treat exactly the issue that is before.

I will say, though, that anecdotally with the fact that disputes are down, that the disputes that our plans are reporting are not over, really, even medical necessity; they're really over provider qualifications and whether or not a service is a behavioral health service or not. Again, I can't speak to the specific allegations here today, but it is something that I've heard people complain about. And every time we've examined it, it's been very expensive to the IMR system to do it. And really, the IMR system gets it right most of the time. Right now they're overturning, you know, where they need to overturn and sometimes we lose those plans and sometimes we win. And I think having an independent body doing that with a license, you know, looking at the evidence, is about the best we can ask for.

SENATOR STEINBERG: Without drawing a conclusion, I suppose there is an argument to be made that having people from outside the specialty actually provides more objectivity versus maybe not—the other side of it, of

course, is that they may not have any expertise to be able to find medical necessity. So we get it and you flagged, I think, an important issue here.

SENATOR STEINBERG: Thank you both...

DR. GRANPEESHEH: Thank you much.

SENATOR STEINBERG: ...very, very much. We appreciate it.

So the hearing, which has been great, and I think the witnesses have largely kept within the time, we still are over. And I know I cannot stay a whole lot longer. But we do want to provide an opportunity for any compelling public testimony. Again, we offer this. I'm going to ask those who want to come up to be very brief and to try to deal with the issues that were raised, you know, at the hearing here. And, you know, if we can't give you full opportunity here to do this, we'll make sure that we connect you with staff afterwards; and written testimony, as well, is fine.

Sir.

MR. RICK HODGKINS: Yes.

SENATOR STEINBERG: Go ahead.

MR. HODGKINS: Okay. Thank you very much. I'll try to be brief. My name is Rick Hodgkins. Some of you may know me as the disability rights advocate, activist, and extremist. I am also a member of the DDSCAC, although I'm not here to speak on anyone's behalf, but, you know, in general.

I know that this hearing was about SB 946, something that I supported last year.

SENATOR STEINBERG: And that's what we're going to stick to. We're not going to—I'm going to limit you to the implementation of 946. Mr. Hodgkins, you're going to have plenty of opportunity through budget hearings to talk about a whole wide range of things. I've got a long line and I need to leave by 4 o'clock.

MR. HODGKINS: Okay. Well, I'm just going to say this: What's good for the goose is good for the gander. If you're going to mandate—I feel uncomfortable. If you're going to mandate private insurance companies to pay for people with autism, for autism treatment, then the state should do the same for those who otherwise cannot get it. Thank you.

SENATOR STEINBERG: I agree with you.

MS. MELISSA CORTEZ-ROTH: Thank you. Melissa Cortez-Roth on behalf of Autism Speaks. We were one of the many cosponsors of SB 946.

SENATOR STEINBERG: Yes, you were.

MS. CORTEZ-ROTH: So thank you once again for all of your work, Mr. Vismara, and the Members of this committee and the legislature who helped make that happen.

I know we focused on some of the problems with implementation of SB 946 but I don't want to lose sight of the good in that conversation, and countless children have access to life changing treatments so we don't want to forget about that.

We are very concerned with the issues on copays and deductibles that have been raised here today. In the event that we can't address those in the

budget, Autism Speaks is a sponsor of SB [sic] 2299 by Assemblymember Nazarian, so there is another vehicle to address that problem if it can't be done in the budget. So we look forward to working with you on this and other issues that have been mentioned.

Thank you.

SENATOR STEINBERG: Thank you very much. Appreciate it.

MS. JAMIE JUAREZ: Hi. Jamie Juarez. I'm a mother of a 13-year-old with severe autism so thank you. And also, thank you, Dr. Vismara, for all your work.

What I would like to say is that answering his question, I have a clinic as well—three—in Southern California. Our rates with insurance companies are \$42 an hour, approximately, which is very difficult. To find quality staff, you have to pay for drive time, you know, workers' comp liability, so I wanted to address that question that he had earlier.

SENATOR STEINBERG: That's the amount the insurance company is paying?

MS. JUAREZ: Yes. Forty-two dollars an hour...

SENATOR STEINBERG: What you're saying is insufficient. And my bill did not address the issue of the amount to reimbursement. I understand that.

MS. JUAREZ: Yes. And regional center, our contract is approximately \$50.86 so it's a little bit higher, which is still considerably low. And I think most of us would agree, that for the work that we do, we are deserving of more.

The denials that we see a lot also include mental retardation. They're notoriously Anthem Blue Cross. We service over 150 children and Anthem will deny based on mental retardation or that they're too old. And they also require that psych testing, which then costs families anywhere between \$3(000) to \$5,000 more and then to find, a, you know, an in-network provider that does that actual cite testing is really impossible.

SENATOR STEINBERG: It becomes onerous.

MS. JUAREZ: And we don't get referrals zero to three years old. Just in my personal and professional experience, from regional center or private insurance companies, we absolutely—it is very rare when you get a child under three.

SENATOR STEINBERG: Zero to three. Thank you so much.

MS. JUAREZ: Thank you.

SENATOR STEINBERG: Next and briefly please.

MS. MAYA BALIZAR ??: My name is Maya Balizar. I'm a parent of a child with autism who turned 17 just now. But back then, when SB 946 was passed, my son was denied ABA at the age of 15 by...

SENATOR STEINBERG: Before the law was passed?

MS. BALIZAR: Yes, SB 946.

SENATOR STEINBERG: Before it was passed?

MS. BALIZAR: No, no, around that time. And the regional center said we should move to insurance.

SENATOR STEINBERG: Okay.

MS. BALIZAR: And insurance denied us saying that he's aged out of the system. And then because I didn't have the money to go to the attorney, I went to the Department of—State Department—like what they said about the IMR; the person from IMR upheld the Blue Cross decision saying that he had aged out at age fifteen.

UNIDENTIFIED SPEAKER: Eek.

SENATOR STEINBERG: But there's no age requirement in the bill.

MS. BALIZAR: So right now, both the Inland Regional Center nor the insurance is paying for his ABA.

SENATOR STEINBERG: I'm sorry. Well, thank you for bringing that to our attention because the law does not have an age limitation so that I don't understand that, but maybe we can follow-up and look into that, okay?

MS. BALIZAR: Yes, I will.

SENATOR STEINBERG: Good. Thank you so much.

MS. KAREN FESSEL: Hi. Karen Fessel, Autism Health Insurance Project.

Okay. We need to get the actual numbers from the health plans. I was at the CalABA meeting this past week and they said 4,500 from Kaiser. And I assume that Anthem is very similar to that, in terms of the number of clients that they're seeing that have autism. Magellan said they had about 1,000, and UBH had about 600. So the plans do have this information and we can get it from them.

The next thing is, Medi-Cal is the largest payer of healthcare for children and more now than ever before because we've gone up to 250 percent of the federal poverty level. So now, more than ever, we need to have something that addresses these children. For those that do not qualify for a regional center, they fall out and they have no access.

Finally, I want to say that we're seeing a lot—I'm sorry—that this stuff about copays has been calculated without considering the out-of-pocket annual maximum and we're looking into addressing that. I'm working with your office. And I look forward to ...

SENATOR STEINBERG: We've got a bill on that subject...

MS. FESSEL: Right, exactly.

SENATOR STEINBERG: ...at least in terms of informing the consumer, yes. Thank you so much.

MS. FESSEL: Thank you.

SENATOR STEINBERG: Thank you.

Next.

MS. MICHELLE HYDE (sp?): Hi. My name is Michelle Hyde, and I'm a board certified behavior analyst representing the Southern California Consortium for Behavior Analysis. Thank you for having us and I will keep it brief. We were able to provide written comment for the binders.

I just wanted to mention that we're really positive about the changes brought by SB 946 due to the increased access. And something that wasn't mentioned is, we feel that there was just increased awareness of effective

treatment through applied behavior analysis, particularly in the medical community, are seeing increased referrals from pediatricians and other professionals for children with autism spectrum disorder.

We also want to mention that effective and quality treatment is being provided because most health plans are recognizing treatments supervised by a board certified behavior analyst and are typically authorizing the amount of recommended service hours that we are recommending. However, it has limited access in some ways with the copayment and deductible issue that has been mentioned several times.

Thank you for having me.

SENATOR STEINBERG: Thank you so much for coming. Hello.

MS. HELEN MADER: Hello. My name is Helen Mader. I'm also a board certified behavior analyst and I'm also here representing the Southern California Consortium of Behavior Analysts. And while overall, as Michelle mentioned, there have been many benefits—thank you very much—from SB 946, as a group, we're the ones implementing the law with the consumers. And there's a couple of things—well, one main thing I wanted to emphasize, which is the supervision component. So as you know, there's a three-tier model that we follow. There's a board certified behavior analyst who directs and designs the treatment on the top; the middle tier would be a supervisor who performs a lot of the on-the-ground supervision with the client and the paraprofessional; and then the bottom tier is the frontline staff, is a paraprofessional, who delivers the bulk of the service. And SB 946 does

promote that three-tier model. It has in there the qualified autism service provider, which is the BCBA; the qualified autism service professional, which is the mid-tier, and then the qualified autism service paraprofessional, again the frontline.

However, with the middle-tier staff—earlier it was Charles Bacchi who mentioned that the middle tier is not often utilized by the health plans. One of the reasons is the wording in the law could be slightly changed and would have a big effect to widen the network of health plans being able to use that middle-tier professional because right now, it says, like he said, that that person has to be vendored by the regional center and all you would have to do is change it to say *qualified* as that code. It's just that—and I think that was the intention of the law; that the person be qualified at the level as designated in the regional center code, not that the regional center would actually vendor them, because most of the providers are vendored under group codes.

SENATOR STEINBERG: So you're saying that there's an easy fix to the problem that was ...

MS. MADER: Yes, a very easy fix. It's just a terminology. I think the intent of the law was that it would be someone qualified at that level; but the way it says now is that the regional center must vendor them and that's not even how it works.

SENATOR STEINBERG: So let us figure out if there's a way to avoid that hassle because...

MS. MADER: That would be awesome.

SENATOR STEINBERG: ...it reduces the number of providers, the more complicated it is. Okay. Thank you so much.

MS. MADER: Can I say one more thing about that?

SENATOR STEINBERG: One more thing.

MS. MADER: Just about that same law, that same little part, it also only says that that middle-tier person can provide treatment and it just needs to be added, *and supervision*, under the qualified autism service provider who is the BCBA. So it just could be added that that person could provide supervision. They're still under the BCBA. But right now it only says they can provide treatment.

SENATOR STEINBERG: So that it will allow more flexibility.

MS. MADER: Yes.

SENATOR STEINBERG: Got it.

MS. MADER: Thank you.

SENATOR STEINBERG: Thank you.

MS. SHANNA MUNOZ: Hello. My name is Shanna Munoz and I'm also a board certified behavioral analyst. I am a provider of applied behavior analysis through various health insurance carriers. And I wanted to talk specifically about the health insurance plans not recognizing the importance of authorizing all requested types of services, including paraprofessional services, supervision by a BCBA, but also case management—the indirect activities that are done behind the scenes—the goal writing, the treatment planning, the data analysis that is often left out, in addition to the parent education that is left out as well.

SENATOR STEINBERG: Okay. And they're denying that, you're saying?

MS. MUNOZ: Yes.

SENATOR STEINBERG: Okay.

MS. MUNOZ: Yes.

SENATOR STEINBERG: Okay. Thank you.

MS. MUNOZ: Thank you.

SENATOR STEINBERG: Thank you. Another thing to think about here. Go ahead.

DR. WILL BRANDON: Thank you. My name is Dr. Will Brandon. I'm also a BCBA. I think you got all us professionals here at the same time.

I just want to echo the thoughts on the Medi-Cal and suggest, that if not full funding, maybe having Medi-Cal fund copays similar to the regional centers.

Having said that, on the regional center front, I have two quick comments.

The first is, that the regional center implementation of ABA and the medical necessity of ABA that is done by the insurance agencies are two distinct animals. Because of Title 17, regional centers are required to be providers of last resort. So when we provide services in settings that the regional center feels, like—for instance, a school district would be the prime example—they are denying the copay even for a qualified family in that regard.

The other issue we have is, that when we become a preferred provider with an insurance network—we're a preferred provider throughout California—

but in order to get copays, we have to go into some type of fiefdom-like manner to get vendored with each individual regional center throughout the state. It would be really nice if there was something that basically said, you know, vendored with one, vendored with all, as far as copays are concerned.

SENATOR STEINBERG: There's that popular word again, *vendored*. I mean, that's—we've got to figure that out. Okay. Thank you.

DR. BRANDON: Thank you.

SENATOR STEINBERG: Thank you.

Hello.

MR. JOSE LUIS HERNANDEZ: Hi. My name is Jose Luis Hernandez. I'm the president and founder for a support group, Spanish-speaking support group. I speak on behalf of them—some of them. We drove from Orange County.

First of all, I'll let you know that's a wonderful bill. But also, we want to ask you if you can include Medi-Cal. We represent those 40 percent of parents who have children with autism. My son, Etson ??, is 18 years old. He's autistic. Because sometimes it's pretty hard to—first of all, through the regional center, to be eligible, if you don't have enough money to pay a private insurance, so you are helpless. So we don't have, sometimes, the money to just hire—you know, sometimes to appeal, we have to hire lawyers, so it's very hard for us.

SENATOR STEINBERG: Let me explain, if I might, because when we did 946 in 2011, we wanted, and I wanted very badly, to include Medi-Cal in that

bill. But we were still in the midst of the budget deficit in California and so it was not possible. And so what we said very consciously was, *let's get started* here, and we did. And so now the budget is better but there still is a rightful requirement for fiscal constraint and restraint. We have to do a lot of things—put money away for a rainy day, pay down debt, make sure we never get back into that deficit mode again because that only hurts the people that you serve and that I serve. And yet, I think there is a compelling case to be made for expanding this service to Medi-Cal—that it's cost-effective, that it actually—well, it's cost-effective because it saves the state a lot of money in the long run when young people get the help that they need so that they don't end up in institutions; they don't end up with more expensive special education services and all that goes with it, and so, we're prepared to make that case. There's no guarantee. We're going to need you this year if we're going to have any chance of success. So thank you, sir.

MR. HERNANDEZ: Thank you very much.

SENATOR STEINBERG: And thank you, young man.

MS. GLORIA HERNANDEZ: My name is Gloria Hernandez. My son is autistic and I come from Orange County. And please, pro Medi-Cal bill.

SENATOR STEINBERG: You came all the way from Orange County for this hearing?

UNIDENTIFIED SPEAKERS: Yes.

SENATOR STEINBERG: You guys came all the way?

MS. HERNANDEZ: Yesterday, we come driving from Orange County—all night.

UNIDENTIFIED SPEAKER: All night.

SENATOR STEINBERG: Oh my God.

MS. HERNANDEZ: We need to drive all night...

SENATOR STEINBERG: That's what it's really all about. (Applause)

MS. HERNANDEZ: Thank you so much.

SENATOR STEINBERG: Thank you. Do you all want to introduce yourselves so we know who you are for the record? Go ahead.

MR. CARLOS VASQUEZ: My name is Carlos Vasquez. I'm part of—we come with a committee from Orange County. We drove, like, eight hours—six, seven hours.

SENATOR STEINBERG: I hope you went the speed limit, by the way.

MR. VASQUEZ: Yeah, yeah, very fast.

SENATOR STEINBERG: And no talking on the cellphone.

MR. VASQUEZ: Thank you for everything. Please include the bill in support...

SENATOR STEINBERG: Medi-Cal.

MR. VASQUEZ: .for the Medi-Cal in the bill, please, and that will help my twins, three-year-old twins.

SENATOR STEINBERG: Thank you, thank you.

MR. VASQUEZ: Because my copay, sir, could be thousands of dollars and I can't afford that. Thank you.

SENATOR STEINBERG: We hear you. It really means a lot that you traveled that far—this far—to come to your building, the people’s building, in Sacramento and have your voice heard. I hear you, okay? Thank you.

MR. CHRISTIAN FONG ??: Thank you, Senator. I’m Christian Fong. I have an 11-year-old child who is autistic. And before the bill was passed, you know, we used to qualify at the regional center and now it’s being means tested. And because of the copay, each year when I do the calculation, we’re going to pay about almost \$6,000 out of pocket for our copay because he needs service six days a week, six days a week, Monday through Saturday. And every time they come, we have to make the copay and it’s really, really tough. So my request is that you should fight for us, as you’ve been doing, so that at least we will benefit from, you know, whatever amendment that you can put on this bill to try and solve the copay. And, of course, Medi-Cal, you talked about the Medi-Cal, so hopefully that will probably help if you are able to get it for us. It’s very tough.

SENATOR STEINBERG: Thank you. Thank you for coming to testify and I’m sorry, and we’ll do our best to make it better.

Young man.

MR. _____: Thank you for help with _____. If I go to Sacramento, mommy and daddy get pillows and blankets to sleeping. Thank you.

SENATOR STEINBERG: Thank you. Where do you live?

MR. DAVID _____: I live as a high school, Huntington Beach, California.

SENATOR STEINBERG: And you came all this way to have your voice heard?

MR. _____: Yes.

SENATOR STEINBERG: Thank you.

MR. _____: You're welcome.

SENATOR STEINBERG: I'll remember it. (Applause)

Go ahead, either way.

MS. CARINA MORALES: Yes. Thank you so much. My name is Carina Morales. I'm David's mom. And please support the bill. We have a lot of kids. We're under Medi-Cal, but it's so hard to get even to regional center to get the services. I fought four years until I get an attorney to get the services—ABA. It was so hard. And before—four years ago, if David came here, he was jumping all over the room. Thanks to the services, thanks to ABA, right now you can see that he's talking a little bit more.

SENATOR STEINBERG: And talk to the elected officials. Wow. Thank you. You're doing a great job. Thank you.

MS. CHRISTINA RAMIREZ: My name is Christina Ramirez and my husband, Juan Ramirez. We come from Orange County too. And we have our son, Josua ?? Ramirez, who has autism too. So just please include behavior therapies on under Medi-Cal.

SENATOR STEINBERG: Under Medi-Cal.

MS. RAMIREZ: Yeah, it helps a lot, and I know in the future there can be better life. Thank you.

SENATOR STEINBERG: Thank you so much. Thank you both.

MR. _____: Thank you.

MS. MARTHA MORA (sp?): My name is Martha Mora and I came from Orange County too. I represent my daughter—autism.

SENATOR STEINBERG: How old is she?

MS. MORA: Fourteen years old.

SENATOR STEINBERG: Fourteen years old.

MS. MORA: She is on Medi-Cal and she needs the ABA program for a better life and successful life in her future.

SENATOR STEINBERG: For her future.

MS. MORA: Thank you for your support.

SENATOR STEINBERG: Thank you.

Whoever wants to go first is okay.

MS. DIANA VARGAS: My name is Diana Vargas and I'm a parent with a child with autism. He's seven years old. And, yes, my son is—he's on Medi-Cal. I'm pleased. I've just come to ask you, please, add the ABA services to the Medi-Cal bill.

SENATOR STEINBERG: To Medi-Cal. Thank you.

MS. VARGAS: Thank you very much.

SENATOR STEINBERG: Message received.

MS. SOCORRO VALDIVIA: My name is Socorro Valdivia and my daughter's name is Caitlin. She's been diagnosed with autism and then she has behavior service with the regional center, but they're going to cut the

service at the end of this month and we don't have any other place to go. If the Medi-Cal go for the ABA, include the ABA, we have another door open to go and that's going to benefit Caitlin.

SENATOR STEINBERG: Thank you.

MS. VALDIVIA: Thank you.

SENATOR STEINBERG: Thank you so much.

MS. JANELLE LEWIS: Hi. My name is Janelle Lewis. I presently serve as a member of the State Council on Developmental Disabilities. I'm also the parent of a 17-year-old son with autism.

Thank you for the opportunity to provide comment on the implementation of Senate Bill 946. Sorry. I'm all emotional now.

SENATOR STEINBERG: It's okay. Take your time.

MS. LEWIS: ABA is life changing; and to hear those stories and the families that came so far, it just, it really hit me.

SENATOR STEINBERG: Yes.

MS. LEWIS: The State Council has been a strong supporter of Senate Bill 946 and of the principles of early and effective behavior treatment for children with autism. Thousands of families have benefited greatly from your bill, and we thank you very, very much.

I have some bullet points which I won't go through. They've been touched on several times. However, I would like to say that it is time to reverse the trailer bill language and make clear that regional centers have an obligation to pay for the cost of IPP therapies that insurance will not cover.

Thank you.

SENATOR STEINBERG: Thank you. Thank you so much for your service.

MS. ELEANOR CASTILLO SUMI: Thank you, Senator Steinberg. My name is Eleanor Castillo Sumi. I'm with EMQ Families First. We're an organization that provides mental health services throughout the state. And so oftentimes, because we're a large Medi-Cal provider, we get the calls from Medi-Cal families asking for services. And I know that the intent of today's hearing is not for Medi-Cal specifically, but I do want to speak for those that are Medi-Cal recipients that do meet regional center criteria and so should be eligible for all these services.

So while you've heard all the statistics that, you know, I don't necessarily disagree with in terms of access to care, the experience is not the same throughout the state. So we provide services in the Bay Area. We don't hear any problems there. But in other areas such as San Bernardino and Riverside where the land is vast, we do hear problems with access to either regional center services or private insurance services. So the question of adequacy of network provider in those areas is still a question for us. That's often the questions that we get as a provider.

SENATOR STEINBERG: Okay. We'll have to look at that. Thank you.

MS. KATHLEEN BERRY: Hi. My name is Kathleen Berry. I'm with FEAT, Families for Early Autism Treatment. I'm also the parent of two with autism; one who is an adult now.

I was asked to turn in some testimony, written testimony...

SENATOR STEINBERG: Sure.

MS. BERRY: ...from the Strucker (sp?) family from Southern California.

SENATOR STEINBERG: We have it, I believe. So we're okay. If you give it to the sergeant there—thank you.

MS. BERRY: They couldn't make the nine-hour drive, apparently. They have two children with autism. The first one was diagnosed in Northern California, Kaiser. They went down to Southern California. The diagnosis was then reversed in Southern California and treatment was denied and discontinued. The second child was born in Southern California. The child was in a university-sponsored research program where they identified the child as having autism. Kaiser would not diagnose the child and therefore would not provide treatment without the diagnosis. So it's an example of what families are struggling with.

Just to touch on everything that the consumer advocates have already discussed, we are absolutely—what we're finding—these are conservative estimates that they've provided to you, in our experience, with thousands of families so we're very supportive and thankful for their work.

It's in the interest of the state to keep our families whole through the regional center. We have to keep employment, jobs, you know, homes and put siblings through college so these siblings can make sure that they're taken care of, their disabled children as they grow older when we are gone.

One of the things that we see as a tool to figure out about SB 946's effectiveness is whether or not it's being used as a tool to eliminate services or is it being used as a tool that was originally designed which was to expand services for everyone within the regional center and outside of the regional center. That's it.

SENATOR STEINBERG: That's the point. Thank you.

MS. JACKIE ____: Hi. My name is Jackie and I'm testifying on behalf of my friend Patty and her daughter Maggie. And she doesn't receive regional center services, Maggie. Maggie currently is in Utah. Her mother, who works for me, cashed out her entire 401(k) to send her daughter, who is on the autism spectrum disorder, to an out-of-state program because the school system denied her services; the regional center denied her services. She currently—her daughter is coming home in mid-March. So I don't get emotional ...

SENATOR STEINBERG: How old is she?

MS. ____: Huh?

SENATOR STEINBERG: How old is she?

MS. ____: She's 15. So her daughter is coming home and her mother is very close to me and she doesn't know what to do. She's, like, I'm trying to prepare for my 15-year-old daughter to come home. The insurance told her she doesn't qualify, so she had to come back and show the bill and say, yes, I do qualify. But then the barrier for her is, she's, like, I don't even have anymore 401(k) money left to pay for the program to come in to set up my

home to meet my daughter's needs. So she doesn't get the regional center; the school doesn't want her. So she said, my daughter's a throwaway.

SENATOR STEINBERG: Nobody is a throwaway.

MS. ____: And she's in Sacramento and she's not a throwaway, and I tell her that. I've loaned her money personally. So anyway...

SENATOR STEINBERG: Maybe we can help you.

MS. ____: Patty would love for...

SENATOR STEINBERG: Is she a Sacramentan?

MS. ____: She's Sacramento.

SENATOR STEINBERG: Is she in my district?

MS. ____: She is in your district.

SENATOR STEINBERG: Okay. Then we'll connect you with my fine staff and we'll try to go to bat.

MS. ____: And I know Lou Vismara. We've talked. So I'm usually here about regional center stuff, but this is very personal. So thank you.

SENATOR STEINBERG: Thank you. Thank you, thank you. Well, the personal stories or the stories of friends bring the issue to life.

I want to thank everybody. I want to thank the great staff work here all around. I want to thank all the participants. I want to thank the members of the public.

Just a few conclusions here. Numbers don't tell the whole story. They never can because the quality of experience is also important. And whether it's one family, 500 families who had service who aren't getting it now, that's one or

500 too many, so I recognize that. But numbers also are instructive and they help us guide our budget deliberations, certainly. And what we know is this: As a result of 946, there are thousands—estimate as high as 12,700 families and children—who weren't getting ABA before who now are.

We know that there are about 11,000 children in the regional center system getting the services who either don't have insurance or are using 946 to continue their services within the regional center system. We also know that there's 19 percent of some number that have had to drop out for some reason because—well, for a good reason—not good reason—but for the reasons evidenced here today, namely that the copay and our deductible requirement has become too onerous.

And finally, we know that there is some number of folks who are in the regional center system who have dropped their insurance so that the regional center can pick up the entire cost, which is a cost to the taxpayers and to the system, which as Ms. Jacobson, doing her back-of-the-envelope math from the audience here, suggested to us, and I think with some credibility, that that cost to the system and to the state and to the taxpayer may be actually more than paying the deductible and the copay for those same families.

So these are all things that we want to take from today's hearing and now really refine and focus during the budget process so that we can fix as much as we can fix and then hopefully use it all as a springboard to advance with the Medi-Cal population, as we heard compelling testimony from people who drove eight hours to get here to tell us how important that was. So this

was very valuable. It was very valuable for me and kind of, you know, is my spring training to get ready for the budget season here around this very, very important issue and gets my head into this as we begin doing the very best we can, to make as many advances to help as many people and families as we can.

Autism, we don't have a cure but we do know the undeniable, that early intervention leads to better lives. We need more of it; it's cost-effective; it's humane; it's the right thing to do.

If there's nothing further, the hearing is adjourned. Thank you so much.

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