

**Senate Select Committee on
Autism and Related Disorders**

Darrell Steinberg, Chair

***Health Insurance Coverage of
Behavioral Intervention Therapy for
Autism Spectrum Disorders (ASD)***

**Thursday, June 10, 2010
State Capitol**

ABBREVIATED & EDITED TRANSCRIPT OF HEARING

The following document represents selected excerpts that have been chosen and edited from the hearing. In some cases, testimonies (or portions thereof) have been deleted. Therefore, some of the comments may have been presented in a different order and/or context. The comments that are highlighted or underlined have been selected by the staff. A complete transcript of the entire proceedings is also available on the Senate Autism Website at www.senate.ca.gov/autism

SENATOR DARRELL STEINBERG:

“Today we want to focus on what might be a more controversial piece of the debate here, and that is, the role of health plans and the role of our public school system in paying for ABA therapy. ABA therapy is not necessarily new but increasingly recognized best practice in terms of helping kids with autism and autism spectrum disorder. And the issue before us today is who pays for this therapy and whether the therapy itself falls more on the medical side, if you will, of the spectrum or on the educational side of the spectrum. And we’re going to hear a wide range of opinions here, not just to have it out publicly here. We don’t want to point—we don’t want this to be a finger-pointing hearing. We want this to be a hearing whereby the end we can all see a pathway towards the only thing that matters, and that is, making sure that more families and more kids have

access to this therapy, period, and I think we can get there. I know we can get there.

DR. AMARAL: I've been asked to address the question, "Is autism a brained-based medical disorder? **There is now absolute consensus in modern medicine that autism spectrum disorders are the result of abnormal brain functioning, the causes of which are many and complex.**

Work being conducted at the MIND institute has demonstrated unequivocally that in the autistic children with rapidly growing frontal lobes, the connections from the frontal lobe are very highly abnormal. **All of these data support the conclusion that autism is a brain-based medical disorder.**

It is our strong conviction that intensive behavioral therapy can materially affect the development of brain connections and decrease or remove the lifelong disability of autism.

DR. SALLY ROGERS: The symptoms of autism, like those of many other physical and mental health conditions, respond very well to interventions that are designed to replace maladaptive behavior and patterns of behavior with more appropriate behavior. **The effectiveness of behavior therapy for medical conditions, including autism, has been examined in hundreds to thousands of scientific studies, and this is considered the most effective medical treatment for autism and for many other medical disorders.**

Each one of the core symptoms of autism, those caused by the biology of autism, is effectively treated using behavior therapy. The core symptoms involve three groups of behavior:

- Abnormal patterns of language development and language use;
- Abnormal social behavior, which includes lack of interest in others, lack of empathy, failure to share experiences and interests with other peoples, and lack of social engagement of peers and family members, and;
- Abnormal repetitive motor movements—repetitive talk, repetitive actions and rituals, repetitive thoughts, and obsessions.

So to conclude, behavior therapy applies the science of learning to change behavior. It's the most effective treatment for many medical disorders, including ASD, and it is the most successful treatment that we have for the core symptoms of ASD, for people of all ages and all levels of severity. It is medically necessary treatment for ASD. And while it can be used—it can be used to deliver both educational goals and targeted medical symptoms for ASD. In that situation, **it falls under the need of medical necessity and medical health needs.**

DR. HANSEN: The three main components of evidence-based medicine that need to be integrated in clinical decision making to maximize individual outcomes for any medical treatment include clinical expertise, patient values, and the best evidence from clinically relevant and methodologically sound research. There's been an increasing amount of very strong evidence to support a variety of behavioral interventions that effectively treat the core social and communication deficits in individuals with ASD, the fundamentals of which are described by Dr. Rogers. **So the preponderance of evidence for effective treatment of the core symptoms of ASD largely supports behavioral interventions, such as those described by Dr. Rogers, and the developmental mechanisms for changing brain structure and function described by Dr. Amaral.**

SENATOR ALQUIST: A question. Is there disagreement among the medical and scientific community about the value or efficacy of ABA therapy, and is there any evidence that is not of great value?

DR. ROGERS: **The empirical evidence is overwhelming of the effectiveness of behavior therapy for autism.**

MS. HOLLY PEARSON (Dept. of Managed Health Care): Now health plans, as you know, sometimes deny ABA on the grounds that it is not a healthcare service. Now the Knox-Keene Act does say that licensed providers by the state are the only people who can actually provide healthcare services. So when plans deny ABA on the ground that it is not a healthcare service, we then have to make a legal determination as to whether that service is covered under the health plan contract; and the way we make that legal determination

is looking at the Business and Professions Code's requirements that say only people who are licensed or recognized by the Business and Professions Code to provide, to treat medical and mental conditions, can actually provide those services or somebody who is accepted or recognized by the legislature not having to hold the license. **So if an enrollee submits or their treating provider submits a document or prescribes ABA therapy for that enrollee because it is medically necessary and that treating provider also says, that because of the enrollee's condition, the services must be provided by the licensed provider, then the department finds that it is a covered service, and then we go to the plans and say, plan, you must now provide this service.** But the plans have the option of either providing the service or then denying the service on the grounds of medical necessity. If the latter, we then send it to IMR for clinical determination of whether the service is actually medically necessary for that enrollee's condition.

MR. GEORGE (Dept. of Managed Health Care): The statement is, Does that particular child's deficits require the skills and expertise of a licensed provider? And if so, we're making the determination then, which based upon that representation, it is a healthcare service and a healthcare service are what are covered services. I think at the end of the day, we're just deferring to, by and large, to the clinical expertise of the provider.

SENATOR STEINBERG: And what you're saying here is, that if they assert that on behalf of a child, that by and large, so long as it's asserted in an appropriate and effective way, that you will not, you're not making a medical judgment, you will approve that, correct?

MR. GEORGE: Based upon that determination, we are concluding that then it is a healthcare service and healthcare services are what are required to be covered pursuant to the act.

SENATOR STEINBERG: Thank you. So I want to press a little harder here with our DMHC leaders here. You've described what I take is a little bit of a back-and-forth process and a dispute about interpretation in a letter that you put out in March 2009, which is now subject to a lawsuit. **Ambiguity, of**

course, breeds lawsuits and the question is, Why wouldn't the department take it upon itself to begin a regulatory process that would clarify the issues that we are discussing here today? Regulatory process under the APA has the benefit of full public input. It's less political, so to speak, compared to the legislative process. Why is the department leaving this out there in a way that continues this ambiguity?

MR. LeBAS: Mr. Chair, again, **the March 9 letter**, we feel, is very clear. We feel that it restates existing law.

SENATOR STEINBERG: Excuse me. It doesn't even mention, as you said, ABA therapy.

MR. LeBAS: No, it doesn't.

SENATOR STEINBERG: I do have one last question from Dr. Vismara. Do you view ABA therapy in the abstract, regardless of the provider, to be an education benefit or medical benefit? I mean, primarily of medical in nature or education in nature?

MR. GEORGE: Again, I think that that's just the issue that we're grappling with and, unfortunately again, don't have the clinical expertise to resolve. So again, we have to go back to the Knox-Keene Act for our resolution and we have to deal with it within the parameters of the Knox-Keene Act. The Knox-Keene Act talks about providing healthcare services, and that's the determination that we're trying to make.

SENATOR STEINBERG: We want to welcome former Senator Patrick Johnston, president and CEO of the California Association of Health Plans; David Ormerod, M.D., the medical director of Blue Shield of California; Dr. Dan Mordecai, the director of Mental Health and Chemical Dependency Services, Kaiser Permanente, Northern California; and Sandra Golze, the vice-president and regional counsel for the Northern California Region of Kaiser Foundation Health Plan, Incorporated, and Kaiser Foundation Hospitals; and Mary Antoine with Nossaman, legal counsel to California Association of Health Plans..

SENATOR JOHNSTON: California health plans provide comprehensive coverage for autism-related healthcare services, including diagnosis, assessment, medication, and speech, physical, and occupational therapies, as

well as psychotherapy for the individual and family. They do so every day. Educational services and behavioral skills training, whether provided by licensed or unlicensed persons, historically and appropriately have been offered by regional centers and schools. We follow the law. We have to do our part. Society and the public sector must do theirs.

What problem did the legislature seek to address in 1999? It was the unequal treatment of severe mental illnesses by insurers in the application of lifetime limits, co-payments, and deductibles for medical services. What medical services? The law says the same ones that always apply to physical conditions.

What did AB 88 not do? It did not move the line; it did not require new medical services, as a matter of law, like prescription drugs, and it did not require non-medical services. Medical treatment services are inside the line. Health plans cover them. Educational and behavioral training services are outside the line. Health plans do not cover them unless and until, unless and until, the legislature changes the law. But the law, the one, Mr. Chairman, that you and Senator Alquist and I voted for, has not changed.

DR. DAVID J. ORMEROD: Good morning, Mr. Chairman and Committee Members. It's my pleasure to represent Blue Shield of California during this important dialog on autism treatment. As mentioned, I'm Dr. Dave Ormerod, senior medical director for Blue Shield. Prior to Blue Shield, I was the medical director of clinical research management for UC Davis Health System; and prior to that, I was in full-time family medicine practice.

For example, we do cover medical evaluations of these patients, which may include genetic testing and genetic counseling. We cover psychological testing, counseling, psychiatric services. We cover speech therapy services, including language assessment, standardized testing, and corrective and/or adaptive speech therapy treatment. We cover physical therapy, including assessment of functioning by the licensed physical therapist and therapy to address functional deficits in movement, strength, gross, or fine motor skills. We cover occupational therapy which includes an assessment of functioning and therapy to develop specific motor skills which will assist in completing

activities of daily living, and we cover audiometric examinations to determine hearing functions and comprehension capabilities.

As a physician, I understand and have dealt with the impacts of this condition on children and their families, just as so many other innocent individuals are impacted by other medical conditions by non-medical, unforeseen circumstance, or even by natural disaster. **However, there is a logical, clinical delineation between what should or should not be covered, health service within a healthcare policy.**

We will continue to support all of our members, including children with autism, in accessing medical services for the evaluation and treatment of their conditions. **We expect to continue to do so only for medical services, for all of our members, with all medical conditions.**

SENATOR STEINBERG: And what is sort of the accepted point of view about the relationship between the physical nervous system and behavior?

DR. ORMEROD: Well, I think the accepted standard is that there is a direct link between behavior and the nervous system. They are linked together.

MS. GOLZE: I'm going to cover two topics—the law about the distinction between healthcare services and non-healthcare services, and the impact of the California Mental Health Parity Act on this distinction.

I'm going to give you some examples of other health conditions where this has been sorted out and where there is a common understanding of the distinction between healthcare and non-healthcare, but first I want to say that this is not my opinion but it's common practice and supported by the regulators. So the first example is **deafness and blindness**, absolutely a medical condition. But sign language, Braille, speaking skills, school readiness and social skills and the ability to navigate home and community are incredibly beneficial but they're not healthcare.

Another example is **Down syndrome, traumatic brain injury, dementia, ADHD.** The special educational techniques to help a person who can perceive, think, problem solve, remember information, and acquire new skills, also incredibly important but not healthcare. Schizophrenia, which is a

parity condition, there are special remedial, educational techniques for social development and school workplace skills because, in this case, patients do lose social and occupational functions, and the services to remediate those aren't healthcare. And the next frontier on this is obesity and making the distinctions between healthcare and non-healthcare. **The Mental Health Parity Act didn't make any changes to this line. It mandated equal access to healthcare services for individuals with the parity conditions.** That's because nothing changed in the general definition of health plans and health insurers when the Mental Health Parity Act was put in.

How do we approach this distinction when services are requested?

First, the health plan has to determine whether the individual requires a healthcare service, and that's the coverage question. Then it can consider whether the service is likely to be the best medical service available. That's the medical necessity question. In the case of an individual where there are learning delays or disabilities, this is the coverage question. Is this about acquisition of skills or knowledge necessary for better functioning in the family community or school, or is it about improving or preventing deterioration in health? And in this, we agree very much with the structure that Dr. Rogers put forth about you have to look at the target symptom rather than who's providing the service. So, for example, services to help a child with ASD family with the symptoms of depression or psychosis or self-injury or using the right muscles to swallow and to vocalize are treatments for mental or physical health and are properly considered healthcare, and we applaud the creators of the programs today that were described earlier. However, we believe that services that foster the acquisition of skills and socialization, communication are properly considered the critical educational services for ASD. They're not medical treatments. And, just like the MIND Institute, **we don't believe that the provider's license is the determinate in this.**

SENATOR STEINBERG: Ms. GOLZE, so it's very important and interesting testimony. It sparks a lot of questions. But isn't it the case, that with this evidence-based ABA therapy, that it seeks to help on a number of the issue that you just enunciated? In other words, at once it can seek to improve

the ability of a child to speak and at the same time have the benefit of helping a child avoid destructive behavior or improve life skills.

MS. GOLZE: So what we do is look at what's being approached, and the part that's about education or life skills, we believe, is educational. It's not about the technique of ABA. It's what it's being used for. So if you get a request for any type of services to approach self-injurious behavior, for instance, we believe that self-injurious behavior is something that is part of mental health treatment. It may not be ABA you use for that. It may be. It may be another technique. **But we can't just say, ABA is or isn't healthcare.** We have to look at the target that is being approached and then look at the right provider.

SENATOR STEINBERG: But the advocacy community and the scientists, the doctors, the research believe—that ABA therapy is the best evidence-based practice for a whole host of these issues—medical and non-medical—that you just described.

MS. GOLZE: I believe that our clinicians have varying views on, with a particular child, whether ABA technique or some other technique is better for depression or psychosis.

SENATOR STEINBERG: For what conditions are health plans now approving the use of ABA therapy, Kaiser specifically?

MS. GOLZE: We have approved it once in the case of very...

SENATOR STEINBERG: Please, everybody.

MS. GOLZE: ...a very specific situation where there was extremely self-injurious behavior for a very—for a short period of time where we felt that was the best way at it, at that behavior. You have to look at the behavior.

DR. ORMEROD: Senator, I don't think that we want to give the impression that we disagree with the science, that we understand that the standard of the literature of the scientific studies show benefit in cases with ABA. I don't think that that...

SENATOR STEINBERG: Then why not cover the best practice?

DR. ORMEROD: Well, because there are things, Senator, that clearly could be shown by research to be beneficial to people with a myriad of conditions. For example, you know, we brought this earlier, the treatment of obesity could involve a nutritionist who's a licensed clinician, spend every day with a patient for six months with three meals a day and modifying their behavior through techniques to get to them to improve their eating habits. We could also assign a physical therapist to exercise with the patient regularly. Those are going to benefit—and if a study would show, those services will be beneficial for the obesity, but we would not consider them medically necessary and appropriate.

SENATOR STEINBERG: Well, we're getting to the core of it because with obesity—let's use that as your example—and you used that in my office as well—I could make the argument and you'd make the argument too—that there are much less expensive and equally effective ways to address obesity. I mean, you know, because I just think that's the case.

In this instance, though, when you're talking about a child with autism, you're not presenting the case here—at least I have not heard it—that there are equally effective ways, equally effective ways, to help a child down a path towards success.

DR. MORDECAI: I'm the clinical director for Mental Health and Chemical Dependency for Kaiser Permanente, Northern California. I'm actually going to abbreviate my presentation to try to get and get to the questions that you're raising.

Kaiser Permanente did not invent the distinction between medical services and educational services. The care that Kaiser Permanente provides for children with ASDs and other developmental disabilities is consistent with the current policy of the American Academy of Pediatrics, and I want to emphasize that point. That is the American body of pediatrics. Essentially it's the premier body for pediatricians and they put out a policy statement entitled *Management of Children with Autism Spectrum Disorders*. And per that policy, we provide medical care and advise parents on potentially beneficial, educational, and other non-medical interventions.

And I want to quote from the policy because I think it really gets at the issue that you're bringing up. So as the American Academy of Pediatrics' policy statement says, **"Education is fostering acquisition of skills and knowledge including not only academic learning but also socialization, adaptive skills, communication, amelioration of interfering behaviors, and generalization of abilities across multiple environments. These services address core features of developmental disorders, including ASDs. We're not disputing that, and we've heard that these services can be very helpful, and we're not disputing that. But the American Academy of Pediatrics—not just Kaiser Permanente, not just Blue Shield—put ABA explicitly under educational services in their policy statement, and that's where our position comes from.**

SENATOR STEINBERG: Speech therapy, speech therapy being the number one example. Dr. Vismara tells me that the vast majority of cases involve speech therapy. That's medical. And even if there are other benefits, which I would sit here not as the expert, acknowledge that it is also social. I'm not saying it's both. But given that part, a large part, of the ABA therapy is intended to address clearly medical issues, why is it not medically necessary?

DR. MORDECAI: Two points I want to make to that. **The brain changes in response to experience fundamentally. That's what the brain does.** It's one of the great things about our brains. It changes in response to experience, education, and medical interventions. Just because something is changing the brain does not make it medical. Exercise changes the brain. It's not medical. It's something people choose to do or not.

The other piece I wanted to say is that there's been a lot of talk about, because there's evidence for something, that that should make it medical. There's a whole field of scientific evidence around education, so I think there are certain—we're falling into certain camps, because something has evidence, it must be medical.

SENATOR STEINBERG: Is there a difference between brain structure and brain activity? I know exercise changes brain activity—endorphins and all that stuff and you feel better and all that. But that’s different from changing brain structure. My question is, Do you believe that ABA therapy changes brain structure, the actual structure, of the brain over time?

DR. MORDECAI: **I think ABA therapy can change the brain.** I’m not sure of the importance of the structure or physiology distinction you’re trying to draw.

SENATOR STEINBERG: Last but not least, we have the challenges faced by the consumers. First of all, I want to welcome Fedal Almaliti—pronounced that right, I think—cofounder of the ASD Insurance Help Users Group. Again, Dr. Barbara Firestone, Ph.D., and president and CEO of The Help Group—and I said co-chair but vice-chair; I was the chair; I was the chair, okay? (laughter)—Legislative Blue Ribbon Commission; and Lorri Unumb, the senior policy advisor and counsel for Autism Speaks.

MS. ALMALITI: So my name is Fedal Almaliti, and this is my son, Muhammed. I want to tell you Muhammed’s story because the story is so similar to the thousands of other children in California with autism. Mohammad was diagnosed by our health provider at 18 months with autism. He doctors recommended many evidence-based treatments for my son and stressed to me the importance of early intervention. On the day of his assessment, I was given a letter by the clinicians. They told me to give it to my regional center. I hadn’t even heard of a regional center at that point. They also told me that having the official diagnosis of autism was the key to getting the therapies he needed. I was devastated that he had autism but happy that there were treatments.

While the diagnosis of autism helped him get funding for this treatment from the regional center, I had no idea it would be the death sentence to getting treatment from my health provider. This was the beginning of our family struggle. They gave me one excuse after another as to why they would not provide treatment for my son. First, they told me to go to the regional center, then the school district. **They told me Mohammad’s treatment was**

academic, experimental, custodial, not medically necessary, basically anything but their responsibility. I ultimately appealed their denial through the Department of Managed Health Care and won. After more than a two-year battle, David/Goliath proportions, my son is finally receiving the treatment he needs. I know all too well how this process is literally all consuming and can wreck the lives of families. While our family was lucky, most are not.

The problem used to only be the insurance companies. Now it's the insurance companies and the regulatory agencies. One parent called me sobbing after multiple bad experiences with the regulatory agency, and she said she felt as though she was speaking to an attorney for the health plan. The state in its current budget crisis cannot afford to keep padding the pockets of the insurance companies at the expense of the taxpayers. We must require insurance companies to cover the treatment of autism and ensure the regulatory agencies enforce it. It is the only hope we have to treat this vast and growing population. So the primary focus of ABA for my son is to ameliorate the symptoms of his autism.

But anyway, so you go and you have to get this letter. If it's not written in the right way, it stops. Let's say it is written in the right way, what happens, the Department of Managed Health Care sends it to this executive committee, and the executive committee has no timelines. I've seen them sit on cases for over six months before they determine whether the treatment is a covered benefit. Then after that, they make a decision; they send a letter to the health plan. Now families are spending one month fighting with the health plan and a year-and-half or more in the regulatory process.

SENATOR STEINBERG: Which is why I just say, to preview what I would say at the end of the hearing, while clarity by regulation or by legislation is absolutely essential here—and, you know, we need to sit down constructively with the health plans; we need to sit down with you; and we need to work this out, and it needs to result in a bill—my view, as opposed to regulation, a bill, that we can move through the legislature to clarify this on behalf of the families and in a fair way, in a fair way, and that's what's going to come out of this hearing here. That's what's going

to come out of this hearing today, okay? (Applause) That's what's going to come out of this.

DR. BARBARA FIRESTONE: Well, I'll make this brief. I appreciate the opportunity to address you, Senator Steinberg, and Members of the Select Committee. Senator Steinberg, I know you recall—I won't go through the recommendations of the Blue Ribbon Commission and Insurance in the interest of time because we know them all, and we've heard all of the issues still echoed this morning. But one of the results of the Blue Ribbon Commission was that, in the bills that were introduced for the autism legislative package was SB 1563 which would have required the Department of Managed Health Care and the Department of Insurance to establish the autism workgroup for equitable health insurance coverage to review guidelines and standards on the screening, diagnosis, assessment, and treatment of autism with recommendations to be developed by October 1, 2009, consistent with conformance to AB 88. The legislature passed this bill. The governor vetoed 1563, and I think it's important to mention his veto message as we sit here this morning: **May I say that it is now almost three years later, and parents and consumers are still struggling with the very same issues that were being addressed by the Blue Ribbon Commission and by that bill.** I, in closing, just want to say Fedra is sitting next to me. She is one parent but she is representative of hundreds and hundreds, probably thousands, of parents in the state of California who face roadblocks and obstacles each and every day in securing the rights for their children with autism. So I want to say thank you to you, Senator Steinberg, and Members of the Select Committee for making this meeting possible where we could bring all of the players together in one room to discuss the situation as exists today and hopefully how we are going to move forward on behalf of individuals with autism and their families. Thank you.

SENATOR STEINBERG: That will be the next step. Thank you very much, Dr. Firestone.

MS. LORRI UNUMB: My name is Lorri Unumb. Thank you for the opportunity to testify here today. I'm the parent of a nine-year-old child with

autism. I'm also an attorney. I'm formerly with the U.S. Department of Justice in Washington, D.C. I'm also formerly a law professor. I used to teach at George Washington University Law School. But I gave up my legal career to advocate full time on behalf of individuals with autism when I saw the inequity in the insurance arena, so now I am senior policy advisor and counsel with Autism Speaks. In 2005 I wrote a piece of legislation for the state of South Carolina that was an autism specific health insurance mandate. **That legislation passed in 2007; and since that time, 20 other states have passed autism-specific health insurance bills. All of those—actually, the 21st state was signed into law this morning since our hearing started. In all 21 states, ABA is being consistently covered, and it's clear in the law or through regulations that it must be covered.**

Now I also want to add that I have testified in many of those states; and in all of those states, the very issues that you've been addressing this morning about the dichotomy between educational and medical services has come up. **The legislature has addressed this issue in all 21 states and has decided that health insurance companies should be covering ABA for autism.** And I'll tell you—let me back off of my lawyer hat for just a minute and say as a parent how I look at that very issue. **As a parent, my child got diagnosed with autism in a medical doctor's office. It wasn't something that the school principal sent a note home and says your child has autism. You get diagnosed by a medical doctor, and treatment is prescribed by a medical doctor.** That really ought to be about the end of the inquiry, in my mind. I have private health insurance. I pay premiums for private health insurance. And thus when my child's medical doctor tells me, here's the treatment protocol that you need to have for your child, I expect my health insurance to pay for it and to contribute to it.

One, that report came out in 2007; and as I have just mentioned, in 2007, there wasn't an option to get ABA covered through your insurance, other than in Indiana. And so that report was just an instructional guide to pediatricians to help them tell families what to do. It would not have been very useful for the ABA to tell pediatricians to tell families, go get ABA through

health insurance when it wasn't covered by health insurance at that time. They deemed it as educational. **They labeled it educational because that was the only place you could possibly get it at the time. And also, that same AAP report calls speech therapy an educational intervention as well.** That doesn't mean that it's not appropriate for coverage by health insurance. That just means it's something that is available in schools. So it's really a false dichotomy between educational and medical.

SENATOR STEINBERG: That was very helpful, the last point, to hear the other side of the story on the American Academy of Pediatrics.

For example, when we talk about cancer, the best practice now for treatment is chemotherapy and radiation. That's what we do. Even when it comes to mental health and, in many cases, autism, the plans do cover psychotropic medications. Those psychotropic medications are intended to change the brain structure, if you will, or the brain chemistry, but they're also intended at the same time to help people living with mental illness or with autism address some of the behaviors, if you will, associated with having those conditions and yet you cover that. So I think fundamentally, as we consider a legislative path here—and, you know, my way is always to want to do it collaboratively—**that we need to grapple with the real question here which is the efficacy, effectiveness, appropriateness of ABA therapy as a best practice.** It either is or it isn't. And the great frustration here, I think, is too much nuancing, right? Well, if proven in this case, we'll authorize it. I think you either should or shouldn't. I think you should. But let's grapple with what it is, ABA, and think about it, I think, in the same way we think about best practices in other parts of the healthcare spectrum.

I will convene meetings in my office, post-haste here, to begin grappling with this. I know I have a couple of bills moving through the process, sort of the general topic, and we have a couple of months left in this legislative session and I'd like to fill one of those bills in with the right kind of deal, right kind of solution—excuse m—and, again, with all of the important stakeholders at the table. Thank you. I'm going to excuse myself.

PUBLIC TESTIMONY

MS. CONNIE LAPIN: Hi. My name's Connie Lapin. I'm in awe of this hearing. The reason I came up, I am a speech pathologist but, more important, I'm the mother of a son with severe autism but I want you to hear his age. You might want to ask why I'm here. He's 42 years old. So I have had a very rich history of understanding autism, trying to figure out the treatment, and fighting for services. **We need to pass something here.** So what I want to say to all of you very briefly, I don't want to have you and other young parents be here in 40 years and say, well, we had this hearing. I mean, you may laugh, but I in 1973 thought we had this situation under control. So please pass a piece of legislation that makes sense to all of us. Thank you.

MR. CHUCK GENSEAL: My name is Chuck Genseal. I am a grandparent to a sweet nine year old by the name of Michelle diagnosed with autism, Rett specifically, a degenerative, debilitating condition. **The missing component in this puzzle of autism is the responsibility of the healthcare insurance industry. Autism is indeed a healthcare issue.** Michelle's healthcare provider, Kaiser, has systematically denied the very services needed by my Michelle. Michelle's quality of life is negatively impact by Kaiser's refusal to deliver OTPT and SLP services, and that is in contrast to what we heard these service providers stand up and say they provide.

MR. JAMES LANTRY: Hi. I'm Jim Lantry. I represent a group of parents of children with autism who use Floortime/DIR services to treat that.

Some children respond very well to ABA; some children don't. We need to stop using the term ABA as all inclusive and start using the term *intensive behavioral services*, including ABA and the others. This is a critical thing because, as long as we use ABA like we use the word Kleenex when we really mean tissue, we're going to find that we are excluding a lot of children from very necessary therapies, and I will tell you that a lot of these children have tried ABA. We need to do it cost effectively but we definitely need to do it in something that's tailored to the child. It is a medical necessity.

MS. JANE HOWARD: My name is Jane Howard and I'm here representing the California Association for Behavior Analysis, CalABA. It's

clear that in many states autism coverage is mandated, that ABA is viewed as a medically necessary treatment, and that it produces substantial benefits for individuals with autism. What needs to be worked out are the terms of coverage, services with the health plans. Maybe that's going to happen with regulation with, by law. What I would like to tell you is that CalABA and the BACB—that's the Behavior Analysts Certification Board—plan to work those details out. Thank you for the opportunity and for spotlighting this very important public health problem.

DR. DENNIS HART: I am a pediatric rehab medical director for Sutter Health. I am also one of those anonymous reviewers that review for one of the contracted people through the Department of Managed Health Care. About 70 percent of the ones that I review come for the diagnosis of autism, and so one of the things that I wanted to relate today is to your question, Senator Pavley. I can also tell you, I've been doing this for about ten years now, and the timeframe for review has gotten longer and longer and longer, and I'm oftentimes seeing cases that have been denied, where it's taken 180 to 360 days. I've had literally a year or more for those denials and the whole process, and so I think that really needs to be corrected. **We need to establish someone who can become that child's coordinator so they can say, this part of ABA is an educational issue; this part of ABA is a medical issue and really coordinate that.**

One of the problems that I've seen with autism is the people who "treat" autism in the medical community typically are providers that diagnose. And once they diagnose, it goes out to the community for treatment, and they aren't given the opportunity to follow up and follow that patient on a serial basis.

MS. KAREN FESSEL: Hi. I'm Karen Fessel. I'm a parent of a 15-year-old son with Asperger's, and I've also become a healthcare advocate. We talk about budget problems at the state level and how severe the budget crisis is, but what's going on right now at the Department of Managed Health Care where cases sit and sit and sit and the DMHC lawyers think about what's going on, that's costing the public more money than it would cost to either mandate the services or to send them through to IMR because, if they go through to

IMR, then they become—the costs of IMR are borne by the health plans and not the state itself.

MS. ANN MOHAN: My name is Ann Mohan and I own a rehab center for mental and physical impairment, and I'm also part of the current Autism Regional Taskforce. I just want to make one recommendation, is that we should use states, such as Indiana, as an example of what are those laws, what services are covered under those laws, what is working, and what may need some further clarification. How do they clarify such things as medical necessity criteria versus education?

MS. KRISTIN JACOBSON: **There is no requirement in California law that ABA be done by a licensed provider. The only requirement is that you must follow the licensing laws of the state. There are no specific licensing laws of the state.**

If you get back to it, what Senator Steinberg says is important, medical necessity, that's what's important. The law says that health plans must provide medically necessary treatment for autism. You can't decide if it's covered first and then only if it is decide if it's medically necessary. If it's medically necessary, it has to be covered, so that has to be the first question and everybody shouldn't have to appeal because, once you have 100 percent wins, it's not controversial. It is medically necessary for autism. The only case should be going to medical review at this point is, it's not necessary for this child because they no longer benefit or it's shown not to be effective. But as a category, ABA is medically necessary for autism, and each case should not have to be fought.

MR. KING: Yes. So I want to echo some remarks made by another one of our witnesses today, that it would be costly and I think premature for the state to conclude that ABA is the only suitable treatment option for people with autism. In fact, there is a longstanding body of evidence, clinical evidence, that DIR/Floortime is quite effective for people with disabilities, including people with autism.

MS. LISA VALERIO: Thanks. I'm Lisa Valerio. I'm also a mother of a child who's now turning seven with autism. What Kristin and Feda had said is

that things are just being hung up when it gets to the DMHC. I have cases that are just sitting there that's been there for three or six months.

MR. DAVE GAINES: My name is Dave Gaines, and I'm a behavior analyst and a special education advocate. The reason I came is because this debate has a lot to do with, Is autism a medical disorder? It is a different type of neurology. It's simply a different type of mind, just as we have different type of people—black, white, Asian, American Indian, and so on—autistic people are saying, we do not want to be cured; we do not have a disorder; we want to be recognized as a natural, diverse, variation of the human condition.

DR. VISMARA: On behalf of the committee, again, our sincere thanks, appreciation and continue looking forward to working with everyone here. Thank you so much. This meeting's adjourned.

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