

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

**Darrell Steinberg, Chair**

***Technology & Autism Spectrum Disorders (ASD)***

***“Adapting ‘Digital Age’ Innovations to Expand Access & to  
Improve Services for Individuals with ASD”***

**February 22, 2012  
State Capitol**

**SENATOR DARRELL STEINBERG:** Good morning, everybody. I want to welcome everyone to the Senate Select Committee Autism and Related Disorders.

I’m Darrell Steinberg, the chair of the committee, and I want to thank all of my colleagues who are here today. You know, select committees sometimes get good attendance; oftentimes they don’t. And I think it speaks to the seriousness of these issues and the commitment of the membership—bipartisan, bicameral—welcome, Assemblymember Logue—that we tackle this. And those of you who have followed the history of this committee and its predecessor, the Blue Ribbon Task Force, know that this is not just a study committee. This is a committee that takes what we hear very seriously. And, like last year, with SB 946, we turned the testimony into action, and we hope we can do that again this year because, as much as we celebrate the success of the past year and past years, we know that the work on behalf of children of autism and their families is far from over. And here’s why it becomes even

more poignant in why today's hearing is so important: It's no secret that our safety net system for individuals with autism and other disabilities are being significantly impacted by the state's fiscal crisis. We don't have to continue to recite the statistics. At the same time, we know that, in part, because of the funding cutbacks, that not every child with autism, certainly not nearly every child with autism who needs the help, is getting the help they need. And then we have technology which has created, as we all know, so many advances in our society, is not a substitute for face-to-face interaction or face-to-face care, but it is something that we can use, we can use, to create greater access to children and families who simply don't have any access at all

So today's hearing is to review the state of affairs, in terms of the autism epidemic in California, the impact on families, but then to go right into the current applications of technology in healthcare in autism—the public policy, the legislation, and future implementation strategies. And what we want to make sure that we have over the course in the next couple of hours is a focused conversation so that the legislators here can come away with an idea about what we ought to support, invest in, incentivize, create, that will create greater access than what currently exists, using technology. That's the simple purpose. And I certainly go into it with an open mind and with an eagerness to learn.

I'd give any of my colleagues the opportunity to make a brief opening statement. If not, I'll introduce the panel.

Go ahead.

**SENATOR CURREN D. PRICE, JR.:** Thank you, Mr. President. I'm just pleased to be part of this group. I appreciate the testimony that we're going to hear and the activists that are in the audience today.

This hearing is important because of the current state of healthcare disparities that exists in California and we all are sort of familiar with them—many low-income families who don't know what autism is or how to access the services to help their family members who are diagnosed with this condition. In LA, there are a number of programs committed to meeting the needs, special needs, and at work, the regional centers, hospital for—the Children's Hospital For Excellence. But these programs weren't able meet the needs with the increasing population, even the organizations that are active. We need to be doing more, and so I think utilizing health technology is a smart way to assist service providers and patients, leveraging limited resources, and providing access in ways that haven't, not only in rural areas but also in urban areas. So I think that's why the conversation today is going to be so very important, so I'm happy to be here and look forward to learning more and seeing how we can provide resources to those who need the most.

Thank you, Mr. President.

**SENATOR STEINBERG:** Thank you very much, Senator Price.

Anybody else?

Assemblymember, welcome again.

**ASSEMBLLYMEMBER DAN LOGUE:** Thank you, Senator. I want to commend you for taking this task on. It's like, for telehealth medicine, that

we're taking our medical field into the 21<sup>st</sup> century, and the people who are going to be testifying today have taken giant steps towards pulling that off. I think it's incredible. It does help the rural areas. It's actually going to save the taxpayers \$1.2 billion over the next ten years, and it'll give complete care to people who have never had it before; and especially in the field of autism, I think this is going to be leaps and bounds and a benefit to the people of California and I commend the senator for taking the steps to do this. I just want to come by and thank you very much for your efforts. Thank you very much.

**SENATOR STEINBERG:** I really appreciate your coming.

Okay. Any other words of praise for the chair? (Laughter)

**UNIDENTIFIED SPEAKER:** \_\_\_\_\_ the chair.

**SENATOR STEINBERG:** (Laughter) Senator Leno. Just kidding. Come on, guys. Geez.

**SENATOR MARK LENO:** Very briefly. Just to say that I don't think that we can hold enough hearings on the subject of the autism spectrum and that there is ever more to learn, I certainly have learned a lot as chairing the San Francisco/Marin Autism Regional Taskforce over the past couple of years. We've come up with some, I think, significant ideas relative to access to insurance and employment and housing. And, of course, this not praise for the chair but praise for the chair's bill last year regarding behavioral therapy that we really got some results out of these hearings. So just welcome,

everybody, and look forward to how we can move the issue of the autism spectrum into the 21<sup>st</sup> century using new technologies.

**SENATOR STEINBERG:** Very good. Thank you all, Members.

Let's get right to it now. We welcome again Drs. David Amaral and Dr. Robin Hansen who kick off our, seem to kick off, all of our hearings, you know (laughter), which is a good way to start, and they are going to speak about a little bit of an overview on where we stand. And then, of course, we want to hear from our great advocate, Rick Rollens, who's a parent advocate, cofounder of the MIND Institute, about what's happening out there in communities with families. And then we're very lucky, of course, to have Terri Delgadillo who has been a warrior in all of this effort for many, many years who is the director of the Department of Developmental Services and dealing with a lot of challenges, I know.

So why don't we begin with the doctors and we'll hear the testimony.

And, Members, feel free to make it a conversation and ask questions.

Go ahead.

**DR. ROBIN HANSEN:** Great. Thank you. Well, I would like to thank you all for the opportunity to speak and also to thank you for your ongoing commitment to improving the lives of individuals with autism in California.

I was asked to present an overview of the clinical aspects of autism spectrum disorder, so I'll just briefly go over the diagnostic features, some of the comorbid conditions that we see in individuals with autism spectrum disorders, and a little bit about the prevalence data that we know.

I think one of the interesting things about autism in the just over 60 years that it was first recognized and described as a very rare disorder that involved children with very remarkably aberrant behavior, we're now—we now recognize sort of a spectrum of autism disorders, and we know that they occur in almost one in a hundred people. So it's something that's become part of our everyday life, and I'm sure that all of you are likely to have had personal experience with someone who's been affected by an autism spectrum disorder.

Let me start with the clinical features. Although the diagnosis is based on behavioral symptoms, these behaviors are the downstream manifestation of a variety of biologically based neurodevelopmental disorders that involve complex interactions, we think, between genetics, epigenetics, and environmental factors that affect early brain development and function. The symptoms fall into three areas related to social reciprocity, communication, and restricted behaviors and interests.

In the social domains, the symptoms include impaired use of non-verbal behavior, such as eye contact, facial expression, gestures to regulate social interactions, failure to develop age-appropriate peer relationships, and little seeking to share enjoyment or interest in things with other people, along with limited social, emotional reciprocity.

Communication deficits include delays or the absence of spoken language. And in those who do develop language, they have difficulty initiating or sustaining conversations, they may have very idiosyncratic and repetitive language, and they also have deficits in imitation and in symbolic play.

In the last domain, behaviors and interest, there are often encompassing, unusual, very focused interests, inflexible adherence to non-functional routines, stereotype body movements, and preoccupations with parts of the sensory qualities of objects. Usually these symptoms arise sometime before the age of three. And unfortunately the timeframe between first parent concerns and the time for diagnosis and treatment is often prolonged, partly because of delays in recognition or referral, and then also long waiting lists for a diagnostic assessment and treatment, and this is particularly true in areas where there are few services and little access.

One thing that we do know is that there are probably multiple ideologies and causes for autism, and we think that that, the increased prevalence rates that we not only see in California but that we see worldwide may be related to this interaction between genetic susceptibility and potentially things in the environment that are increasing. Our most recent data in the United States suggests that the prevalence is somewhere around 100—1 in 110. Because boys are more affected than girl, the prevalence rate in boys is 1 in 70, so very, very common. Because the Department of Developmental Services has such an excellent statewide data base, we are really lucky in California to have some of the best and most consistent documentation of the increasing numbers of individuals who have been diagnosed with autism and are receiving services. And we know that in California, based on this data, we've had an increase of over 600 percent since 1987 through 2002 and continues to increase.

We know that certainly some of this increase, both internationally, nationally, and in California is probably related to some degree to better detection, certainly to increased awareness, and also the use of broader diagnostic criteria. But using the DDS database, Drs. Irva Hertz-Picciotto and Lora Delwich tried to control as best we can statistically for all of these factors and found that it still doesn't explain the dramatic rise of autism in California. And we do have emerging research that's beginning to link gene environment interactions as one of the factors that is affecting this risk.

Then briefly on comorbid conditions that occur as well as the behavioral disturbances, we see other disorders of brain and biologic function that are very common in people with autism spectrum disorders, and it's very important that these are recognized and diagnosed and treated as separate conditions. Intellectual disability occurs in probably half of individuals who are diagnosed with autism. It varies across studies. And we know that this is really the most important predictor of long-term outcome. Seizures have been reported in around a third of individuals with autism and much more commonly in those who also have intellectual disability.

For many families, the comorbidities of gastrointestinal and sleep disturbances present additional significant challenges, and these impact all of the family members. GI disturbances are just chronic diarrhea, constipation, food selectivity and sensitivity are reported in anywhere from 45 to 85 percent of individuals with an autism spectrum disorder, as are sleep disturbances, such as delays in getting to sleep, maintaining sleep, and shorter sleep



duration. Psychiatric comorbidities are also very common, such as attention deficit and hyperactivity disorder, anxiety, and depression. And again, these are much more common in older adolescents and certainly in adults.

So the autism spectrum disorders have a very wide range of outcomes, and we know that people of all ages and at all levels of function respond to well-delivered and empirically-based treatment and education practices. And it's this access to high-quality diagnosis and treatment services for all individuals with autism spectrum disorders that we hope we can impact through the expanded use of technology, research, and services. Thank you.

**SENATOR JUAN VARGAS:** If I can ask a quick question. I mean, you did say that there is a dramatic rise in autism in California, even though there's more recognition and detection. How, the rise, how dramatic is it? I mean, I have to say that it does seem to be a dramatic rise from friends of mine whose family members have autism compared to when I was a kid, and I'm 50. I don't remember it being this prevalent.

**DR. HANSEN:** That is definitely the case, you know. And again, if you look at the data that we collect through the regional centers - a rise of 650 percent is huge and it's, you know, unheard of, particularly in a disorder that we think is very highly heritable or genetic in its basis.

**SENATOR VARGAS:** But it's not because of recognition or detection. It's not because...

**DR. HANSEN:** Not solely, no.

**SENATOR VARGAS:** Okay. Thank you.

**SENATOR LENO:** Dr. Hansen, I have a question as well.

The rates of increase in California are greater than in the national averages, and how do they compare to Europe, potentially developed nations, and Asia? Are we standing out in any particular way?

**DR. HANSEN:** It's hard to know whether California is really unusual because we're really the only state that has our regional center system and the database that we have. So we can't really compare ourselves to other states. I can tell you that every state feels that they have a dramatic rise in the number of individuals diagnosed with autism, and our prevalence rates are fairly similar to Europe, and there is quite a bit of variation across different nations. And again, it was partly ascertainment and the availability of identification services and diagnostic services, but it seems to be increasing in every country that's looking at it.

**SENATOR LENO:** But to look more specifically, we just don't have the data?

**DR. HANSEN:** Exactly.

**SENATOR LOU CORREA:** To the chair.

**SENATOR STEINBERG:** Yes, of course.

**SENATOR CORREA:** A quick question. You said a 600 percent increase in the time period you discussed. Can you break that down? Better detection versus maybe other factors?

**DR. HANSEN:** The study that I mentioned tried to control for those and also tried to adjust for families moving into California for services. So this is

really based on the birthrate controlling for the change in diagnostic criteria as best we can statistically, and it only accounted for a moderate proportion of the rise so the rest of that rise is unaccounted for.

**SENATOR CORREA:** So do you have a break, broken down, percentagewise, or not?

**DR. HANSEN:** No.

**SENATOR CORREA:** Okay. Thank you.

**SENATOR STEINBERG:** Oh, I'm sorry. Senators Emmerson and Berryhill, go ahead.

**SENATOR BILL EMMERSON:** Thank you. Mr. Chair, I know who the chair is and I thank you for having this hearing and appreciate your hard work on this matter.

But Dr. Hansen, I'm interested in the studies where you're seeing some correlation or information with gene environment interaction. Is there any preliminary data that's available that's showing us what part of environment is part of this, and will we be discussing that in later panels? Okay. I'll just...

**DR. HANSEN:** That may be the perfect lead in to Dr. Amaral who does the research.

**SENATOR EMMERSON:** All right. We'll listen to the doctor.

**DR. DAVID G. AMARAL:** Well, thank you, Senator Steinberg and Ladies and Gentlemen. My name is David Amaral. I'm the research director of the MIND Institute and I've been asked to give a short review of some of the science that is taking place. And I think, to start off, I'd like to say, that with the

increased awareness of the emerging health crisis of autism spectrum disorders in the 1990s, it really mobilized the scientific community to produce a dramatic increase in the research nationwide and actually worldwide. So one measure of the advances that we're seeing is, that if you simply look at the number of scientific papers at the National Library of Medicine, in 1990 there were only 213 papers on autism. In 2000, that jumped to 441 scientific papers. But last year in 2011, there were 2,477 papers, so much, that it's impossible to keep up with all that's coming out. This has been fueled in part by increased funding for autism research and the National Institute of Health, and other private foundations have increased the amount of funding for autism research. It was only \$22 million, believe it or not, in 1997, and now it's approaching \$300 million—still not enough but a dramatic increase in the amount of money that's going into research on autism.

So given all this scientific effort, what have we learned? I think in part over the last decade, we've wised up to how complicated autism really is. We now know that autism is a biologically, incredibly complex disorder that, as Dr. Hansen has said, has many causes. It always affects the brain; and because it affects the brain, that's what leads to the behavioral disturbances that characterize autism. But as Dr. Hansen has said, it's a medical disorder and it affects other bodies systems, particularly the immune system, the gastrointestinal system, leading to GI problems, epilepsy, and dysfunction of the immune system.

So in many respects, I think of autism like I think of cancer. We all know that cancer has many causes and many types. Some of the causes of autism are environmental, some of them are genetic, and some are genetics and environment coming together. In cancer, despite all these different causes, all have the common feature of uncontrolled and pathological cell growth. Well, autism, as we now are understanding, also has many causes and again there are some that are genetic and some are environmental—and all of these causes come together to produce a syndrome that has common features of, as Robin was saying, social impairments and language impairments.

So again, we now know it's incredibly complex. And let me just tell you a little bit about what's known. For example, in the genetics of autism, you know, a decade ago, people were still saying that we were going to come up with an autism gene. We now know that's not going to happen. There are over a hundred genes that have already been identified, mutations of genes, that lead to increased risk of autism. The problem is that any one of those gene mutations are only found in 2 to 3 percent of kids with autism. And in fact, what makes it even more complicated is that you can have those gene mutations in people that are typical, that don't have autism, and you can find those gene mutations in people who have other diseases, like schizophrenia, so we're dealing with an incredibly complex genetic environment here. And again, it may be that what we're dealing with is genes that increase risk but something else has to happen. It has to be an environmental hit, and I'll get to that in a moment.

In brain research, one of the consistent findings is that the brains of children with autism, at least a substantial subset of the brains of children with autism, actually develop too fast. And you can say, Well, why is that a problem? Well, it turns out, it's a problem because it's not all parts of the brain that are developing too fast. In certain regions, the brain is like a complex city. It has different parts that do different things. And certain parts of the brain are developing too fast, and the unfortunate thing is that the brain development is like a symphony. If all of the players aren't playing in tune, something bad is going to happen. And what we think happens is, that because certain part of the brain are forming earlier, they do a bad job of making connections with the parts of the brain that they should be communicating with and that this mis-wiring of circuits in the brain leads to some of the behavioral abnormalities that we see.

The immune system—this is a rapidly growing area of research. There is a huge body of literature that's just emerged over the last five years that indicates that the immune system and problems with the immune system and how the immune system handles challenges from the environment is contributing to autism. Very intriguing data indicate, that if a mother's immune system is challenged during pregnancy, for example, like with something like the flu, that the fetus is at a greater risk for autism and for other psychiatric diseases, such as schizophrenia. While this line of research was considered to be on the fringe as little as a decade ago, some of the best

labs in the country, including here in California, are exploring the lengths between immune dysfunction and psychiatric diseases like autism.

Finally, the environment is being more heavily evaluated as cause of autism, particularly in genetically vulnerable individuals. So for example, exposure to pesticides has now been clearly shown to increase the risk of autism. There's a paper that just actually came out from the MIND Institute yesterday showing that exposure to flame retardants that used to be actually in children's clothing, but has been removed thankfully from children's clothing but still is in the environment, exposure to these flame retardants, which are called PBDEs, also increase the risk of a child having autism, particularly if they have a certain genetic vulnerability to that.

There's some good news, though. So as Robin was saying, Dr. Irva Hertz-Picciotto and her colleagues have been surveying autism throughout California and they find, for example, that if mothers take pre-pregnancy vitamin supplementation, particularly, we think it's a folic acid, this actually dramatically reduces the risk of a child have autism. So that's actually an easy fix, in a sense.

**UNIDENTIFIED SPEAKER:** Why?

**DR. AMARAL:** We don't know why. Folic acid actually is a molecule that does what's called epigenetic modifications. It actually conditions how the DNA is expressed. We think if you don't have enough—we know if you don't know of it, it can produce things like spina bifida. That's a very severe developmental abnormality. But we think, if the levels are not optimal, it may

actually produce alterations in brain development that can go on to lead to autism. So again, in this case, the finding that pre-pregnancy supplementation decreases risk should actually translate very quickly into common pregnancy practices, and that is, take a vitamin supplement three or four months before pregnancy.

So let me just finish by saying that at this point, we still don't have any drugs to treat autism. We are—I think we still need to understand more of the basics about autism before we can get to that point. But as Robin was saying, behavioral therapies for autism are effective. And what's happening in research is, people are trying to detect autism earlier and earlier so that behavioral therapies can be used as early as 12 months of life, even before a diagnosis is absolutely confirmed. They can be used prophylactically, and we think that they're going to increase the quality of life for children who have advantage to those therapies.

So again to conclude in five minutes, I can't possibly summarize all of what's going on in autism research. But let me just say that I think the last decade has seen a mobilization of scientists who are now engaged in autism research. I'm confident that the next decade will see the emergence of clear evidence for causation, at least in a few types of autism, that will lead directly to strategies for prevention, in some cases, and more effective pharmaceutical treatments, so thank you.

**SENATOR STEINBERG:** I've just got to go back to the vitamin issue again because the way you just stated it was so clear. So what are we doing to



promote this research finding? What are we doing to make sure that every pregnant woman takes these vitamins? I mean...

**MS. ALDRICH:** I'll let Robin answer that.

**DR. HANSEN:** What's interesting is that we've known for a long time that prenatal and preconception folate in prenatal vitamins are important for healthy brain development. So this is new that we've connected it to autism risk. So I think that the news is out there, that you should be taking folate if you're a woman of childbearing age for multiple different reasons. The new link is that, particularly in women who have a genetic susceptibility, who have polymorphism that decreases their rate of methylation, that it's even more important for them to be taking...

**SENATOR STEINBERG:** I'm sorry. The term (laughter)...

**DR. HANSEN:** So what we found is that, again, it's this gene environment interaction, that if you are a woman who has perfectly normal functioning except that you just function—your enzymes function at a lower level of activity than someone who has a high-powered form of metabolism, it's most important for you as a mother to be taking extra folate in terms of reducing your risk of having a child with autism. So again, it's this brand new ability to sort of—it's like personalized medicine is, if we knew that, you know, if we had the genotype of every woman, we could say it's really important that you take folate if you're even thinking about getting pregnant so we're just beginning...

**SENATOR STEINBERG:** Do all the family physicians know this and are they telling their patients, young women, women of childbearing age, to do this?

**DR. HANSEN:** What we're not doing is sort of saying, you know, we're going to test you genetically because we want every woman to be taking folate and that's standard practice...

**SENATOR STEINBERG:** It is?

**DR. HANSEN:** ...and should be standard practice. It's one of the guidelines in obstetrical medicine.

**SENATOR STEINBERG:** Yeah, Bill.

**SENATOR EMMERSON:** There is a relationship between epilepsy and folate; is there not? Folic acid, is there?

**DR. HANSEN:** There's some forms of, some forms of epilepsy. That's true.

**SENATOR EMMERSON:** So it's recommended in those forms that they take more folic acid as part of the regimen?

**DR. HANSEN:** Um-hmm.

**SENATOR EMMERSON:** But we don't have the science. Science doesn't tell us that that's a general factor of epilepsy?

**DR. HANSEN:** Right.

**SENATOR EMMERSON:** All right. Thank you.

**SENATOR CORREA:** The chair.

**SENATOR STEINBERG:** Yes. Of course. Senator Leno and Senator Correa, go ahead, any order.

**SENATOR CORREA:** Question for you on the issue of diet. Have you researched? Does that come up with any conclusions there?

**DR. AMARAL:** Robin can also, has done some work on this. But I think the bulk of available evidence suggests that the diet may have limited value in therapeutic for autism, although the caveat is that it may be that the right subset of children with autism hasn't really been thoroughly studied. So the kids who have the gastrointestinal problems haven't been sort of set aside and say, okay, well let's look at diet in those kids alone, not autism generally.

So do you have a different take on it?

**DR. HANSEN:** No. I think part of what's so complex about it is that there's not just one autism. So if you look at large groups of kids who are put on usually gluten, casein fruit diets, as a group, they tend not to respond. And what we're really starting to try and figure out is, if there's a subgroup that responds, what is it that's unique about that subgroup of children who seem to respond to some dietary interventions that we can then say, well, if you have this type of autism, then it is important for you to restrict your dietary intake of gluten or casein.

**SENATOR CORREA:** Let me ask that question.

**DR. HANSEN:** But in general, the studies looking at large groups of kids with autism don't see that there's a significant difference on diet.

**SENATOR CORREA:** I ask that question because the more and more I speak to parents, the more and more I find that many of them say different diet, eating something or not eating something, actually affects the behavior quite a bit.

**DR. HANSEN:** Right.

**DR. AMARAL:** I mean, we hear that all the time as well. I think it opens, still speaks to the need of looking at kids, as Robin has said, that have, you know, a certain profile to their autism. A lot of times, you know, I think it makes perfect sense—and this is a case where the treatment of putting a child on a restricted diet is not going to be dangerous. I think it certainly is worthwhile and valid for parents to try that. The problem is that the scientific basis for that is critical at the moment, and it's a very difficult kind of study to do, as it turns out. So I think that's one of the reasons why we don't have, you know, a definitive answer.

**SENATOR CORREA:** That's an interesting point you make which is scientific evidence because it is scientific. You've got to go through the research to come up with that determination. Most of the parents that are actually saying this works—of course, I'm not under a scientific study—they are just, you know, trial, hit and error at home. You know, Johnny or Jane, this is how they react when we give them certain things and this is how they don't react.

**DR. AMARAL:** Just as sort of a funny aside, that we have a thank-you party at the MIND Institute every, and last year we had 1,300 people that came

where we thanked our young participants in the research program. When we first started that in 2003, we had free food...

**SENATOR CORREA:** You gave them cheese.

**DR. AMARAL:** Well, we had all gluten-free food for the first couple of years and families were going for that. And then what we found over the years, nobody was going for the gluten-free food. Everybody wanted the pizzas and the hamburgers and things like that. So, you know, at our last one, just this last year, we had a very small table of gluten. I mean, that's anecdotal (laughter). But I think it's a complicated issue that needs more attention.

**SENATOR CORREA:** Thank you.

**SENATOR LENO:** Dr. Amaral, can you tell us a little bit about this recently published report by the MIND Institute regarding the relation, I guess potentially, between autism and toxic flame retardants?

**DR. AMARAL:** Right. So that was a study that was done in mice, as it turns out, and the advantage for that is that you can actually construct mice that have particular vulnerabilities, and the lead author on that is Dr. Janine LaSalle who studies this issue of methylation and how DNA works. And the bottom line is that they found that exposure to these flame retardants in these mice who were genetically susceptible to environmental insults led to alterations in their behavior, actually made them hypo-social, one of the symptoms of autism, and they also showed that these flame retardants were actually adversely affecting the neurons in the brains of these mice.

So if you extrapolate, then if we identify children that have these same kinds of vulnerabilities, we would expect that exposure to flame retardants in those children actually may have more of an impact than children in general. This is always the problem with personalized medicine. You have to sort of figure out who has these risk factors. And it's the same thing for autism as it is for cancer or heart disease. We're still struggling to figure out what the risks are, like the flame retardants, and then who is vulnerable to those risks. You know, when you think about how many chemicals there are in the environment, there's tens of thousands that are coming online all the time and it's a struggle. But this, I think, this study clearly showed that just having the genes that were impacted wasn't enough. Just having the flame retardants wasn't enough. But having both of them together caused the problem in these mice.

**SENATOR LENO:** You made mention that the federal government had taken chlorinated biphenyls, one of these flame retardants, out of children's sleepwear...

**DR. AMARAL:** Right.

**SENATOR LENO:** ...35 years ago because it was determined it would be carcinogenic. But unfortunately, we find that these same chemicals are now in their pillows and their comforters and their strollers and their cribs and any number of juvenile and infant consumer products...

**DR. AMARAL:** Right.

**SENATOR LENO:** ...and we've been trying to deal with that here unsuccessfully in recent years. But what has made me evermore curious on the subject and the potential relationship is that the very decades that Dr. Hansen referred to, with regard to the 600 percent increase from the mid-80s to early, well, 2002, I think you said, almost directly overlaps the creation of California's unique fire safety standard in the mid-70s which created the standard. No other state has created and no other country has required these chemicals to be poured into so many different products, and now we have evidence that shows that they don't actually keep us any safer from fires anyway. So my question is, Why are we continuing to do this?

**DR. AMARAL:** Right. Well, you know, I think over and over again, what I've learned about the autism world is that searching for the causes brings up these ancillary problems. I think some of the additives to, you know, to some of the vaccines, for example, were only looked at when people worried about the vaccines as a cause. You know, so you asked, Well, why do you need these preservatives? I mean, there's a lot of things that are coming up. I do think that, you know, as Robin was saying, the prevalence of autism across the country, in different states that have different regulations, is about the same. We'd love to see a smoking gun, you know, that is one of these things. I think it's going to unfortunately be much more complicated but, you know, as you get evidence for any one of them, you can do something about it.

**SENATOR LENO:** Thank you.

**SENATOR STEINBERG:** Yes.

**SENATOR TOM BERRYHILL:** With autism, are these kids—I mean, you can take your pre-vitamins and all that stuff—are these kids born with it or do they acquire it? I mean, what percentage of kids have it when they're born and what percentage of kids come out fine and then because of whatever end up with it?

**DR. AMARAL:** I mean, I think the bottom line is that the field would say that the vast majority of children with autism are either born with it or manifested very, very soon in life. It's interesting that, you know, there is a form of autism that's called regressive autism so that the symptoms—so a lot of kids with autism you see at 12 months of age, they're already showing developmental delays and other problems. But then there's another group of kids—and we call those the early onset. If you're starting to see some problems at 12 months, you sort of figure that things started very early on.

**SENATOR BERRYHILL:** And you've gotten much better at identifying that?

**DR. AMARAL:** Absolutely, absolutely. But then there's an equal number of kids that at 12 months they look fine. They're gaining words; they're social. If you look at their first birthday videos, they're happy; they're engaged. And then somewhere between 18 and 24 months, they regress back into autism. They lose language; they lose social ability. And then they look like the other kids who have the early onset formed.

What's interesting is, that even in those kids who regress back into autism, we now have evidence that their brain was starting to change at four to



six months of age, long before we actually saw the behavioral symptoms of it. So I would say that the vast majority of evidence, regardless of when the autism symptoms come up, that the autism is starting very early, whether it's...

**SENATOR BERRYHILL:** At conception, you mean?

**DR. AMARAL:** At conception. It could be through maternal, through the gestational period or very soon thereafter, but it looks like the majority of autism is happening very early on. You know, it's not to say that there aren't a small number of cases that have some environmental insult later on, but I mean, that's where the science is pushing us, to a very early onset of the disorder.

**SENATOR BERRYHILL:** Thank you.

**SENATOR STEINBERG:** Bill or Juan? Senator Vargas, Senator Emmerson.

**SENATOR VARGAS:** Thank you.

A couple of questions here, and I asked it before. The increase was 634 percent from 1987 to 2002, so we do see this increase. However, my youngest daughter is eight years old and the oldest one is about to turn 16 so there's quite a space in between them. We have difficulty having biological children. So my wife tried to do everything she possibly could, you know, for that second child. I don't remember this issue of the folic acid. I don't remember eight years ago, them saying that this was so important for her. And if the increase is so dramatic, why aren't—maybe I'm wrong about this, but is it really that

well known by the doctors attending pregnant women? I mean, I have to be honest with you. I don't remember that. I remember a whole bunch of other things but I don't remember that.

**DR. HANSEN:** Right. Well, part of the way that we've, that we did this research is, we asked mothers to remember who had children with autism, who had children with other developmental delays, and who had typically developing children, Do you remember when you started taking prenatal vitamins? So we already had—the children were already diagnosed. So what we found is that there was a subgroup of mothers who were taking prenatal vitamins before they conceived. Most mothers started taking prenatal vitamins within their first trimester. Once they knew they were pregnant, most of them, almost all of them, started then taking prenatal vitamins. So it's really this window where there are differences in the rate of mothers taking prenatal vitamins. So if you're taking it preconception, before you even get pregnant, that seems to confer a decrease in risk. And if you take it very early on, before most women are even sure that they're pregnant, that's another critical period. So I think that it's very clear, that once women are diagnosed, once they know they're pregnant, they start on prenatal vitamins. So the message—I think you're right—that has been out there in terms of public health is, childbearing women should be taking—if you're planning to get pregnant, don't wait till you get pregnant; start taking extra folate in your diet. So the easiest way to do that is prenatal vitamins.

**SENATOR VARGAS:** And that is well known?

**DR. AMARAL:** I think it's getting better known, probably only in the last several years. So perhaps, you know, if you go back eight years, we weren't aware of that.

**SENATOR VARGAS:** Honestly, I don't remember that.

**DR. AMARAL:** Not that well known.

(Inaudible comments)

**SENATOR STEINBERG:** So—was that it? Okay. I have one last question and then we'll move. I'm sorry, Bill. No, no. Go ahead.

**SENATOR EMMERSON:** I'm fascinated by a couple of things. We talked about the gluten issue. In medicine, we have a difficulty, even diagnosing celiac disease today which is gluten related.

How can we test if gluten becomes a problem in an autism situation? Is there some definitive test or is it just...

**DR. HANSEN:** So most of the time, would do blood testing to screen for markers of Celiac disease. But many parents, even without, you know, without evidence, biological evidence, still feel that it's important for them to try taking gluten and casein out of their diets, partly because of the theory, that if you absorb those dietary proteins, that they can get into your bloodstream and act centrally in your brain, like opioids and really change brain function. So that's the theory behind it. There's not good scientific evidence that that's really happening, and we don't know because we don't have evidence from scientific studies when children respond to taking, if they do respond to taking, gluten or

casein out of their diets, what's the mechanism for changing, you know, brain function and then changing behavior.

So again, it's the issue of there may be a small subset of children who have gluten sensitivity or casein sensitivity or leaky gut and that it's just those proteins that get absorbed that then affect the brain function and so perhaps our task is really to figure out a way to determine which are those kids with autism who also have gluten and casein sensitivity.

**SENATOR EMMERSON:** My second question was with respect to the vaccinations. Today it seems less important to have preservatives in vaccines because of the ability to ship vaccines, keep them in a refrigerator, et cetera, than it did years ago when I was growing up. And so it seems as though we're having an increase in autism today versus when I was a kid. My senator here may think that I have that problem as well, but so we've ruled out pretty much that the whole thing about preservatives in vaccine is a cause or where are we on that whole issue?

**DR. HANSEN:** So multiple studies have not shown a relationship between autism, risk, and vaccinations. Having said that, those are large epidemiological studies that looked at huge groups of kids—with and without autism—and they correlated it with who was vaccinated, who wasn't, what kind of vaccination did they get, at what time did they get it, so there's no relationship that's found. Having said that, you know, we can't not say with absolute certainty that there is not a small subset of children potentially who

have immune dysfunction who may not be affected by vaccines but we don't have any evidence for that.

**SENATOR EMMERSON:** Thank you.

**SENATOR STEINBERG:** My last question before we move on is this: Aside from General Fund budget dollars, which we don't have, is there any other public policy changes that you suggest that we ought to undertake to improve research capability to improve the research side of the autism question?

**DR. AMARAL:** One thing that I think still needs a lot of discussion, but I think it would actually be valuable to be able to communicate with all families throughout California who have individuals with autism through some consolidated effort and whether this is a registry or some other form of communication channel like that. It actually is sort of difficult still to do research because it's a difficult prospect to do recruitment of families.

In some of the studies, what we've learned, because autism is so heterogeneous and complicated, the studies have to be bigger and bigger. You have to enroll more and more subjects into the studies and it's a complicated process. And conversely, I think if we can communicate better to the families in California who have children with autism, maybe these issues about folate and others could be disseminated more rapidly.

**SENATOR STEINBERG:** And the advocacy organizations, as great a job as they do, they don't have a comprehensive list of families?

**DR. AMARAL:** Not that I'm aware. I may be missing something.

**SENATOR STEINBERG:** Okay. Just food for thought because, you know, we need to know how to respond to some of your testimony on the public policy side here, and we focus a lot on the services obviously; but on the research side, if there are things we can do that don't involve more money right at this point, I'd like to know what they are. Thank you.

**DR. AMARAL:** Thank you.

**SENATOR STEINBERG:** Mr. Rollens.

**MR. RICK ROLLENS:** Thank you, Senator Steinberg.

First of all, I want to thank each and every member of this committee for the good work that you're doing on behalf of the families here in California with children with autism. As many of you know, I worked in the Senate for 24 years as Secretary of the Senate and spent a lot of time here, so I keep track of sort of procedural things, and I was quite frankly blown at the fact that this select committee has 20 members. I don't think you have a policy committee in the senate that has as many members on a committee as a select committee, and I think that speaks volumes to the interest and the commitment that this body has for the issue of autism.

I'm here today as a parent. This is my son, Russell, who graced the cover of *Newsweek Magazine* a few years back, and Russell is one of those regressive kids. His Apgar scores at birth were much higher, quite frankly, than my typically developing son. He regressed significantly after a series of vaccinations he received, and we're one of those families that strongly believes that the increase in autism is real and that we are fighting tremendously for

research at the MIND Institute and other places to find effective treatments and a cure for his disorder. He's also a gluten, casein-free kid who responds very well to a limited diet.

I'm here today really to talk about the parent's perspective on the impact of autism—the emotional toll, the physical toll, and the financial toll the families undertake at the time of diagnosis and moving forward. Life really takes on an under-siege state of mind once the diagnosis of autism is given to a family. The divorce rate among families of children with autism is well over 70 percent, and studies have shown that next to the death of a child, receiving a diagnosis of autism is the second most stressful event in a parent's life.

Families are really overwhelmed in trying to navigate and coordinate the multiple systems of care which include but are not limited to a medical education, educational, social, and regional center support. Families are faced with major out-of-pocket expenditures related to expenses that we basically refer to as families as the autism tax. Wading through all the information and finding and securing the appropriate individual interventions and treatments for our families and our children is a daunting task, and please understand that many underserved families from various parts of the state have numerous other obstacles and more often do not have access to care at all.

Challenges include receiving a timely and accurate diagnosis of our children's condition, coordinating supports within the medical community, insurance companies, education, and regional centers, as well as dealing with the many medical appointments and doctor visits and other major stress items,

including much redundant paperwork that all of us as family members are required to deal with.

As a parent, you are overwhelmed with a sense of urgency and the breadth of navigating through these systems. At the same time, you're grieving for your child and trying to be the best spouse, parent to your autistic child and your other children and also trying to earn a living on the side.

The autism parent community long ago embraced and has maximized the use of the digital age to establish family support groups and advocacy organizations. You'll be hearing later today at this hearing from other witnesses before you of the incredible opportunities to address many of the areas I have outlined today to assist with autism and their families through the use of telehealth and digital-age technology to help those impacted by autism by simplifying overly an complicated task, reducing the workload and stress of everyday activities involving having a child with autism, as well as providing critical services to many of those who currently do not receive those services and especially those in underserved areas of the state and underserved populations that are hard to reach here in California. I appreciate the opportunity to testify and welcome any questions.

**SENATOR LENO:** Thank you, Mr. Rollens.

Ms. Delgadillo.

Thank you for all of your advocacy these many, many years.

**MR. ROLLENS:** Thanks.

**SENATOR LENO:** How old is your son now?



**MR. ROLLENS:** Russell is 21.

**SENATOR LENO:** How is he doing?

**MR. ROLLENS:** He's doing okay. It's a question, when you ask a parent of a child with autism, you never get an immediate response because there's a lot of thought that goes into it, as you know. But right now, he's doing well. He's currently living at home with us and I appreciate your interest.

**SENATOR LENO:** How far could he go in his education?

**MR. ROLLENS:** He will term out in special ed at the end of this year and we're, right now, looking for daytime activities for him once he terms out of school. He's been in a special class with other children with autism all the time he's been in public school.

**SENATOR LENO:** Thank you.

**MR. ROLLENS:** Thank you.

**SENATOR LENO:** Ms. Delgadillo.

**MS. TERRI DELGADILLO:** Thank you, Members. Thank you for inviting us here today. It's a hard act to follow all of these guys. You get to hear the cutting edge research and always to hear from Rick about what's going on from the family perspective. I was asked to give you a little bit dryer testimony to tell you some of the data, about the people that we serve, and about the budget.

Basically we serve about 252,000 people in California that have developmental mental disabilities. About half of them are children; about half of them are adults. Of those, a little less than 1,800 are served in four

state-operated developmental centers and one community facility. The balance, 250,000, are served in the community. They're served by 21 nonprofit regional centers. And so the regional centers work with the families, identify the services that each individual needs, and then they acquire the services that aren't available from other generic resources. Of those that reside in the developmental centers, again approximately 1,800, about 10 percent of them have a diagnosis of autism. In the community, overall about 20 percent of the individuals have a diagnosis of autism, and that diagnosis may also be coupled with other types of diagnosis so that they may not have just one single diagnosis.

Again, at the high level, the people that we serve, about three-quarters of them live in their family's home or live at home, again, with 50 percent of them being children. That makes sense. Of those that don't live at home, we have about 15 percent that live in community-care facilities and about 10 percent live independently.

To focus specifically on individuals with a diagnosis of autism, most of them are children and you heard a lot of that. And I, like Senator Vargas, think back to, you know, when I was younger and growing up—and early, I worked in special education in special ed in the '70s. I remember the three children we saw that had autism. It just wasn't something that was normal. I think back then, many people may have been diagnosed as having mental illness at the time versus having autism, unless it was a real involved autism. About 60 percent of the people in our system with autism today are under 14

years of age. So again, mostly children. About 24 percent are between 14 and 21 and 16 percent are adults, so it gives you a sense of the population of the people that we serve.

Looking back just the last few years, there's an increase of about 10 percent of individuals with autism each year, just looking back the last three years. So we have in 2011 58,146 individuals that were diagnosed with autism that were being served through our system, and that was at any point on the spectrum.

I was also asked to talk a little bit about the services. We provide a whole array of services and, again, it's based on what each individual needs, so the individual services may involve support services for the family; they may involve behavioral services. As I mentioned, so many of them are children. They're in school right now. But they may also involve afterschool-type activities. For those that are adults, they may involve day programs.

Significantly, I think its family support and behavioral support are probably the two highest number of services that we provide overall. I think, when you look at our system, again, as you look at the fact that 60 percent of them are under 14, they're in school. Most of their services during the day are being provided by the school system. As we look going forward, these individuals are starting to age out of the school system and they're aging into adult-service programs. And when I go back again to the '70s and '80s, the services back then when the system was developed, I was looking at people that were born, you know, largely people with Down syndrome and other types

of developmental disabilities that early intervention isn't necessarily going to change the outcome.

With autism, it's very different. We have individuals now with early intervention. They can definitely be very successful and it can definitely change what happens with them. Our system also wasn't prepared for dealing with individuals with autism later in adulthood, especially in terms of their needs. They may need more one-on-one support. They may need more behavioral support than what you might see with somebody, for example, with Down syndrome.

So as we look in our system going forward, we're going to have a significant increase of people coming out of school into adulthood and it's imperative that we look at everything we do today—how can we better support these individuals; how can we look at what type of programming they might need? It may not be sitting in a day program. Oftentimes they may need different types of interventions. Oftentimes, with a little bit of support, they'll be very successful. We've been holding, as you all know, budget, workgroup meetings. It seems perpetual, unfortunately. But we've been holding them again this year and we had a young man at our workgroup meeting in San Diego who is an individual, who himself testified about being an individual with autism. He has his doctorate degree; he drives across the country; he's very successful, very amazing; and he participated in the whole meeting, but he also said sometimes he needs support. And I think there's a whole spectrum and a whole array of the types of supports and activities that are needed, and I

think that's important for us to look at which is different than maybe where the system was back in the '70s and '80s.

Unfortunately, we are facing budget reductions again. I ever so wished it had been the director before me. (Laughter) I ever so wish for those days where we weren't always focused on budget reductions.

**SENATOR STEINBERG:** We can relate.

**MS. DELGADILLO:** I'm sure (laughter). So we're faced this year with, in the budget year, looking at about \$200 million reduction in General Fund and so we've been doing the budget workgroup meetings and trying to identify ways that we might achieve that. And one of the things that we have asked everybody who came to the workgroup meetings to look at was: Are there opportunities to use emerging technology; are there opportunities to do things that have the virtue of providing quality services and at the same time at the virtue of saving money?

We haven't received a lot of ideas yet, although there's been a lot of discussion. We've got two more workgroup meetings, and so this is a very timely hearing for us. So if there are things that maybe can provide us with opportunities—I know I've spoke with Dr. Vismara before, you know, things such as providing maybe training for families, using technology versus having them all come together. I think that's an important thing and oftentimes families can't drive to or get to because of their work schedules and so looking at some of those things. So I think that's a very timely hearing for all of us; and if you have any questions, I'd be happy to try to answer them.

**SENATOR STEINBERG:** Senator Emmerson.

**SENATOR EMMERSON:** Thank you. I would just like to have Mr. Rollens and Ms. Delgadillo comment on the prospect of regional centers using telemedical, telehealth technology in terms of treatment for autism cases.

**MS. DELGADILLO:** Senator, you know, I think there's a lot to be learned here. I can tell you, I visited all regional centers, except to one. I still need to get to the far, far, far north. But one of the things that I really noted when I visited a Southern California center was that they were using technology to do things a little bit different. They weren't going all the way to the telemedicine. But, for example, when the caseworker went out to the home, they could use their computer and they could hook in with people, experts, that were other places that could witness the child in their natural environment and they could identify from witnessing that via telephonically or electronically. I'm IT challenged so I may have the wrong word.

But they could then identify, well, what this person might need. And by seeing that in their natural environment versus taking them to a doctor's office, you may see something very different. And so they were beginning the stages of it. I think there are opportunities to do things. The most important thing is, we've got to make sure we never lose the human touch, which I know you appreciate. We've got to make sure that the services are delivered in a way that they're going to be effective, but I think there are opportunities here. I really do.

**MR. ROLLENS:** Thank you. I think you're going to be hearing from some terrific witnesses after we're done.

**UNIDENTIFIED SPEAKER:** \_\_\_\_\_.

**MR. ROLLENS:** Sure. Well, from my perspective, I think the good news is, the technology is there. I mean, the old days of telehealth of having someone across the screen from you, across the state, moving five minutes after you say something and so forth are long gone, and I've been very personally impressed with what's available out there on the technology side. I think there's a number of areas that hold great promise in the telehealth and technology area, including the family group meetings that are necessary, family work with various intervention issues with crisis intervention—I think many of the medical issues that can be dealt with over this way—and for me, as a parent and as a parent advocate, accessing families right now because of geographical problems and cultural issues and others, to make sure that we get these absolutely critical interventions available to those families as well. I think it holds a lot of promise. Thank you.

**SENATOR STEINBERG:** Senator Leno.

**SENATOR LENO:** Director Delgadillo, I just wanted to go back a little bit to your comments with regard to some of the cuts that you had to endure over the recent years, and I just wanted to be a little more specific about it because I think we're going to have a lot of debate in the coming weeks and months about the state of our social safety net, what it actually means to those who participate in our regional centers, what it means in terms of human impact.

So if you could give us some of the broader numbers and how it translates to a family dealing with an autistic child.

**MS. DELGADILLO:** In terms, Senator, I'll try—in terms of looking back at the budget cuts or looking forward?

**SENATOR LENO:** In recent years.

**MS. DELGADILLO:** In recent years.

**SENATOR LENO:** What's already...

**MS. DELGADILLO:** Yes. I think it's been a rough three years in terms—and throughout state government. It's not unique to us. But I think within our system, it's definitely been the most challenging time, probably since they originally started the system. And there have been reductions that crossed our entire system. The way we've gone about it is we've tried to bring everybody to the table and I think we've spread the cuts across the system. I think we're wrapped up like we have so many Band-Aids, we're like a mummy at this point. We've got a whole bunch of little cuts. And I think that, as a result of that, families are impacted. I think one of the big things, that if you look in the area of autism that had an impact was a change to the early STAR program which is our program for zero to three years of age. And in that program, California served children beyond what the national requirement was. And so we brought babies in that were at risk. They didn't necessarily have a delay or a developmental disability but they were at risk.

**UNIDENTIFIED SPEAKER:** \_\_\_\_\_.



**MS. DELGADILLO:** Back two or three budget cuts ago. I'm sorry, Senator. I don't remember which year. We then reduced it to the federal standard. And I think as a result of that, that there are babies that were at risk that aren't getting the services. They're now being referred to a prevention program. I think that's probably the most direct impact. If you look at the area of autism, I think...

**MR. ROLLENS:** I think, Senator, the other area, of course, is respite. Respite is a very important service that the regional centers provide for families. And God knows, families with kids with autism need respite and that service was also heavily impacted, as all. Again, when you look at these numbers of what our system has, we have more six- and nine-year-olds in the system than we have all the adults currently combined, which means, we've got this tsunami wave of young children moving through the process and we need to get in front of that wave. We need to start developing those programs for the adolescents and adults or we're going to be, in my view, tragically being forced to put folks like my son and others in the most restrictive environments, things like developmental centers and places where we're trying to move in the exact opposite direction.

**SENATOR STEINBERG:** Okay. Senator Alquist had a question.

**SENATOR ELAINE KONTOMINAS ALQUIST:** Thank you for the presentation, and what I'm going to say probably fits nicely into the next segment but I think it also fits into things that you have just said. I just really wanted to mention that I do have legislation that promotes the use of

technology and telehealth systems for the screening diagnosis and evaluation of children with ASD and that it does it in conjunction with establishing an academic institution, collaborating with the regional centers and with one or more school districts, and focusing on providing services also for underserved populations...

**SENATOR STEINBERG:** It's great.

**SENATOR ALQUIST:** ...and that's 1050.

**SENATOR STEINBERG:** What's...

**SENATOR ALQUIST:** SB 1050.

**SENATOR STEINBERG:** SB 1050. Okay. That's great. And part of what we want to hear today is how bills like that can move in ways that are consistent with the best research and the best technology.

So let's move onto the next panel because that's—you know, it's very important we start these hearings with the foundation so that we never forget the challenge and the opportunity. We thank you very, very much. But the specific subject of this hearing is, All right, how do we use technology? How do we use telehealth? What are some of the best applications that are actually working in the community? How can we bring them to scale? We have many questions, more. Come on up.

Let's ask—Tom Nesbitt, unfortunately, had a family issue and is not able to be here, but we have Jana Katz-Bell, MPH, the assistant dean of the Interprofessional Programs at UC Davis School of Medicine and the Betty Irene Moore School of Nursing. Welcome to you.

I'm going to ask the other panelists to come on up as well—Jenise Shin-Lee, the director of the Capitol Autism Services; Doreen Granpeeshel.

**SENATOR STEINBERG:** Doreen Granpeeshel —thank you—the executive director for the Center of Autism and Related Disorders; Patty Schetter from the Autism Education Initiatives at the MIND Institute; and Juan Perez, family participant in Telehealth Services.

The two topics here—we're kind of mixing and matching here but it's all the same subject—current applications of technology in healthcare and autism and recent advances to improve the access and delivery of services—and as you're testifying, if you can please remember that up here our job is to translate all this good information into what we might do in the public policy arena. So if you can tell us how we take your findings and work and what we might do bill-wise, budget-wise within our means and resources, that would be most helpful.

Welcome.

**MS. JANA KATZ-BELL:** Well, thank you so much for the opportunity to speak with you today. UC Davis has been involved in telehealth actually for 20 years this year, and our interest in it stemmed from the same interest of many of the, from the conversation earlier. It really is about addressing the concern about the disparities in healthcare, the greater difference between the have and the have-nots. So as we heard from the previous panel, the explosion in clinical knowledge is happening at a pace that it's very difficult to keep practitioners, educators involved in those conversations and using it for the

people that really need it. And as you can imagine, if you live in an urban center, your access to clinical trials and these interventions is so much greater than if you live in a rural area or an inner-city area without those services. But telecommunications technology, which brings us here today, offers a chance to really reduce those disparities, and I'm pleased very much for the attention that we're giving it today.

So telehealth in the United States really dates back to the 1960s, and the early work that's very interesting came from the Department of Defense and NASA in the need to try and care for the astronauts and the need to avoid a million-dollar ambulance ride, as it's been shared. But that was really changing in the early '90s when we saw a lot of growth, particularly in state programs and academic-based programs, and now telehealth is very prevalent in all states, but I need to recognize the leadership that California has played in this field, both in the deployment of technology and the policy world so I think we should be very proud of our work in this particular area.

There are important examples of telehealth in all sectors of healthcare, acute care, inpatient care, emergency room care, schools, but I wanted to highlight the types of telehealth applications that we're seeing in the most pertinent areas to our hearing today—home care and chronic disease management, and also outpatient care.

Just to pause for a moment, telehealth often refers to the legal framework of a direct patient provider relationship, but there are really important examples of patients and families using email with their providers

and how that satisfaction has really increased, particularly in pediatric practices. So while that's not often included in the umbrella of telehealth, because of broadband and information technology, that's really an important additional application that's creating synergy and partnership between practitioners and families.

Back to telehealth, I wanted to talk a little bit about chronic disease management and the homecare examples, and the VA actually offers some of the best evidence for the impact of chronic disease management in telehealth, and they have actually demonstrated through wide, fairly widespread deployment, tens of thousands of units directly to the home, a decrease in utilization, and important high-cost care elements, such as inpatient days and emergency room visits. So we often turn to the VA for the most important evidence that we have of how to manage chronic disease care differently.

In the outpatient services, which is probably an important topic for us today, there are really two ways of providing care and it was mentioned, the video-conferencing element or real-time telehealth, and that's used in a number of different specialties. We deploy that usually to primary care providers and we use attachments, such as electronic stethoscopes, special cameras, and scopes so that that telehealth encounter can be effective, and that's more of a common experience to what you would experience if you went to see your clinician. You're essentially using video conferencing to talk to an additional provider.

Store-and-forward, or asynchronous telehealth, is a little more of a departure from that real-time experience. In that encounter, the provider with the patient would capture the important clinical information history, information-medication information, capture that in a structured file, electronic file, and then take images, for example—a lesion on your skin or a retinal image—package that file and send it to a provider to take a look at. And as you can imagine, that offers some very important screening opportunities, efficiencies of how we use clinicians, and that’s a growing area in California and in the nation. Nearly all specialties in clinical services have been tried through telehealth. Some are quite prevalent and mental health services is one that has been really widely adopted over the last 15 years. And I think that—I think my panelist colleagues will talk more about the telehealth elements specifically for people of autism spectrum disorder.

I was going to talk about satisfaction in California but I’m happy to...

**SENATOR STEINBERG:** No, that’s fine. If you just, a couple more minutes, that would be great...

**MS. KATZ-BELL:** Absolutely.

**SENATOR STEINBERG:** ...and then we’ll move on.

**MS. KATZ-BELL:** So I wanted to note that the body of literature on satisfaction is very strong. Patients, families, and providers feel very positive about the experience and there’s also a growing body of literature on clinical outcomes, demonstrating that it can be effectively used, and I’m happy to discuss that during the conversation.

California has a strong infrastructure. We have a broadband network that supports healthcare called the California Telehealth Network, and we have a bond that passed in 2006 that provides workforce development for people training to be physicians and clinicians in California so that's a very positive environment in California. So I will certainly close and take any questions.

**SENATOR STEINBERG:** Okay. Well, I mean, the overriding question, I know that I have and I'm sure many of the other members have, is the issue of quality. And just common sense in our own life experience, in most instances, I prefer meeting with somebody to interact important business as opposed to being on a telephone or a video conference. It's not always necessary but it tends to be a more substantive, engaged conversation. And so obviously, as we're talking about all this, we want to, want to have an honest discussion about whether or not there's some sacrifice of quality, which may be acceptable, by the way, given the access issues. I'm not saying it's all or nothing. But until we have the full proof, you know, virtual life or virtual thing where you're not in a room but you feel like you're in a room with somebody, then those questions are always going to arise. So as you're talking, you can focus a little on that too.

**MS. KATZ-BELL:** The satisfaction data again is indicative that patients and providers feel very, very good about this experience. They actually see a coordination often between their primary care provider and other clinicians that they don't often experience in the face-to-face encounter which is an interesting reporting element. They also stay in their home community so their

social network and their family network is very proximate to them which is another advantage that this offers rather than in many cases driving two hours or two-hour bus ride within the inner city. So there's some other elements that are emerging that offer us something to think about, the benefits.

**SENATOR STEINBERG:** Right. That's exactly the kind of thing we need to understand. Very good.

It looks like you've got me. I'm sure members will be back. That's okay. Go ahead.

**MS. JENISE SHIN-LEE:** I feel like I'm going out of order because...

**SENATOR STEINBERG:** Go, go. That's fine. Name and serial number.

**MS. SHIN-LEE:** I'm Shin-Lee. I'm the executive director for Capitol Autism Services in Land Park Academy. We provide applied behavior analysis services, evaluation treatment care, education in both home-based programs and center-based programs in schools. Some of the challenges provided in the in-home programs, as you were alluding to before, that face-to-face contact, some of the challenges in providing that, is that not all caregivers are always present at the home when our professionals are there, whether that's both parents or alternative caregivers. And that direct contact with the professional, in terms of the training and the feedback, is critical to the successful outcomes of the programs for the children. Some of the skills to be taught are problems encountered in the home do not always occur while we're there face to face. There are a shortage of qualified ABA professionals in terms of meeting the needs of all the children diagnosed and especially in the outlying areas. And



the cost of travel and time to reach those more remote locations, you have a professional in a car driving to get there.

So over the last five years, we conducted two telehealth pilot studies, and we're treatment providers. We're educators; we're applied behavior analysts, and our objectives were very practical. We wanted to see based on the research. We just wanted to test the technology and would it work and could we implement our direct-face services in that way, and we wanted to gain feedback from parents in terms of receiving service delivery in that manner.

In brief summary, the children that we did the pilots for and these families had either already received ABA services in their home or they were receiving services concurrently face to face. The pilots ran eight weeks to six months. There were one to two hours of telehealth contact per week. During those sessions, we were able to do what we did in home. We provided direct feedback, we guided intervention and interactions between the parent and their child, and we provided training and all in the areas of the major deficits—communication, self-help, social skills.

With the advances in technology, the most recent pilot we did, we were able to use cost-effective consumer-grade equipment—laptops with built-in or external cameras. The sessions were conducted through a HIPPA-compliance, a secure third-party platform. And both parties simply logged on at the agreed-to or needed time and were able to go into a secure teaching room. The sessions were live and interactive between the family and the child and the professional. They could also be recorded and played back later, at any time,

in secure location so that the session could be reviewed, the recommendations could be reviewed.

We were also able to share documents that enhance the program—lesson plans, acquisition data, behavior-challenged data, training materials, and session notes. The outcomes from the pilot showed that the average parent satisfaction rating, on a scale of 0-5, was 4. This included feedback from the parents that the telehealth sessions were effective, an effective means of maintaining skills learned in parent training or previous services in problem-solving challenging behavior, and receiving effective feedback and guidance from our professionals. Their technical, the parents' technical satisfaction, was 3.75 out of 5. And this measured ease-of-use efficiency in resolving technical difficulties and the effectiveness of receiving services and feedback, we had the technology.

**SENATOR STEINBERG:** Did you do any analysis of cost savings compared to face to face?

**MS. SHIN-LEE:** We did not do an analysis of that. I mean, immediately, what you have removed is the drive time for the professional to get to the home and back or to the home, so I don't have immediate data on that.

**SENATOR STEINBERG:** Okay.

**MS. SHIN-LEE:** From our company's perspective, it's more cost-effective.

**SENATOR STEINBERG:** Just the travel time, or are there other efficiencies that you can describe?

**MS. SHIN-LEE:** I think the travel time—and it's not just travel during the day but it's being able to access different caregivers. Parents, where you have parents working in the home and are not available during the day, we can provide the access to those family members in a more efficient manner at a time of day that works for them, so it's not even sending professionals out twice in a day to see different routines of the child or different challenging times of day but reaching the parents and caregivers across the day and the routines.

**SENATOR STEINBERG:** Right. So it allows the professional to essentially meet with the child and family more than once a day.

**MS. SHIN-LEE:** If needed.

**SENATOR STEINBERG:** If it's an hour session, you can do a half hour at one point in time and a half hour later in the day when there's a different form of interaction that the a provider wants to observe?

**MS. SHIN-LEE:** Yes, whether we need to provide training to a parent or feedback or observe skills that naturally occur at different times of the day, yes.

**SENATOR STEINBERG:** Okay.

**MS. SHIN-LEE:** The children—in the pilots, we tracked the child progress as related to historically their progress in direct face-to-face services. In the skills that we were looking at, the children made similar rates of progress with the skills that we were targeting within the telehealth model, so all participants made gains, similar to their historical gains, in other programs. And I think this in general indicates that parents are able to effectively learn

and implement teaching strategies via the guidance of a professional through telehealth, and all the parents involved gave us feedback that they were very supportive, accepting, and encouraging of this service delivery model.

**SENATOR STEINBERG:** Very good. So again, just go back to the very beginning of your testimony. This was a pilot over what period of time, and how many people?

**MS. SHIN-LEE:** We ran two pilot studies—our first in 2007, our second in 2010. They were not formal research studies. They were definitely pilots. We were looking at how we could implement our services through the technology and how were parents receptive of it. And in the first study, we had five clients and those were clients who had previously received services, either via telehealth or in the home, and they were across the United States. Some families were in Florida; some were in Idaho—and we tracked them for six months. So these were families who had received services, services that stopped and we continued consultation in the areas that the parents indicated they had a high level of need.

**SENATOR STEINBERG:** Are there plans for any future studies?

**MS. SHIN-LEE:** Yes. I think we learned something from each study or each pilot, and so I think the next one, the last pilot we did in 2010, we have a parent here who was involved in that. There's other indicators we'd like to look at and things that we've learned.

**SENATOR STEINBERG:** I just wonder now if you should team up with Dr. Hansen, Dr. Amaral, the MIND Institute to bring the good work that you're doing in the study but bring the scientific...

**MS. SHIN-LEE:** Yes.

**SENATOR STEINBERG:** ...control group process to the whole analysis because, you know, for example, if you could come back to the legislature and say and show that you have virtually equally effective results for children and families at an X reduction in costs, well, then that's something that we could then, you know, do something around the state budget. So this is an example why this kind of hearing is important, and I don't know whether Dr. Amaral, Dr. Hansen, whether you guys have all connected, but come on up for a second.

**MS. SHIN-LEE:** And there is a large body of research that's in the packet showing the outcomes from ABA services via telehealth.

**SENATOR STEINBERG:** Right. But it's not, no control groups.

**MS. SHIN-LEE:** No.

**SENATOR STEINBERG:** It's not scientific. We're science oriented here.

(Laughter)

I want to welcome Senator Liu, by the way. Senator Carol Liu, thanks for being here. Go ahead.

**DR. HANSEN:** Well, we are definitely engaged in trying to push the research in terms of using telehealth, and there happens to be an excellent young investigator whose name is Laurie Vismara at the MIND Institute who is

doing some wonderful work, along with Sally Rogers, using technology for parent training, for ongoing face-to-face intervention over Skype. I mean, it's sort of face to face. So I think we are developing a lot of research to support the use of technology as a very effective way of increasing access and we're also involved with—Patty Schetter is going to talk about a project that we have that's an online parent-training project.

**DR. AMARAL:** I'll just add that—well, first of all, just say that...

**SENATOR STEINBERG:** There we go. It's collaboration. (Laughter)

**UNIDENTIFIED SPEAKER:** We're collaborators.

**DR. AMARAL:** ...that the work that Lorie Vismara is doing with Sally Rogers, I think, is coming to the point where it will be published and has the...

**UNIDENTIFIED SPEAKER:** Is published.

**DR. AMARAL:** Is published. So, yeah, actually the first paper's published but it has shown strong benefit. Now I'm not certain—I don't remember if they have the cost benefit analysis in those papers, but we'd be open to collaborating. We're always open to having people from the community come and...

**SENATOR STEINBERG:** Cost benefit.

**DR. AMARAL:** Yeah.

**SENATOR STEINBERG:** Important. We need to know because we direct the dollars, and we ought to be directing more dollars to telehealth projects than what we're doing now. We can't make that case unless we have the cost

benefit analysis in front of us, or at least we don't make it as effective a case unless we have more definitive research.

**DR. AMARAL:** But I think also you want to make sure that it's doing the job as well compared to what you're saying.

**SENATOR STEINBERG:** That's the benefit side, right.

**DR. AMARAL:** Yeah.

**SENATOR STEINBERG:** Good, very, very good.

Okay. Next.

Before we go on, I want to make sure we recognize Dr. Firestone who's sitting in the front of the room, Barbara Firestone, head of the Health Group here who's here and not testifying today but we all know what she's done in this field and continues to do. So thanks for being here. Good.

Let's go on.

**DR. DOREEN GRANPEESHEH:** Thank you so much. I promise I'll be five minutes.

**SENATOR STEINBERG:** State your name for the record.

**DR. GRANPEESHEH:** Doreen Granpeesheh. I am the founder and CEO of Center for Autism and Related Disorders.

I'm going to hand out some things because this will make things a lot easier.

**SENATOR STEINBERG:** That's great. If you could give it to the sergeant there.

**DR. GRANPEESHEH:** Okay. First of all, thank you very much, Senator Steinberg. We really appreciate everything you've done for autism.

I started in this field in 1978, so I'm a licensed psychologist and a board-certified behavior analyst so I've sort of seen autism go in all different kinds of direction and know pretty much most of the main people involved in this field.

I have a center called CARD, and I have 20 centers in the U.S. and four international and growing, and so I've had to use technology just in order to provide services on an ongoing basis for my patients. I have about 1,200 kids who have autism in our practice. And so if you look at the handouts that I gave, we use telehealth and various forms of technology for everything from remote training of our staff, assessing our children, treatment planning, implementation, and supervision.

On page 3, you'll see that one of the biggest areas for us has been remote training. We also do have a pretty large research department, so we have published on exactly what you mentioned earlier, which is comparing didactic training in class to the remote training and the two came out to be pretty equivalent in terms of efficacy and of course in terms of costs. We've done cost analysis and it is very, very effective for us because the remote training is a web-based e-learning series of modules that include all sorts of tests and all that sort of thing.

You're going ahead of me on the presentation but I'll keep up with you.  
(Laughter)



So the next one is remote assessments which is what you were looking at, and this is a massive technology that's taken us about 16 years to develop and it's web-based as well. It's a series of questions that the parent or the person who knows the child or individual best answers. And once they do, it generates a series of profiles for the child in terms of what skills we actually need to teach the child because I'm sure you know that autism spectrum kids are very different.

The next page, you'll see the publications we've done on that aspect of the technology which has to do with showing that our assessments are valid, age normed, and the results of the assessments, if you go onto the next page, go to Treatment Planning. And when the child can't show a particular skill or the parent says this particular area is lacking, it goes to a series of programs. Our technology has everything from IEP goals; it produces reports, et cetera, et cetera, so it's pretty advanced. And treatment implementation, you can see how the therapists actually can print or teachers because we're in several hundred school districts as well. Teachers can print these, the therapists print these, or actually don't have to but I'll show you in a minute why.

Then the next page is remote supervision because our system generates graphs for supervisors to be able to see the child or individuals progress on a day-by-day basis together with other interventions. This is one of the issues that is very bad. In the field of autism is that we don't consider the effect of behavioral together with medical, dietary, speech, et cetera, and so we're collecting a lot of that data very, very quickly. The data base that's at the back

end of this—we have about 2,000 users right now—is just being federated into the NIH database, the national database. This is a system which we use for our staff, our therapists, and all it is, is a tablet PC and it gives you everything you need for a staff member.

**SENATOR STEINBERG:** Show it to the audience here too.

**DR. GRANPEESHEH:** It has the staff members' appointments on it. It shows the profiles of the children's addresses. It has a GPS system. It has a video where the therapist can actually turn on the video camera and allow the supervisor, wherever they are, to see what's going on, and it has this database in it. So for every patient, our therapist actually goes to their appointments, just hit the child's name, receive the child's program on here, can bring up all of the programming, and hit the data that they're collecting on the child, and that transfers to our data system at our servers, and then all of that is automatically graphed for supervisors to be able to see and monitor.

So just a very quick thing is that this allows us, this, and the use of the video monitoring and the database and all of that—I mean, I have patients in South Africa that we oversee. We have patients in Dubai and Columbia, all over the world. We're right now translating the entire thing into Spanish. And so all of it is incredibly useful. I mean, I can't tell you how much of a benefit it is to be able to use technology.

**SENATOR STEINBERG:** Are there plans to transfer into multiple languages in addition to Spanish?

**DR. GRANPEESHEH:** Yes. But I'm a private organization so we go as whatever we earn...

**SENATOR STEINBERG:** You go as you can.

**DR. GRANPEESHEH:** Yeah.

**SENATOR STEINBERG:** So the other question I have connected to the issue of telehealth itself, do your assessments actually determine and/or make a recommendation whether or not a child or family can benefit or would not benefit from a telehealth approach as opposed to an in-person approach?

**DR. GRANPEESHEH:** No.

**SENATOR STEINBERG:** Okay.

**DR. GRANPEESHEH:** But that's a really great area to look at.

**SENATOR STEINBERG:** Well, what I'm thinking of is how we connect all this, right?

**DR. GRANPEESHEH:** Right.

**SENATOR STEINBERG:** You're doing the assessment, okay, and you're sort of laying—it's like an IEP; you're laying out a...

**DR. GRANPEESHEH:** Right, and the programs, all the curricula.

**SENATOR STEINBERG:** You're laying out a plan for the family...

**DR. GRANPEESHEH:** Correct.

**SENATOR STEINBERG:** ...and the child. Okay. And then that plan gets implemented. And here we've got, you know, the technology, which is hopeful and provides more cost-effective options. We need to make sure they're equally effective and they may be effective for some kids in some families and

not so effective for other kids and other families. Is there an assessment tool that helps to decide well, geez, you know, this child, the telehealth approach, is not going to work here for the following reasons?

**MS. GRANPEESHEH:** Right.

**SENATOR STEINBERG:** Need to know that. Okay?

**MS. GRANPEESHEH:** Thank you.

**SENATOR STEINBERG:** Thank you. Terrific.

Next.

**MS. PATTY SCHEPPER:** Hi. I'm Patty Schetter. I'm the coordinator of Autism Education Initiatives for the Center of Excellence in Developmental Disabilities at the MIND Institute.

Thank you very much for the opportunity to come provide you information about some of the projects that we're doing at the CEDD related to the use of technology. The one that I wanted to highlight today and share with you is a project that actually has been in development for several years. It started out of a telehealth initiative. Back in around 2005, where we were interested in basically looking at how technology could be used for community outreach and education and specifically how we could use technology to address parent training, we started out with an initial survey that was sent throughout California asking families, first off, their interest in using technology to receive parent training and information. And the response was really quite overwhelming.

We got responses from more than 500 families in the Northern California region, indicating they would be interested in using technology to receive basic parent training information. While a lot of the families had a primary interest in receiving face to face, many of them expressed an interest in using solely technology. Most of them expressed an interest in using some kind of a combination format. So that was usable information for us as we went forward in starting to develop the parent training modules.

**SENATOR STEINBERG:** Excuse me. Did you run—have you run into the digital-divide challenge with families of limited means who don't have a home computer?

**MS. SCHETTER:** Also a question that we asked. We convened the survey both electronically as well as in paper format and did it in both English and in Spanish to try to reach a broader audience, to see what kind of interest we would see. And there was an issue of accessibility to the computer. So when I start to talk a little about how we went about developing the parent training modules, we decided that the first go round, we would not only make it accessible through the internet but also through DVDs that could be widely distributed, to make it a little bit more broadly accessible.

The surveys also gave us some valuable information about the top areas that families needed information and training in. Obviously the three core areas of impact in autism were high on their list of priorities. They wanted to learn about how to manage behavior; they wanted to learn about how to teach their children basic skills; and they wanted to learn how to support

communication and social interactions; the fourth was the area of navigating complex social or complex systems within the state of California. We developed a curriculum initially...

**SENATOR STEINBERG:** I'd like to see that training. Whoa.

**MS. SCHETTER:** We didn't touch that one. (Laughter) The one that we did address initially was developing a training module on teaching skills. We know parent training is in evidence at base practice, and we know that there are multiple evidence at base practices that can be encompassed in a curriculum to help families learn how to teach some basic skills to their children. So we piloted first a face-to-face model to gather some data on the effectiveness of the curriculum and then developed it into an on-line or web-based module.

You were asking about cost and about outcome data and those sorts of things. In our pilot, we saw an equal level of effectiveness through web-based as well as face-to-face formats in the area of both information acquisition as well as the parents' perceived level of confidence, and I think that's a really important aspect of parent training, is making sure that the families leave the experience feeling more confident and comfortable in their ability to work with their children, so that was a measure that we did see increase in both formats.

The other component that we learned is, How do you go about and what is the cost of developing these modules? And in our first two pilots, the first two modules that we developed, the estimated cost of developing each module is between \$15,000 to \$20,000 to be able to do the development. But then

once it's developed, it's accessible and it's delivered cost free to anyone who has access to the internet.

The actual development of web-based training, we wanted it to be accessible, user friendly, and not passive in nature. We know that learning occurs best using technology when the interface is very interactive. So we added that element to the modules that we've developed where parents can not only hear the information but interact with different activities on the computer as well as print out different offline activities to do with their children, and the feedback on that interactive component is really valuable.

**SENATOR EMMERSON:** I'm going to interrupt you for one second. There's a question that the doctor has for you.

**SENATOR VARGAS:** No. You go ahead, please.

**SENATOR EMMERSON:** Okay.

**MS. SCHETTER:** I just wanted to end by saying that, you know, we have this available now and it has been available, this first module on teaching adaptive skills, for 14 months. And the response, I think, speaks for itself. We've had over 7,700 hits to the modules since its inception. That's the English language version. We also have a Spanish language version that was launched a few months later that's received over 2,000 hits. This isn't taking into account anyone who's accessed it, via the DVDs, that we distributed throughout the state, to the family resource centers, regional centers, and school districts. And I did want to share just a couple of brief stories about how this has been used and how it's been impacting and touching families.

I recently made a trip up to the Lake Tahoe Basin and was there doing some support and work with the school district and met a young man, age five—his name is Marcos. He has autism and he's been on a wait list for parent training for 18 months. So Marcos's family didn't know about this resource and we were able to share it with them. So 18 months of not knowing how to support Marcos's behavior in the home, how to take him out in the community, how to work with him on basic self-care skills, they now have access to some basic information to be able to start their path and their journey.

Another one is this need for and this desire for many to have a combination kind of a model. They want to use technology but they also want to have some connectedness. And a couple of the pilots we've been doing are providing this curriculum and helping school districts and family resource centers who are in more rural areas, use it as the curriculum where they bring families together in a group format, show them the modules, use the modules as the curriculum for supporting the families but then, because they're local and an ongoing support to these families throughout that child's educational career could be there as a continued support to provide them with individualized feedback and guidance as needed.

**SENATOR EMMERSON:** Thank you. There is a question. I apologize for interrupting earlier. The doctor has a question for you.

**LOUIS A. VISMARA, M.D.:** Yeah, thanks.



I'm just wondering if you have any thoughts about aggregate costs and the utilization with telehealth and what you think utilization will spike up will the costs be more efficient based on that model or do you have any thoughts about that?

**MS. SCHETTER:** Well, it seems to me, at least in the first two modules we've developed, the cost of developing them is fixed. It's a one-time cost to develop the curriculum and potentially to update it as new practices and things emerge. But, you know, once the outlay of developing the modules is there, that cost is fixed and then it can be distributed, you know, as widely as we can reach.

**DR. VISMARA:** But that would keep costs down, you feel...

**MS. SCHETTER:** Absolutely.

**DR. VISMARA:** ...on that? Okay.

**MS. SCHETTER:** And not only that, but I think it would free up other more specialized providers, like the two ladies sitting next to me, to be able to do the individualized services that are kind of that next level of support. If we allow and free up the vendor providers of the regional center to do that more individualized support, free up the parent training aspect of that, then I think we'll be able to get better use of our trained professionals.

**DR. VISMARA:** Good. Thanks very much.

**SENATOR VARGAS:** Any other questions? I do have a question. Obviously, I should say, it did catch my attention, the 7,700 hits in English,

and then you said the Spanish module was a little bit later, a few months later, and there was 2,000 hits.

Can you comment a little bit on the Spanish language modules, if you would, just to expand on that?

**MS. SCHETTER:** Yeah, we went to, I think, kind of an extra link in developing the Spanish language module in that we didn't do a direct translation. We actually had the curriculum adapted by a board-certified behavior analyst who is, is culturally and linguistically aware of and familiar with the Spanish language. So the translation was more than just the language translation. There was a lot of content that needed to be shaved and developed, so it took us longer to do that aspect of the development of that particular module. The dissemination took place later—and again, we have data on the number of web hits. We do not have data knowing the number of people who have accessed the Spanish-language version via the DVD which we specifically really developed for that population knowing that that might have broader use.

**SENATOR VARGAS:** Thank you. I appreciate that.

Okay. Any other questions?

We'll go to the next witness. We welcome you. Please do give us your testimony.

**MR. JUAN PEREZ:** Yeah, hi. Thank you very much for having this hearing. And I'm one of the parents that they've been speaking about using the telehealth. My name is Juan Perez. I live in Folsom. I'm an electrical engineer

with Intel so I may not be the typical parent that use the telehealth (laughter), so I have a lot of computers at home.

So I have two boys that I mentioned; they're in the spectrum of autism. My oldest boy, his name is Juan Carlos, and he's ten years of age and he was diagnosed with PDD, and my second—and he's verbal and he's made a lot of progress, thanks to, in part, of the Capital Autism Services via Alta Regional Center, and the school and everybody else pitching in. I have a younger son. His name is Diego and he's eight and he's nonverbal, so it's a lot more challenging providing services for Diego and caring for him.

As you can imagine, as a parent of two kids with autism, it's quite challenging for my wife and I and it's actually harder for me because I'm not there during the day when a lot of the therapy was going on. So actually having the telehealth, at least in my case, actually helped quite a bit to get me back into the game of basically helping my kids and my wife.

Two ways that it did that simply was by flexibility of being able to meet when it was convenient for me over when it was—you know, if I'm traveling a lot, I will say we'll connect with the therapist and actually troubleshoot some of the issues that I was having with the kids and try to understand how to best help them. For example, I was doing—they had a PEC system, because he's nonverbal, the use of the PEC system to communicate needs and help. And so, you know, not being in the everyday sessions with the in-home folks and my wife, I was doing the PEC system incorrectly. Okay. So the therapist—her name is Xena—was able to see what I was doing and say, okay, first of all,

that's incorrect. And the right approach—and she visually showed me, this is what you need to do and here the best, you know, do the procedure. That saved a lot of time. Otherwise, it would have taken me about two weeks later to find out I was doing it all wrong where I was able to troubleshoot the issue right there and then.

I mean, it helped in that sense to—it made it very flexible for me, and it also helped in the sense of being engaged in helping and understanding what my wife is going through and as part of the in-home program. It's still no substitute, in my opinion, for face to face. Obviously that would be better because you really get into a lot more discussions and hands on, and you can't substitute that just looking at a video screen. But in my case, it helped me in those two areas where I was able to, you know, connect back with my wife and understand what she was going through and be able to help.

She's learning English, primarily Spanish, so the therapist, the in-home people are all English and there was a challenge there. So me coming after work and asking her, so how did it go, was not exactly the best communication there. So having the telehealth actually helped me to expand and ask questions and have better knowledge based on what was going on. And the telehealth pilot went for, excuse me, about four to six months, and this was at the tail end of the services that was being provided by the in-home program. So I was pretty happy with it. And actually that led into me using the iPad and other tools to also help both of my kids.

So I'll take any questions if you have any.

**SENATOR VARGAS:** Any questions?

I do have a couple of questions. You said at the beginning of your testimony you're not the typical person because obviously you're with Intel and you're really savvy with technology.

**MR. PEREZ:** Right.

**SENATOR VARGAS:** How simple is it to use the system for someone that's not savvy with technology, in your opinion?

**MR. PEREZ:** The biggest challenge initially was just to make the proper connection, and it had to do with just the setup. So if it had been my wife trying to figure out what the setup was, I think she would struggle a little bit. But within like minutes, we got a resource on the phone and it was just a couple of clicks away and it was done. So for me, it was really, really simple. For my wife, it would have been a little bit more challenging. But, you know, it was overall very simple to use and worked within the program itself to share information back and forth—documents, video, hands on. I mean, for me, it was quite simple.

**SENATOR VARGAS:** You also mentioned a language issue.

**MR. PEREZ:** Right.

**SENATOR VARGAS:** Now since it is now for—let's assume somebody doesn't have the language ability or the technology ability that you have. Since you are from the tech world, how difficult is it then for a person that doesn't have both the language ability in English and—I mean, I guess I'm trying to get

to—I know there’s a whole group of people out there, probably going to be hard to reach because of language issues and technology issues.

**MR. PEREZ:** I think probably the language will be a challenge. But, you know, I think that effective training and people or bilingual can certainly help there. In terms of the technology part, I mean, things are getting a lot easier. In fact, if we implement some of the same features that you find in an iPad, for example, my grandmother can use that. It’s not very complicated. It is actually quite simple. Once you remove that element of, Well, how do I use it?, you just touch it or just click here and it just instantly comes on and you can see the person real time. You forget about that you’re actually using the technology. You’re just talking to that person. So I don’t think that will be...

**SENATOR VARGAS:** It’s the setup more than anything.

**MR. PEREZ:** Once you eliminate the setup, it’s easy, quite simple.

**SENATOR VARGAS:** Other questions? Seeing none, thank you very much for your testimony. I appreciate it. Any questions you have from us? Seeing none, okay. Thank you very much. Appreciate it.

Yeah, I’m one of those people, your grandmother, that would have a very difficult time. That’s why (laughter) I asked. I still can’t Skype.

Okay. We’re going to go ahead and bring up the next panel. If the next panel could please come up.

I believe you’re Panel Number—this is Public Policy, Legislation, & Future Implementation Strategies.

We welcome you. Please give your name for the record and give your testimony. We welcome you here. Go ahead, sir.

**MR. MARIO GUTIERREZ:** (Inaudible Comments)...go by funding from the California Healthcare Foundation to look exclusively at issues of barriers and development of solutions in the world of telehealth. We have been, as I said, in operation for three years, and one of the first things that we did was to look at the current legislation that's in place. It was passed in 1996, the first Telemedicine Act, and convened a group of experts from around the country to make recommendations for what would be a considered a model statute, looking at all aspects of healthcare delivery, of reimbursement of workforce, for practice; and from that, we produced a report, which was called the Model Statute Report for Telehealth. Last year, the State Rural Health Association sponsored a bill, AB 415. Assemblymember Logue carried that bill and had cosponsors from both sides and was signed into law this year.

This bill was landmark legislation for a number of reasons.

One is, it changed the whole definition of telehealth from telemedicine as a way of delivering care to a clear description of all the aspects of what telehealth is. So number one, it's as a tool that can be used for appropriate delivery of healthcare in the context of, as was described earlier in real-time video but also now defined to include asynchronous and store-and-forward which increases the efficiency and the cost of delivering of telehealth. And third, the fastest growing area of telehealth is remote patient monitoring and the aspects of how, as you heard before, devices and being able to monitor

people in their home and long-term-care facilities or other kinds of places. So that, plus changing the definition of who can provide telehealth services, AB 415 expanded that definition to include all licensed providers and remove some outdated barriers that were created within the Medi-Cal administration that required, for example, written consent for every single telehealth encounter. That has now been removed. It only requires oral consent and the fact that you have the document, a barrier, of in-person consultation before you can actually provide telehealth. So in essence, it streamlined a law and expanded the who can provide it and it really created the potential for the full use of telehealth.

Telehealth for us, I think, is one of those, without question, increases access and quality of care and services in the medical field. But beyond that, what's less understood, is how telehealth helps to achieve what's considered a triple aim that the federal government has defined for healthcare reform, that is, it improves the quality of the healthcare experience. Secondly, it improves the cost of care on a per-capita basis, and it also includes the efficiency of care so that the care is provided at a much earlier time so that it's much more cost-effective with prevention and early intervention. These were all aspects of telehealth. They have great potential that we have yet to see the impact of.

Questions that had been—Senator Steinberg raised questions about cost. Well, we just recently published a study which was made available to a committee that was conducted by the Blue Sky Consulting Group that looked at all aspects of telehealth to identify where there could be real concrete cost



savings and scanning the field of all the studies that had been done, and to determine, that in the area of, just in the area of, diabetes care and heart-failure care, with remote patient monitor, telehealth could save the state \$1.3 billion a year. And that's just in those two specialties. So I think that the evidence is there that telehealth is not only a tool that can improve quality but also really get to the hardcore issues of saving on cost.

The issue of in-person care and the loss of the touch factor, I think, is something that we're always going to be challenged with. I think that telehealth is the tool that enhances the ability of our primary-care provider who is always with a patient to be able to consult with a specialist when the specialist is no longer available or to provide the linkages between the specialist and that patient in their home, in the delivery of remote patient monitoring.

In store-and-forward, it's not an issue of touch in the sense that what you're doing is really providing efficiencies for a provider to be able to review dozens and dozens of files with video clips, with X-rays, with all the information, and to provide consultation to avoid unnecessary travel and unnecessary cost.

So just to summarize, I think what I want to provide to the committee is a resource, that we would look at very specific issues related to telehealth in the delivery of care to children with a spectrum of autism, and to help address those issues of policy. And with that, I'll turn it over to my colleague, Jenny Kattlove.

**SENATOR VARGAS:** Welcome you, welcome. State your name again for the record and give your testimony. Welcome.

**MS. JENNY KATTLOVE:** Hi. My name is Jenny Kattlove, and I am with The Children's Partnership. The Children's Partnership is a nonprofit California-based national research and advocacy organization working to assure that, working to ensure that all children, especially those at risk of being left behind, have the resources and opportunities they need to grow up healthy and lead productive lives. We do our work through research, policy development, and advocacy. One of the issues we work on is ensuring that we see the real benefits of technology, improving the lives of children through, both in improving their health and increasing access to social services, and that is why we play a significant role in the health-information technology conversations and in technology in general. What I'm going to talk about briefly is I'm going to dovetail a little bit, echo a little bit, of what some folks have already said about the benefits of telehealth and then talk about future policy direction, where we need to go.

I think there has been a lot of great conversation and comments about the advantages of telehealth to meet the needs of children and adults with autism spectrum disorders. I want to just sort of echo the need of underserved children, children who live in rural and underserved areas in the urban, in urban areas of California. Low-income children, they face geographic and economic barriers to accessing care. One of the barriers that I think is we're talking about here is specialists. A lot of specialists, pediatric subspecialists,

reside and practice in urban areas, and that makes a lot of sense. We don't need a pediatric cardiologist in a rural area when there's only one or two patients there. So telehealth really helps those families get the care that they need.

Back to the need, underserved families have more difficulty accessing care—transportation costs, the cost of missing school and work. Low-income workers often miss pay when they miss work. Some of us who are salaried have sick leave. A lot of low-income workers don't and their children and family suffer and they, you know, can't afford the transportation, so being able to bring care to where they are makes a lot of sense.

The other thing I want to emphasize is the benefits of telehealth. Earlier in this hearing, we heard about the comorbidities that children with autism spectrum disorders oftentimes have behavior health issues, have gastrointestinal issues. They may have neurological issues. We heard about seizures. Those pediatric subspecialists again are in urban areas often and we need access to those providers. And because these children are receiving so many services, that the benefits of being able to stay in their community and stay where they are is—that's just an additional benefit because they won't have to travel as much. If a child has to see four or five doctors a month, to have to travel to that is quite a burden for that family.

Then the last thing I wanted to say about that was, because children with autism spectrum disorders have issues around, it makes more sense for a number of reasons for these children to stay where they are. There's a lot of—

they have some issues with transition to different areas, to being transported to the doctor. There was a program that's no longer running in Akron, Ohio, that worked in schools that served children with developmental disabilities. A lot of these children had autism spectrum disorders and other developmental disabilities, and they used telehealth for the acute care. So when a child had a cold or when a child had a sore throat or an ear infection, that this saved this child from the transportation. Many of these kids needed an aide, so having an aide transport with this child, so keeping the child where they are in the school. So again, my point was really just to kind of dovetail on what other folks were saying about telehealth and the benefits.

What I want to conclude with is where we need to go policy-wise. In 1996, we had the Telemedicine Development Act of 1996, and that was a huge seminal piece of legislation that led the nation in telemedicine. Then AB 415 this year was enacted, and that's just another step in where California can be a leader.

There are a few more things we can do to make California a leader in telehealth and making sure that Californians get the care they need using the advances of technology. And this is sort of a difficult one to say but, you know, we do need money (laughter) and it's hard to say, especially, you know, right now, when budget negotiations are happening. But what AB 415 did was allowed for so many things to happen, changed policy so that we had the platform for using telehealth for various modalities but those modalities need to be paid for. Right now, Medi-Cal pays for video conferencing, for a patient

and a provider to meet via video conferencing. It also pays for three store-and-forward applications where data are collected at one site and reviewed later for a diagnosis and/or for evaluation and treatment recommendations. Those are its teleoptometry, teleophthamology, and dermatology. However, it's been clinically proven that other forms of store-and-forward are clinically proven to improve care—teledentistry, telecardiology. Therefore, so with the change in the terminology from telemedicine to telehealth, we need to have the finances follow that, and so we need reimbursement for all store-and-forward applications.

We also need to—and this is probably a longer conversation—but we also really need to look at how we're transforming our healthcare system using technology and start to pay for outcomes rather than for individual services. And let's say it makes sense to use email and it makes sense to do a teledermatology visit. Let's look at not just paying for how those services are provided, but let's look at outcomes using those technologies so that we're not constantly looking to pay for certain services but we're looking for overall health, and I think that we can reduce costs in the long run.

Finally, and this has been emphasized already a lot in this hearing, is we really need to invest in pilots and really need to demonstrate how telehealth can improve the lives of children and adults with autism spectrum disorders. We really need to use public/private partnerships to do that. I think Senator Alquist and Senator Steinberg's legislation, SB 764 and SB 1040, are great first

steps and I think we should all be supportive so that we can demonstrate how these work to improve the lives of Californians in cost-effective ways.

**SENATOR VARGAS:** Than you. I have a number of questions, if you don't mind.

I couldn't help but think of Mr. Perez who was up here just before you and said, you know, the ability to hook up at the beginning, that's sort of the complicated part. I was thinking, he's so talented in high tech. What if the poor person that you described doesn't have, one, that ability, and second, doesn't have the machine? I mean...

**MS. KATTLOVE:** Yeah.

**SENATOR VARGAS:** ...you know, I think of myself. You know, I still can't Skype, and I think the reason for that is because I have old technology, and my daughter has the newest stuff and she just pushes a button and it seems like it all happens.

**MS. KATTLOVE:** So it's a huge issue. This is a very complicated, complex issue. And another area that the children's partnership focuses on is increasing access to technology for underserved communities, an initiative that we started, that we spearheaded a few years ago and it sort of spun off into itself, is we are a project called School2Home whose ultimate goal is to ensure...

**SENATOR VARGAS:** I'm sorry. What's it called again?

**MS. KATTLOVE:** It's called School2Home. And if you want to look it up, it's School with the number 2 and Home. And the goal of that project is to

ensure that all children and families who attend underperforming middle schools go home with a computing device and the skills to use them as well as access to broadband, affordable access to broadband, so the program is being beta tested in a middle school in Los Angeles and in a middle school in Riverside County and we can talk a little bit more about that later if—you know, we would love to talk more about that.

So the point is, you raise a huge issue. It's not totally resolved. I think Mario can talk about some of the resources.

**MR. GUTIERREZ:** We do have in California the largest single grant in the country for the creation of the technical support and access to broadband with the California Telehealth Network and receiving funds from the FCC to be able to provide subsidized access to high-speed broadband for all kinds of healthcare facilities and health systems. In addition, we also received a grant from the federal government for improving—it's called BTOP grant which is about the sustainability of broadband and other applications beyond just the usual forms of it, to think real creatively as to how we can make broadband access to people and all over the state. We have 15 demonstration projects that are in place, that are pilots, that we're providing technical assistance and support to people on the ground, grassroots support, that hopefully will be, you know, taking to scale.

**SENATOR VARGAS:** I guess, to follow up with this question—as you were explaining this, I thought, you know, in the case of my own family, we didn't speak—at home, we spoke Spanish. My parents didn't speak English.

We were the translators. We were the ones that were able to take the information, whether it was medical information, dental information, and translate it to them so they could understand it in Spanish growing up.

Now in the case of autism spectrum disorder, you know, a family that's challenged with language, in that context, how would you bring that information to that family?

**MS. KATTLOVE:** So there's—I think the great thing about your questions is that with technology, we can use our imagination and probably identify a solution for everything. So the use of technology for translation services is widely used and can—and it's actually very cost-effective. So instead of—so let me give you an example of a hospital-based system, and then we can probably translate that to like a home based. But it used to be—and it still is—that if a hospital—if there was a non-English speaking patient, an in-person translator would go to that doctor's appointment with them. It's oftentimes, families do and children do that which is not the best use of children. It's fairly inappropriate.

Now you can actually pool translators into one room, right here, and we can be doing translations to hospitals all over the country. And you can do that either by phone, video phone, or telephone, or you can do that by video conferencing. Oftentimes, video conferencing is better because you can help with that cultural piece, in the cultural sensitivity piece. So you can bring that kind of service to a home-based service. There's also other programs that do translation.



**MR. GUTIERREZ:** I was going to also mention that using your imagination and the advantage of the technology allows us to really eliminate the border as a barrier, and the University of California's School of Medicine has now entered into a partnership with the state of Sinaloa, Mexico, to look at issues around research around telehealth and healthcare delivery systems so that we're really bringing the communities closer together where you have psychiatrists and psychologists and specialists in Mexico who would be available to provide that consultation through the telehealth technology, so that's just one area where we can really bring our families closer together.

**SENATOR VARGAS:** Thank you.

Okay. Seeing no more questions, thank you very much for your comments and the information provided today, appreciate it.

**MR. GUTIERREZ:** Great. Thank you.

**MS. KATTLOVE:** Thank you.

**SENATOR VARGAS:** Yes, of course. Before you go, we do have some comments?

**DR. VISMARA:** Thank you again. I think it's very compelling testimony. Senator, your questions are very insightful. I've been working in the area of autism for about 16, 17 years. It just occurred to me that I have never encountered a situation where the promotora model has been used in the evaluation and treatment of autism and yet we know it's very effective in the communities. I think that from the comments and the discussion, it would be a great opportunity using technology to integrate the promotora model with

technology, with the curriculum and training, that that could be implemented and to again overcome those barriers and provide that access to underserved communities.

**SENATOR VARGAS:** Good point.

**MR. GUTIERREZ:** If I may also, we have seen the promotoras in traditional healthcare systems in rural farm working communities with PDAs being able to go out into the fields and provide that service and bring that technology right to the family and to the community, so it's already happening in that aspect.

**MS. KATTLOVE:** And the one thing about telehealth is that we have to remember, it's not just the patient connecting to a provider far away. It's the primary care provider or somebody or a teacher or a school psychologist who is there with the patient, who the patient is comfortable with, connecting to somewhere outside. So that's a great role for a promotora.

**SENATOR VARGAS:** Thank you.

**MR. GUTIERREZ:** Thank you.

**DR. VISMARA:** Thank you very much.

**SENATOR VARGAS:** Thank you very much. Appreciate it.

Okay. We're going to go now to the next section which is public comment. I know that some people have already signed up to speak. I'm going to call your name and please feel free to come up and give your testimony. If I mispronounce your name, I apologize.

Cornee Lapin? Connie—I apologize—Connie Lapin—and Lisa Britton?

If anyone else would like to speak after that, we'd be happy to hear from you.

Go ahead and start and give your name and give your testimony.

**MS. CONNIE LAPIN:** My name is Connie Lapin, and I want to thank you so much for having this hearing and giving attention and power to a potentially innovative solution that can help in these challenging times. I know the word we're not supposed to ever use in this room anymore is *money*, and that's what makes it so challenging.

As I said, my name is Connie Lapin. I'm the mother of a son with severe autism and he next month will be 44. So I don't call myself the older parent anymore. I call myself now an historian. But I want to say that we were here. Our family was here before there was any mandated services and actually autism was legally excluded. So why am I here? You know, why am I still here? Because our family experienced the birth and the growth of a system that met the needs of people with autism. And now, unfortunately, because of the economy and the fiscal restraints, I'm seeing all our service delivery systems become extremely fragile and fiscally challenged. So I want a solution that makes sense and improve the needs of our children. And like other people have said, with positive outcomes and not forgetting the human touch, I love this hearing because they said it, a lot of the speakers said it so eloquently about the complexity of autism. There is no cure but absolute great success can happen with early intervention and positive treatment.

I love the idea that we talked about the comorbidity of the disease or the symptom or the syndrome because the medical issues are very often left on the side, and a lot of us in the autism world say, if you've met one person with autism, you've met one person with autism—very unique disability. And thank you so much. I've never heard so much at a hearing like this, talking about the underserved. It needs to be talked about—language problems and ethnic minorities and lots of stuff.

I want a solution and I think that I see potential here and I want to thank all of you, and especially Senator Steinberg, for putting autism out there when things are rough. The Blue Ribbon Commission, the taskforce—we even had a housing bill and then, my God, the celebration for the autism insurance. I wanted my son to become young again. I mean, if I can figure out how to do that.

So I'm the optimist and we know that Apple was successful in a downturn, so why can't we be the next Apple? So I want to tell you all and everybody in this room, *carpe diem*, seize the day, and I hope I last long enough to be here next year and the years after and say, look what we did, so thank you very much.

**SENATOR VARGAS:** Thank you. Thank you for being here. Appreciate it.

Okay. We're going to go to the next person.

Go ahead and give your name and testimony. Welcome to you.

**DR. LISA BRITTON:** Thank you. My name is Dr. Lisa Britton and I'm the vice-president of Clinical Services and Integrity Assurance for Spectrum Center Schools. We provide educational services for students with autism, and state superintendents and a member of the Senate Select Committee have toured our sites previously. We've had the opportunity to utilize telehealth systems to improve the quality of our services and to provide training to our staff with great success. There is some research out there that indicates that telehealth systems can be used to provide quality services to children and training to parents. This research is coming out of the University of Iowa and they've shown great success and with a reduction in costs for those services compared to in-person services.

Our students at Spectrum Center sponsored a bill that became law that calls for more technology in the classrooms, and our students feel like there needs to be greater dialog in this area. And because of this, we're really thankful for Senator Steinberg in really taking leadership on this issue. Thank you.

**MS. LYNN FRAMPTON:** Hello. My name's Lynn Framptom. I'm a medical case manager for a large agency here in Sacramento that provides support to adults with developmental disabilities, and autism in that category. We provide supportive living services, ILS services, both services.

We want you to know that the crossroads of technology and health services, it's already happening. You're way behind. It's already happening. It's going to continue to happen; it's going to expand regardless of the

committee's paradigm, and it's driven by how ethical it is and how pragmatic it is. The agency I work for supports a lot of people with developmental disabilities that are also deaf, and the deaf are on the technology curb, way ahead of the rest of us hearing folks. They have every gadget and they know exactly how to use it. They have video relay in their homes, and my staff and my patients have provided me with this, where it goes everywhere that I go. It's just an iPad2 and I can talk to them in their homes, on the video. Really, I can do triage out in the field. Somebody can call me and ask me, you know, should we go to ER; should we just make an appointment with a doctor? They can send me pictures of things; they can take vitals for me. I can keep people out of the emergency room, which is when you don't know what to do. That's kind of where people tend to pile up. That's just going to continue to happen. And like I said, it happens because it's pragmatic. If you work with somebody, if you know anybody with autism, they like their schedules and routines maintained. They don't like going to the doctor's office or the really noisy, smelly ER. They're not really cooperative with things that are out of the ordinary for them. And so this is a way for them to talk to me. They like two dimensional communication better than three dimensional. It just works on a lot of aspects.

One of the things that I urge the committee to consider, this is going to continue to grow and expand. Let's use what we have already. Let's use the internet; let's use the iPad. It's \$600. If I wanted to buy an augmented communication device from DynaVox for somebody, it's \$15,000 and it's going

to be a dinosaur in five years. If this breaks down, I go to the Apple store and I tell them to fix it. If there's a new app, they load it up. Let's just be really pragmatic about this. Let's not create a whole boutique communication system. Let's use what we already have. Thank you.

**SENATOR STEINBERG:** Thank you very much.

Please.

**MR. JIM LANTRY:** Thank you. I am Jim Lantry with the DIR Floortime Coalition of California.

And Senator Steinberg, I know you didn't want any more praise for what you did last year.

**SENATOR STEINBERG:** No, please.

**MR. LANTRY:** But all I've got to say is, wow, and I'm not talking about last year because this hearing has been great. The idea of using technology for remote treatment and assessments is amazing.

In San Diego, the San Diego Regional Center has done some experiments, particularly with going out into Imperial Valley, into Senator Vargas's district, where we just can't get people to, you know, train people out there to service a need. It is a very real need throughout the eastern portion of the state, and I applaud you for what you're trying to do.

One thing I will add is that, as it was said before by Connie Lapin, you know, when a child with autism is just one child with autism, we need to expand this to all the evidence-based practices and I believe that's what we're doing. If you look at Floortime, there are experiments going through right now

about delivering some services remotely, particularly assessment and parent training. I think RDI is the same. ABA is also doing it. I think that all in all, we are forming a delivery model that is going to be much more cost-effective and I applaud this committee for exploring this, and we stand ready to help in any way we can. Thank you.

**SENATOR STEINBERG:** Thank you so much for testifying. We appreciate it.

Is there any other public testimony? That's it.

Senator Vargas, any thoughts, closing comments?

**SENATOR VARGAS:** Yes. First of all, again, I praise you, thank you again for putting on this hearing. I appreciate it and the work we did last work.

One of the things that did come out in the testimony to me, and I appreciate the speaker—one of the speakers at the end that noticed this was the underserved and people with language issues and how do we reach those individuals and their families, and I think that that is a great need. Again, I appreciate that it was brought up here today and see how we can work together to help those people. I think in particular, we want to make sure that everyone is helped, that no one's left behind. It seems like they might be some of the more difficult people to help because of language issues and poverty and some of their living arrangements where they are rural or hard-to-reach areas, so I appreciate that very much. Thank you. Thank you.



**SENATOR STEINBERG:** Well, thank you very much, Senator. I appreciate your being here today and your interest on the issue. I also want to thank the other members, as well as Lou Vismara again, for putting together a very thorough hearing—the advocates and the members of the public. You know, just, again, the attendance here today, both in the audience and among the membership for an informational hearing, I think speaks volumes about the levels of interest here. So again, I put out this challenge: How do we take what we heard today and translate it into public policy that helps further these opportunities? Do you use technology appropriately to serve more children and more families?

There are certainly some research imperatives here I think that we heard about today, and there is some marketing and communication imperatives when it comes to some basic research, like the impact on vitamins, on reducing incidents of autism. And then how do we take the best practices here, and how do we make sure that we use our existing funding to expand it? So I'm looking forward to the rest of the year. I don't know that we can and will replicate 946 this year but certainly there's a lot of work to do.

I know we have a hearing again in March...

**UNIDENTIFIED SPEAKER:** March 28.

**SENATOR STEINBERG:** ...if I'm not mistaken—March 28<sup>th</sup>—where we're going to look at the issues of diversity, diversity and equity, when it comes to the workforce and also when it comes to the providing of the services themselves. So let's just keep going here—all right?—until we have achieved

our big goals here, which is to make this disorder a top-tier public health priority, to have the funding, the attention that it needs and deserves, and make sure that every family has what they need to help their child. That's what it's about, so thank you.

Nothing further to come before the committee, we'll be adjourned.

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