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"

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State Capitol

ABBREVIATED AND EDITED TRANSCIPT OF THE HEARING

The following document represents selected excerpts that have been chosen and edited from the hearing. In some cases, testimonies (or portions thereof) have been deleted. Therefore, some of the comments may have been presented in a different context. The comments have been selected by the staff. For a complete transcript of the entire proceedings please select the following link: Transcript of Telehealth and Autism Spectrum Disorders hearing – complete version

SENATOR DARRELL STEINBERG: Good morning, everybody. I want to welcome everyone to the Senate Select Committee Autism and Related Disorders. This is a committee that takes what we hear very seriously. 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 go right into the current applications of technology in healthcare in autism—the public public policy, the legislation, and future implementation strategies. We want 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.

SENATOR CURREN D. PRICE, JR.: This hearing is important because of the current state of healthcare disparities that exists in California and 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. 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. 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.

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 21st 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 just want to come by and thank you very much for your efforts.

SENATOR MARK LENO: I don't think that we can hold enough hearings on the subject of the autism spectrum. 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. I look forward to how we can move the issue of the autism spectrum into the 21st century using new technologies.

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

DR. ROBIN HANSEN: I was asked to present an overview of the clinical aspects of autism spectrum disorder. 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 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.

In the last domain, behaviors and interest, there are often encompassing, unusual, very focused interests, and preoccupations with parts of the sensory qualities of objects. Usually these symptoms arise sometime before the age of three.

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. 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 see other disorders of brain and biologic function that are very common in people with autism spectrum disorders. Intellectual disability occurs in probably half of individuals who are diagnosed with autism. Seizures have been reported in around a third of individuals with autism and much more commonly in those who also have intellectual disability.

The comorbidities if gastrointestinal and sleep disturbances present additional significant challenges. GI disturbances are reported in anywhere from 45 to 85 percent. Psychiatric comorbidities are also very common, such as attention deficit and hyperactivity disorder, anxiety, and depression.

So the autism spectrum disorders have a very wide range of outcomes, 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: There is a dramatic rise in autism in California, how dramatic is it?

DR. HANSEN: The data that we collect through the regional centers indicate 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 LENO: 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: 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.

SENATOR CORREA: 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 BILL EMMERSON: 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?

DR. DAVID G. 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. 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. This has been fueled in part by increased funding for autism research and the National Institute of Health. It was only $22 million, 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.

Some of the causes of autism are environmental, some of them are genetic, and some are genetics and environment coming together.

A substantial subset of the brains of children with autism, actually develop too fast. 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. 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.

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 showing that exposure to flame retardants, which are called PBDEs, also increase the risk of a child having autism, particularly if they have a certain genetic vulnerability.

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. 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. If you don't have enough it can produce things like spina bifida.

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 lead directly to strategies for prevention, in some cases, and more effective pharmaceutical treatments, so thank you.

SENATOR STEINBERG: What are we doing to make sure that every pregnant woman takes these vitamins?

DR. HANSEN: 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.

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

DR. AMARAL: 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.

SENATOR LENO: Can you tell us a little bit about this recently published report by the MIND Institute regarding the relation between autism and toxic flame retardants?

DR. AMARAL: The lead author on that is Dr. Janine LaSalle who studies this issue of methylation and how DNA works. 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.

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 TOM BERRYHILL: With autism,—are these kids born with it or do they acquire 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. 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 VARGAS: I don't remember this issue of the folic acid.

DR. HANSEN: So if you're taking it preconception, before you even get pregnant, that seems to confer a decrease in risk. So the message 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 EMMERSON: How can we test if gluten becomes a problem in an autism situation?

DR. HANSEN: So most of the time, would do blood testing to screen for markers of Celiac disease. 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: 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 STEINBERG: 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 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. 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.

MR. RICK ROLLENS: 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.

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.

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.

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.

MS. TERRI DELGADILLO: 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 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.

About 60 percent of the people in our system with autism today are under 14 years of age. 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.

Significantly, I think its family support and behavioral support are probably the two highest number of services that we provide overall.

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.

This year, we're looking at about $200 million reduction reduction in General Fund and so we've been doing the budget workgroup meetings and have asked if there are 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?

So if there are things that we can provide such as providing training for families, using technology versus having them all come together. 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 EMMERSON: I would just like to have comment on the prospect of regional centers using telemedical, telehealth technology in terms of treatment for autism cases.

MS. DELGADILLO: When I visited a Southern California center was that they were using technology to do things a little bit different, 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. 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.

MR. ROLLENS: 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.

SENATOR LENO: With regard to some of the cuts that you had to endure over the recent years, 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: It's been a rough three years in terms—and throughout state government. 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 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.

SENATOR ELAINE KONTOMINAS ALQUIST: I just really wanted to mention that I do have legislation SB 1050 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.

MS. JANA KATZ-BELL: UC Davis has been involved in telehealth actually for 20 years this year, and our interest is about addressing the concern about the disparities in healthcare, the greater difference between the have and the have-nots. 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 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.

In the outpatient services 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.

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. Nearly all specialties in clinical services have been tried through telehealth.

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.

SENATOR STEINBERG: The overriding question is the issue of quality. 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. We want to, want to have an honest discussion about whether or not there's some sacrifice of quality.

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.

MS. 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, 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.

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

MS. SHIN-LEE: It's not just travel during the day but it's being able to access different caregivers. We can provide the access to those family members in a more efficient manner at a time of day that works for them.

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.

DR. DOREEN GRANPEESHEH: I am the founder and CEO of Center for Autism and Related Disorders. 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. One of the biggest areas for us has been remote training. 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.

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.

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 a system which we use, it is a tablet PC and it gives you everything you need for a staff member. 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. I can't tell you how much of a benefit it is to be able to use technology.

SENATOR STEINBERG: 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.

MS. PATTY SCHETTER: I'm the coordinator of Autism Education Initiatives for the Center of Excellence in Developmental Disabilities at the MIND Institute.

Back in 2005, 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 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. 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. The surveys also gave us some valuable information about the top areas that families needed information and training in. They wanted to learn about how to manage behavior; how to teach their children basic skills; how to support communication and social interactions; the area of navigating complex social or complex systems within the state of California.

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.

We wanted web-based training to be accessible, user friendly, and not passive in nature. We know that learning occurs best using technology when the interface is very interactive. 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.

LOUIS A. VISMARA, M.D.: 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. 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.

SENATOR VARGAS: Can you comment a little bit on the Spanish language modules?

MS. SCHETTER: 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.

MR. JUAN PEREZ: I'm one of the parents that they've been speaking about using the telehealth. I have two boys that are on the spectrum of autism. 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. I was able to connect back with my wife and understand what she was going through and be able to help.

Having the telehealth actually helped me to expand and ask questions and have better knowledge based on what was going on.

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 with just the setup. It was overall very simple to use and worked within the program itself to share information back and forth—documents, video, hands on.

MR. MARIO GUTIERREZ: Last year, the State Rural Health Association sponsored a bill, AB 415 that 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. It's as a tool that can be used 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.

Telehealth, without question, increases access and quality of care and services in the medical field. It improves the quality of the healthcare experience. It improves the cost of care on a per-capita basis. It’s much more cost effective with prevention and early intervention.

We just recently published a study that looked at all aspects of telehealth to identify where there could be real concrete cost savings. 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.

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.

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.

MS. JENNY KATTLOVE: I am with The Children's Partnership, 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.

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 we're talking about here is specialists. Telehealth really helps families get the care that they need.

Underserved families have more difficulty accessing care—transportation costs, the cost of missing school and work. 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 comorbidities that children with autism spectrum disorders oftentimes have behavior health issues, have gastrointestinal issues. 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.

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: What if the poor person that you described doesn't have, one, that ability, and second, doesn't have the machine?

MS. KATTLOVE: 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 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 affordable access to broadband.

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; 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.

DR. VISMARA: 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.

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.

SENATOR VARGAS: We're going to go now to the next section which is public comment.

MS. CONNIE LAPIN: I'm the mother of a son with severe autism and he next month will be 44. I want to say that we were 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. I want a solution that makes sense and improve the needs of our children. I love this hearing because they said it, a lot of the speakers said it so eloquently about the complexity of autism. 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.

DR. LISA BRITTON: 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. 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.

MS. LYNN FRAMPTON: 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. 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. If you work with somebody, if you know anybody with autism, they like their schedules and routines maintained. 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.

MR. JIM LANTRY: I am with the DIR Floortime Coalition of California. 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.

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 VARGAS: Thank you again for putting on this hearing. 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.

SENATOR STEINBERG: 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. 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? 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.

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

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