

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

Darrell Steinberg, Chair

***Ensuring Fair & Equal Access to Regional Center Services for
Autism Spectrum Disorders (ASD)***

**Monday, April 30, 2012
State Capitol, Room 3191**

SENATOR DARRELL STEINBERG: Good morning. The California Legislature, Senate Select Committee on Autism & Related Disorders, will come to order. This is a select committee so we don't have to call roll to establish a quorum, but I want to welcome my colleague, the chair of the Senate Budget Committee, Senator Mark Leno. Because we always work in a not only bipartisan but bicameral manner, I'd like to give a warm welcome to Assemblymember Holly Mitchell who has taken great leadership on these issues and related issues. I want to welcome all of you. It's just amazing to me that it can be Monday morning, you know, the toughest time to hold a hearing; and when it comes to autism and related disorders and advocacy, the room is always full and I'm sure that there are more people watching on television here.

Let me make a couple of brief comments. Let me welcome Senator Curren Price as well, been an active member—make a couple of opening comments—I give my colleagues an opportunity to do the same—and then we will begin with our very important panels.

You all know the history of this committee and you all know about the prevalence of autism in our society, and this select committee has been oriented around action. We were instrumental last year, all of us, in the passage of Senate Bill 946, passed by partisan support, which will ensure that health plans are doing their fair share in providing appropriate medical treatment therapies for children with autism. The estimates indicate that this bill will save millions of dollars annually for the developmental services that are currently funded by regional centers where we know that the dollar is precious.

Today we tackle another important problem to ensure that these precious resources are distributed equally and fairly. This is the issue of disparities, disparities when it comes to accessing these important services. Last December, the Los Angeles *Times*, in a multipart series on autism, presented compelling estimates on the rising costs of state-funded developmental services that have increased by over half a billion dollars annually. What was most shocking to me—and maybe it shouldn't have been but it was—were the disturbing details of disproportionate public spending of state-funded services through the regional center system, especially applied to underserved communities. For three- to six-year-olds with autism, DDS spent an average of \$11,723 per child on white children compared with \$11,063 for Asian/Pacific Islander children, and only \$7,634 on Latino children, and \$6,593 per African American child. Latino and African American children with autism lived in particularly underserved areas of Los Angeles, received less than one-half of the state funds for developmental services compared to their

white counterparts. At 14 of the 21 regional centers, average spending on white children exceeded that for both African Americans and Latinos.

Today's hearing will explore the how and the why that these sorts of disparities can exist in 2012 in California. We don't want to necessarily point fingers; although, if it's appropriate and necessary to change these disparities, we will do whatever it is we have to do as lawmakers and as advocates but we have many questions.

Are these disparities equal, greater than, lesser than the kinds of health disparities we see across the board in California? Is there a difference between, when it comes to disparities, between physical and mental illness? Are there differences among physical conditions? Why? And more important than the how and the why is, What can we do about it? Yes, it may be appropriate to end here by making a commitment to a statewide taskforce that begins to look into this, but that can't be all we, all we decide upon today. What levers can we pull here, either at the state level, at the local level; what can we do to change this situation now so that kids get the help that they need? That's always what this agenda has been about and it continues to be about.

Senator Leno, Senator Price, Assemblymember Mitchell, anything you want to add?

SENATOR CURREN D. PRICE, JR.: Well, Mr. Chairman, thank you. I appreciate being here with my colleagues and members of the public that are present.

This hearing is important because of the current state of disparities that exist across California's healthcare service system. As a representative of the 26th Senate District, which includes the highly populated city of Los Angeles, I'm personally concerned about the growing need for health services, particularly those, for those, who live in the poor segments of the community, and who seem to have the worst access to care. It's a particularly important for families who have children with developmental disabilities, such as autism. Many low-income families do not know what autism is or how to access services to help their family members diagnosed with autism. Further, without early intervention and outside support, families can be torn apart and children can be left with the behavioral problems that ruin their chances for adult independence.

In Los Angeles, I'm pleased to say there are programs that are committed to serving these families—the regional centers, the USCs, Children's Hospital, Center for Excellence in Developmental Disabilities, and a number of community-based organizations like the Special Needs Network. But these programs are unable to meet all the needs of an increasing population, individuals with autism. Even more important, we need to ensure that services specifically offered by our regional centers are equitable and appropriate.

This hearing is an important step that I hope will manifest in a series of conversations about autism spectrum disorders and an action plan to change our overburdened service system. And so I look forward to learning how I can

become a more effective legislator on these issues, and I look forward to the comments from our panel and from the public.

SENATOR STEINBERG: Thank you.

Assemblymember Mitchell?

ASSEMBLYMEMBER HOLLY J. MITCHELL: Thank you very much, Senator Steinberg, for the invitation, allowing me to sit in on today's select committee. As chair of the Assembly Budget Subcommittee 1 on Health and Human Services, I wanted to participate in today's select committee hearing, just because of the ongoing budget issue facing the department that oversees this issue, and I wanted to just make sure that I was fully informed. I really wanted to be involved in this conversation.

I too was equally disturbed by the *LA Times* article, recognizing that it wasn't completely new information based on a California audit, the State Auditor's Report, a number of years ago on a relatively similar issue. So thank you for allowing me to participate, and I look forward to learning and hearing from the expert panel that will be participating today. Thank you.

SENATOR STEINBERG: Thank you.

Senator Leno, have anything?

SENATOR MARK LENO: Thank you. I'll be brief.

Thank you, Senator Steinberg. It's a pleasure to join you once again. You know, we all sit on many select committees and chair many select committees, but I think one of the things that distinguishes this select committee from so many of the others is that it is focused and goal driven, and

we've already seen some significant success with regard to behavioral therapy. Addressing the issue of disparities among our communities is, of course, very disturbing and must be addressed.

Also bringing my budget committee chair perspective today, I'm also very concerned about the health and well-being of our regional centers, and we see now a slight trend reversing what we've been doing in years—for many years—which is having those who have been served by regional centers now going back to mental centers because they can't get the kinds of services that we know we want to provide at the community level. And this, of course, is not only counter to what we've all determined to be good public policy but also is going to cost the state much more money, so we have to be looking at that as well.

SENATOR STEINBERG: That's a very good point.

Senator Emmerson welcome to you. Thank you for being here. Would you like to make any lengthy speeches? (Laughter)

SENATOR EMMERSON: I will just say nothing and listen.

SENATOR STEINBERG: Very good, very, very good. We all intend to do a lot of listening here today.

So let's bring up Terri Delgadillo who's our director of the Department of Development Services who's an excellent public servant and who's appeared before our committee a number of times.

We're going to ask you to, since we're already a tiny bit behind—our fault—if you can just be brief about the Lanterman Act and the regional center

system, how it works, so that that sets the stage then for the discussion we're about to have.

MS. TERRI DELGADILLO: Sure, Mr. Chairman and Members.

As you mentioned, I'm Terri Delgadillo. I'm the director of the Department of Developmental Services. And thank you for the opportunity to be here today. I'll try to be really quick so that I can respond to questions and let everybody, your experts in the audience, have an opportunity to testify.

First, I do want to acknowledge the extensive work that the committee did putting together their materials. A lot of what I was originally was going to say has been covered so I'll try to skip over stuff.

Currently today, we serve about 252,000 consumers in the community and they have the Down syndrome, cerebral palsy, autism. Our budget is approximately \$4.4 billion. We provide the services in the community under the Lanterman Act which was passed about 40 years ago and it was passed originally, as Senator Leno just mentioned, because of an increase in the utilization of developmental centers. At the time, the only option available to the families was to place their loved one in a state hospital. So the Lanterman Act was passed so that there would be services in the community so that individuals wouldn't need to go into state hospitals.

The vision was, not only that they'd get the services at home and in the community, but the services would be individually based, based on each individual's needs, and that they would be provided at the local level by nonprofit regional centers and not by—the decisions would not be made by

government. They'd be made locally. California's the only state in the nation that has a comprehensive developmental services entitlement program, and under the program we have both the regional centers and the department have differing roles and I'll just highlight, if I could.

First, there are 21 regional centers. By law, they are governed by a board of directors and that board of directors must reflect the geographic and ethnic characteristics of their community with at least 50 percent of their members being consumers or their families. The regional centers provide diagnostic services, assessment services, they help them access services in the community. And if generic services aren't available, the regional centers purchase the services that are needed.

The decisions about what services an individual gets occur at the individual planning process so there's a plan that's developed for each consumer. As we talk about things going forward, I think, unlike some of our other sister departments in the Health and Human Services area, because of the individualized nature of our services, there's an opportunity to impact changes pretty easily because of that relationship that's already in place. Once a planning team determines the resources that are needed for the individual, they coordinate them. And under the law, like I said, they access generic first.

As stated earlier, the system has 252,000 Californians that we serve. The vast majority of them live at home. So in the case of all consumers, 73 percent live at home, 10 percent live independently, 15 percent live in community care facilities, and less than 1 percent reside in state-operated

developmental centers. Of that population, 25 percent have a diagnosis of autism. They may have other diagnoses as well, but roughly 58,000 individuals have a diagnosis of autism; 60 percent of those are under 14 years of age; 24 percent are under 21 years of age. These are very important as well as you look at things that the committee wants to do going forward because the service delivery system for people living at home is different than people that may be living out of home. Approximately 45 percent of the new consumers coming into our system last year had a diagnosis of autism. One distinct difference with our broader population is that 90 percent of those individuals are living at home, so a much higher percent of individuals with autism live at home.

The regional centers, as I mentioned, provide a wide array of services for individuals with autism, including early intervention, behavioral services, respite, residential, supported living, day and work programs. As this population ages, the needs in our system are really becoming quite distinct in terms of providing services for individuals who are adults. As I mentioned, most of the people that are diagnosed with autism in our system are kids and they're in school, and the schools are required to provide the services now and so you will see, as they age, the shift is more to our system versus to the educational system.

As a department, we're very committed to providing services to everybody and making sure that everything is provided in compliance with the laws and regulations governing our system. We have contracts, individual contracts,

with each of the regional centers of which there are provisions that prohibit any type of discrimination for services. We provide oversight in a number of ways, and I'll just do it at a very high level because I know you're tight on time.

We perform audits; we perform programmatic reviews; we monitor for the waiver; we also monitor the purchase of service policies, we monitor significant incident reports, complaints, appeals, and other indicators to determine, Were there problems within our system?

The one thing the committee staff asked me to address specifically, that I'll go a little slower on, since I think most of what I just said many of you are familiar with, was the funding streams and how the money flows through our system. The committee asked that I specifically talk about that.

The Department provides approximately \$4 billion for community services and about 42 percent of that is now federal money. We've had a very aggressive pursuit of federal money in recent years, so almost 42 percent is federal money. Budgeted funds are allocated to the regional centers for two things. They're allocated for operations which is their staffing and their administration and they're allocated for the purchase of service. The operations funding was based on a formula, a core staffing formula, that was developed many, many, many years ago and originally it was tied to state employee salaries. And since, like the '90s, it's been frozen. So for the regional center side, their operations funding has not gone up. If anything, it's gone down and you'll probably hear a concern having to do with caseloads and those types of things as the budget's impacted them.

The other major funding obviously is to purchase services; and in purchasing services historically, how the Department had allocated money to purchase services, was based on what the regional center, each individual, had spent the prior year. That was called their base. So whatever they spent the prior year, they got the next year. And then if there was any additional money, it was distributed for caseload and for utilization growth.

A few years ago, a number of concerns came to us having to do with disparities between regional center funding and the average amounts spent by a regional center on the consumers. We entered into discussions with the regional centers to develop a new funding formula. We have agreed on the formula being driven by client characteristics, so it will be driven specifically by the characteristics and the needs of the individual clients. In the interim, we have what we call a bridge formula that starts to balance them out a little bit, although it doesn't completely, because in order to move to client characteristics, we need to do so very carefully because many of the services that are being received today for the consumers, we don't want to disrupt. At the same time, we want it to provide more equity in the distribution. Unfortunately, the three experts that were working on it too—from the regional center side and one of our deputy directors—all retired so we've had a little bit of a lag in getting it completed, but we are on track in terms of developing a new formula that is based on client characteristics that will help address the concerns of today's hearing.

SENATOR STEINBERG: And maybe that's where you ought to spend the rest of your time, if you don't mind, because that's the core of this. It sounds similar to me like a weighted, kind of a weighted, student formula, the governor's talking about in the education arena. How—give us some examples, if you would—I know it's early in its development—how would it impact the disparities that would have been reported.

MS. DELGADILLO: Yes, Mr. Chairman.

First of all, one of things that we looked at was, Where are we spending the money today, on what types of services? The bulk of the expenditures today are on residential services, number one; number two, on day and work services; and then they go down from there. But those are the largest percentages, close to a billion dollars each. They're \$800, \$900 million each, or in those two areas. So clearly, we didn't want to have anybody move out of home because of how the expenditures were distributed. What we're looking at is, What are the characteristics of the individual consumers? What are their needs and how are we providing the money? We had a done a number of reviews of this, not only for the developmental centers but we had also done it for the regional centers when we looked at, when we were trying to move to a self-directed services model. And we actually contracted with Stanford University, one of their programs, to do modeling for us to look at, if you're going to move an individual budget that's client directed, which is something we all hope to do in the future, was, What are the characteristics for determining the budget? So the characteristics of the person—what types of

services do they need? Do they need out-of-home placement services? If so, obviously, they would need funding in that area. Do they live at home? If so, they don't need out of home—so types of service needs. Based on intensity of the individual's needs, is the person very high functioning—goes to school, goes to college, goes to work, and they just need supports to help them do those things, or are they totally dependent? Do they need 24-hour nursing services? So really it's based on the client characteristics but the service needs of the individuals and what types of services they're going to need. So the goal is to get to that. So it would not—it would be blind to ethnicity. It would be based totally on the individual's characteristics, the individual service needs.

SENATOR STEINBERG: Right. So I want to understand how, if it is blind ethnicity, how in the end it would address these gaps that show, that if you're a child of color, you're much less likely to get the services, or at least the intensity of services, than if you're not a child of color?

MS. DELGADILLO: I think, Mr. Chairman, one of the things that you see also when you look at all of the data that was behind the *LA Times* article is that you do see that a number of the centers that are in lower economic areas are ones that had lower expenditures and had lower budgets. So they started every year at a lower rate than where they were before. And while we're an entitlement program without regard to income, the legislature gives us a budget every year and we are supposed to live within that budget. But if we don't, we come back. Obviously we'd come back and request a deficiency, which we've done in the past. So each regional center would receive their

allocation and they would try to live within their budget, so this would be so that their allocation would be based on the client characteristics and the needs of those clients, first of all. That doesn't totally address the issue you just asked.

But our system's individually based. Each and every consumer has a personalized plan with the family, with the service providers, determining what their needs are, and I think, as we look going forward, there are a number of things we need to look at. So when you look at the data, for example, those children less than six years of age is where you see the significant disparity. As children age, you see that disparity decrease, not in totality, but you see the disparity go down.

So what are causing those things? One of the things that we have heard is that oftentimes, lower-income children are diagnosed later. So they are coming into our system later, so they may have less years of service in our system. We need to be looking at that. So how do we do a better job of outreach and coordination and making sure that people get a diagnosis earlier?

So another is, What services are available in the community, and are there generic resources available in the community? And so I think there are a number of things that we need to do, but the funding formula is a basis of a starting point to make sure that the money is allocated in such a way that it is distributed based on client characteristics.

SENATOR STEINBERG: Okay. Yeah, Ms. Mitchell.

Let's ask some questions and I think we're going to—are you able to stay?

MS. DELGADILLO: I can stay till about ten till 12, and then I'm meeting with the Governor's Office and the budget director on our budget.

SENATOR STEINBERG: Aw, they can wait. (Laughter)

MS. DELGADILLO: I don't know. That's not a good thing when they hold the purse. (Laughter)

SENATOR STEINBERG: Okay. I want to make sure, though, because we're going to hear obviously some opinions on what the problem is with some of those solutions might be. It might be good in the end if you could respond. But let's take a couple more questions.

ASSEMBLYMEMBER MITCHELL: Thank you, Mr. Chair.

The last point you made, because I'm really trying to—I appreciate the chairman's kind of peeling back the onion layers to really try to get to the root cause of the problem. I understand that their budgets are based every year on the previous year's base, so here's always been kind of a disparity. It will continue. It normally doesn't allow for adjustments, kind of in real time.

Secondly, you talked about the availability of services in the community. So does that mean, if I lived in Community A, I get my services through Regional Center A, that a kind of therapy or service that's provided in another community is not available to me, just based on whether or not that service is provided in my community? I can't go across town if I so desired to receive that service?

MS. DELGADILLO: Chairwoman Mitchell, you can, and there are people—one of the directors is going to testify today, can even address that. He had indicated to me oftentimes, families wanted a specific provider, not necessarily a specific type of service, in one of the issues where the provider may have been all the way in a different catchment area or in a different area.

The way the law works is that an individual plan is developed. And whatever service that consumer needs, the regional center is supposed to first try to access generic resources, whether it be IHSS, whether it be Medi-Cal, school services. And if those services aren't available to meet the child's needs—and under the law, the regional center purchases those services. They try to develop services within their community to meet the needs. And I think, for the most part, they've done a very good job doing that. There are times where maybe there's a special need that isn't available statewide. And one of the things we've been looking at with our whole budget reductions because we're, as you know, working on a \$200 million budget reduction right now, and one of the things that we were looking at is trying to have a centralized system to track specialty needs.

An example, we are sending people out of state to get services for Prader-Willi, which is an eating disorder. There's no reason why California can't and, at some places, does provide Prader-Willi services. And so we're trying to—while that's not specific to this hearing, it's an example of we're trying to determine how do we do a better job as a state in identifying available resources so, that if one regional center doesn't have some specialty service,

we'd be able to say, well, we know this regional center has developed that. I think over the years, because it's been so tight in terms of the availability services and the funding that's available, you know regional centers develop them for their community, and understandably so, because they're trying to meet their needs of their community.

ASSEMBLYMEMBER MITCHELL: I just wanted to make sure that any child could have access to services...

MS. DELGADILLO: Yes.

ASSEMBLYMEMBER MITCHELL: ...whether they were provided in their catchment area and their regional center would have the opportunity to provide reimbursement for that.

MS. DELGADILLO: Yes.

ASSEMBLYMEMBER MITCHELL: A second quick question, the client characteristics model you talk about, the transition that you've been challenged, based on retirements, what's your current timeframe? When will that happen?

MS. DELGADILLO: I really couldn't give you an answer today. We had, like I said, three people that had worked on it that had extensive experience. The least amount was 25 years in our system, and the other two were up in the 40s. And so in terms of working on it, they've done a lot of work. We need to get back and take a look at where we are with it. I think we may need to actually bring in some external people again to help us with it because we want

to make sure we don't disrupt service delivery to people. But at the same time, begin moving down that process.

So I'm hoping, I'm really—I'm sure you are as well—hoping that this next budget here will be one that, once we get done, we can get through a few months without additional cuts so that we can focus again on getting this resolved.

ASSEMBLYMEMBER MITCHELL: So at this point, you will continue your current funding formulary indefinitely?

MS. DELGADILLO: No indefinitely; but this next year, I think, I don't think we'll be ready because we start—July 1 is the funding, the allocation for the next year, and there's no way with doing the budget reductions we'll be ready by July 1 but our hope is to get it done quickly.

SENATOR STEINBERG: Okay. I'm going to call on Senator Alquist, but I ask everyone to be brief because we've got till noon. We have three panels and Ms. Delgadillo is just supposed to be the introductory. So if you have a lot of questions about the whole subject, you might save it for, at least wait to hear from the regular panelists, okay?

SENATOR ELAINE K. ALQUIST: Thank you, Mr. Pro Tem.

SENATOR STEINBERG: Thank you.

SENATOR ALQUIST: Thank you. I just wanted to mention to Ms. Delgadillo and the advocates that I have a bill, SB 1050, that would establish the autism and Telehealth Taskforce within DDS so that families could more easily access services for those with autism spectrum disorders.

MS. DELGADILLO: Thank you, Senator.

SENATOR STEINBERG: Very good. Thank you, an important bill.

Senator Leno, you had a brief question.

SENATOR LENO: Ms. Delgadillo, you had mentioned that 25 percent of consumers in regional centers today number about 25 percent, though 45 percent of those coming into the system are on the spectrum. Can you compare that with five or even ten years ago? It's a dramatic increase, isn't it?

MS. DELGADILLO: I can actually give you data. I think that there's a significant increase. I think two things happened. We did—we used to have our data system based on a very old national model, the Diagnostic Manual, the DSM. It was based on DSM-II, which was back many, many years ago. We just updated the system which expanded the diagnosis, the definition of autism. And in doing so, it did increase our numbers. So some of the increase in the existing population is related to the change in the definition. That being said, without a doubt, there's an increase, a very significant increase, in the number of diagnoses. And we can give you what it was before and then when we stopped doing the data reporting in 2008 so that we could transition over to the new system and we can tell you now. But as of today, yes, 25 percent, and I had them do a data run looking at in 1011 ??, all of the people who came in, in intake, that stayed in our system, what percentage of those were individuals with a diagnosis with autism and that was the 45 percent.

SENATOR LENO: Thank you.

SENATOR STEINBERG: I want to welcome Senators Alquist, Liu, and Dutton. Thank you for being here. I appreciate it.

Let's go right to the panels.

Thank you very much, Madam Director.

Let us go to Panel III which is Identifying the Gaps & Inequities in the Regional Center Services for Autism Spectrum Disorder, and let me ask Ms. Areva Martin who I don't think needs any introduction in terms of her incredible advocacy. Dr. Freeman was not able to be here, as I understand it, due to illness, but we have Martha Matthews, the directing attorney for the California [sic] Rights Project, Public Counsel; and Catherine Blakemore, the executive director of Disability Rights California.

Ask you to, if you three would address the public policy perspective and overview the issues, the impact of disparities and, you know, again, we have a really compact time here. So if you can kind of hone right in on what we ought be doing here to change this, that would be most helpful. Thank you.

MS. CATHERINE BLAKEMORE: Good morning. Catherine Blakemore, Disability Rights California. I want to thank you for the opportunity to speak on this very important topic.

As you may know, Disability Rights California is the protection and advocacy agency for the state of California. We provide advocacy services statewide to any individual with a disability, including individuals with developmental disabilities and autism.

The issue of access to services for Californians with developmental disabilities from diverse communities has been a subject of conversation for much of the last two decades. There have been numbers of studies about purchase of service expenditures, the most recent study showing that individuals from traditional minority groups were somewhere between 23 and 31 percent less likely to receive regional center services at comparable levels to their white counterparts. It's also not unique, as we know, to the regional center system, there's similar disparities in school districts, in the In-Home Support Services system, Mental Health, and so forth.

Of significance since 2005, the legislature has considered this issue in at least three bills, all of which, in my view, were modest. The first would have required annual reports of expenditure based on ethnicity; the second would have required DDS to monitor expenditures and provide technical assistance to regional centers about those expenditures; and the third would have required a stakeholder group to—would have required stakeholder groups to reflect the diversity of California. None of those bills were successful, and I think that's a piece of what the legislature has to look at, some effective ways of changing that. Most troubling is that the last bill, the one that simply would have required diversity in stakeholder groups, was held in appropriations because the analysis said, that if we convene a diverse stakeholder group, they might increase the actual amount of expenditures because that would be a portion of their role. That's quite troubling.

I think we also have to recognize that the adverse economic climate and the budget cuts have impacted our ability to take leadership on this issue. Regional centers and the Department have been focused on implementing 40-some pieces of trailer bill legislation. And in addition, some of that legislation may have adversely impacted individuals from communities of color. There's changes to the Early Start program which is where individuals at younger age get into the regional center system; there's caps on respite services; there's requirements about parent participation and behavioral services, all of which may have an impact on access to services.

I do want to say that we have made some modest gains in this period of time. First in 2005, we worked with DDS to ensure that all of the notices of action and hearing information was translated into 11 languages, and Disability Rights California has been working with two regional centers to do joint trainings and outreach to communities, diverse communities, in their catchment areas to ensure everyone has access to services.

We believe what needs to happen is the convening of a statewide commission, and that commission should look at the following:

First, ensure that all consumers and their families have access to information about the service delivery system and languages that they understand;

Second, strategies to help regional center meet the language-access obligations, including providing interpreters at IEP meetings and written translations of the IPP;

Third, ensure greater consistency with eligibility standards and services so that families of children with autism spectrum disorder can be determined eligible and receive similar services between regional center areas;

Fourth, ensure that the array of services offered by regional centers reflect the norms of individuals and their families and offered by vendors who are culturally and linguistically competent to provide those services, ensure that the regional center boards are reflective of the ethnic diversity in their catchment area, and develop a mechanism to publicly report on expenditures for the purchase of services and denials and terminations of eligibility.

Disability Rights California is dedicated to working on this issue. We think what can be accomplished can be done by clear, focused, deliberate, and collaborative efforts to enhance the system's models of cultural and linguistic competence in all areas of service delivery.

Thank you.

SENATOR STEINBERG: Thank you very much.

Welcome.

MS. AREVA MARTIN: Welcome. Thank you. (Laughter)

SENATOR STEINBERG: Thank you for welcoming me. I appreciate it.

MS. MARTIN: Thank you for welcoming *me*, Senator Steinberg. Good morning to the esteemed panel.

My name is Areva Martin and I am the president and founder of Special Needs Network, and I'm also a special rights attorney and a mother of a child who has autism and I'm honored to be able to testify on behalf of thousands of

black and brown children in underserved communities that Special Needs Network represents. As Chairman Steinberg mentioned, I have testified on numerous occasions before this committee and others on the issues of underserved communities and families and the struggles and challenges that those families face in trying to access services.

After the *LA Times* article was released in December highlighting the huge disparities in services and spending on African American, Latino children and white children, Special Needs Network launched a campaign called Equality for Our Children—for Our Kids—and it was about holding DDS accountable for funding and equalizing spending of public dollars for black and brown kids. We wrote a letter to the governor. We sent thousands of postcards to our elected officials and we asked that this issue become a priority issue because we are concerned as a mother and as a leader of an organization that represents families in underserved communities.

From our perspective, this is an issue of discrimination. Black and brown kids are being discriminated by the Department of Development Services and the spending that the state does. The *LA Times* article also said something that was really disturbing to families, and the article talked about parents having to become warrior parents. If parents have to become warriors, the system is flawed and we, all of us collectively, have failed parents. Parents should not be expected to sell their homes, quit their jobs, relocate, become destitute in order to access services. Black and brown families, families in underserved communities, should have the same rights, the same access to

services, as their white counterparts; and unfortunately, the system that we've heard about this morning doesn't allow for that.

The concept that services are provided based on the needs of children isn't working. Parents are not being given access to the information that allows them to request the services. So if you are an uneducated parent, you live in an underserved community, you go to your regional center, your experience will be very, very different than an affluent family that lives in a different part of our state. Those families aren't told what services are available. Once they are told what services are available, they are not provided the services. They hear the word *no* over and over and over and over again. They're forced to participate in training classes, to go to support groups, and to do everything except receive the services.

So I am here today to speak on behalf of those families and to urge this body and the legislators to look at changing the system, making the system accessible to families, and that doesn't require the families—the families are not the problem in the system, and sometimes the articles and sometimes the experts say the families need to be more effective advocates; they need to ask for more. Black families and brown families—they don't get services because they don't ask. That is simply not true, and we cannot allow the system to continue that puts the onus, the burdens, on the families who are already working 24/7 to care for children with disabilities. We have worked closely with Public Counsel and other nonprofit groups in the LA community, and we've come up with what we believe to be some points that will allow the

system to change to better serve all kids and to end the discrimination against black and brown children.

The first point, similar to Ms. Blakemore's point, is requiring regional centers to comply with the case-finding provisions of the Lanterman Act by engaging culturally and linguistically appropriate community-based outreach activities. We heard today that black and brown kids who are not diagnosed at the same time as their white counterparts—we need our kids to be identified earlier and to get into the system earlier so that they can get the services that they need.

We need regional centers to provide eligible clients with clear and accessible information about the range of services. No more hiding the ball. We cannot have families go to regional centers and be told, this is not McDonald's. We don't have a menu of services. What we understand, it's not McDonald's. But families can't access services if they don't know what the services are.

Third, to require regional centers to provide written materials, translated into languages that families can understand.

The fourth, which is one of the bills that wasn't passed, is to require the regional centers to publicly make available how their POS dollars are spent, those billions of dollars that are being spent. We need to know as a public how they're being spent, based on age, disability, race, and ethnicity on an annual basis. At the very least, our public dollars, and how they are being spent,

should be accessible to all families that are impacted by this disability and everyone that pays taxes and makes these dollars available.

And lastly, we also are calling for a statewide commission to be established to review how point-of-service dollars are being spent and to provide greater oversight in monitoring of regional centers so that all of our kids can receive the services that they deserve. Thank you.

SENATOR STEINBERG: I think this is an important point to clarify what the state of the law is now. It is not a legal requirement now that the regional centers provide a family, upon first meeting the family, and the family seeking services, it is not a requirement to provide a listing, if you will, of all the services that the regional center has to offer; is that correct?

MS. MARTIN: That is correct.

SENATOR STEINBERG: And what is the law around requiring that written materials be made available or translated to be made available in the language appropriate and necessary for the particular family seeking services?

MS. BLAKEMORE: Disability Rights California believes that that is a current requirement. I think there are some different opinions about that.

SENATOR STEINBERG: Is it the practice in the regional centers?

MS. BLAKEMORE: It is a practice that varies widely.

SENATOR STEINBERG: It varies widely.

MS. BLAKEMORE: Particularly when it comes to translation of IPPs which are not, in our experience, in a timely manner.

SENATOR STEINBERG: So certainly just thinking colleagues here, thinking about legislation, the idea of requiring that the center provide the listing of potential services in appropriate language, or at least have the ability to translate that listing, might be a good common-sense piece of solving this puzzle here. I just put that out there because that's—we're always looking here to, okay, then what do we do with what we're hearing here.

MS. MARTIN: Yes, that would be a huge first step, Senator Steinberg, in terms of addressing some of these issues because that is a common complaint that parents have, is that they don't know what's available and they're not able to find out what's available; and often they're only finding that out once they talk to their neighbors or other family members who they encounter in the system.

SENATOR STEINBERG: Okay. Thank you very much.

Ms. Matthews.

MS. MARTHA MATTHEWS: Senator Steinberg, Members of the select committee, thank you so much for allowing me to speak today.

Public Counsel has worked with hundreds of low-income, mostly Latino and African American, families in Los Angeles who are parents or caregivers of children with autism and other developmental disabilities.

My name is Martha Matthews. I'm the directing attorney of the Children's Rights Project at Public Counsel. So we, are own project, has seen firsthand the barriers and inequities that these families face.

The other panel members so far have focused on systemic issues. I just want to tell you a story. I want to tell you about one family whose experience, very sadly, is typical of those of our clients. I'm going to call this young man Angelo. He's six years old. He's a six-year-old boy with autism. He babbles; he cannot speak. He has no control over his bladder or his bowels; he has to wear pull-up diapers. He's too big for the diapers you can buy in the supermarket, so his family has to get special, more expensive diapers from a medical supply store. He can't bathe himself or dress himself. He only eats pureed or liquefied foods. He's severely hyperactive; he can't focus, even on an activity he likes, for more than one minute. He has chronic insomnia. He will sleep only two or three hours a night for weeks at a time. He cannot play or interact socially with others. He needs close supervision due to tantrums, self-harming behaviors, and a tendency to wander away from the adults who are supervising him.

Those of us here who are parents, imagine the challenges of taking care of this child. Even with the education we have, the connections, the resources, family support, everything we've got, imagine what it would be like to have this child.

Now imagine what it's like for Angelo's actual parents. His father is a laborer; his mother is a seamstress. They both are monolingual in Spanish. They live in a low-income area in Los Angeles and they do not have a car. When this family came to Public Counsel for help, Angelo was six years old. He was receiving neither special education nor regional center services, despite his

obvious eligibility for both. We got them a pro bono attorney. He started receiving special education services. That part was taken care of. For six months, the skilled advocates that I supervise tried to get services for this family from regional center.

This is their experience: The family asked for in-home behavior intervention services. These are services where someone, a trained person, comes into your home and helps you learn to deal with these challenging behaviors. The regional center said, well, the insomnia and the feeding problems, those are medical, not developmental. Go away. Go to a doctor. All right. Get services for that.

So they went; they went to a doctor. The doctors tried medications. They got two letters from doctors saying, no, these problems are developmental, not medical in origin. There's nothing we as physicians can do about it. So they went back to regional center. Regional center still refused to provide in-home behavior interventions. Instead, they sent the family a two-page, single-spaced letter in English, which I as a lawyer had trouble understanding, explaining the denial, and offering the family weekly group classes in behavior management, saying that they had to attend these classes, which are generic—they're not individualized for that child—try the techniques taught in the classes. And then if that failed, come back again to seek in-home services. Now remember, the parents are just barely making it as a laborer and a seamstress. They're required to attend ten group classes that are not—they're scheduled completely without regard to their work and other obligations.

Okay. Next experience. As I said, Angelo requires diapers, which are expensive, because they're diapers for a six year old. Regional center said, well, Medi-Cal should pay. Go to your Medi-Cal HMO. Well, their Medi-Cal HMO did not offer reimbursement for diapers so the family had to switch their healthcare provider from the HMO to fee for service. Well, to do that, they had to get a medical exemption form signed by their doctor so they did that. So then, once with the new fee-for-service Medi-Cal, they then had to find a provider that would be willing to submit a funding request to Medi-Cal to get the diapers covered. All of this took three months. Regional center refused to provide any funding for the diapers in the interim, all right?

When the family asked for help with transportation, because Angelo had all kinds of doctors and treatment and therapy appointments—the family doesn't have a car—regional center said, no, we're not giving you a bus pass. Go apply for City Ride. City Ride said, okay. Can you give us some written documentation of your child's disability? They go back to regional center. Can you give us a letter saying that Angelo is disabled and we need this transportation? No, we're not going to give you any documentation. Go to the Social Security Administration and get a letter certifying this child's disability.

So I'm proud of my attorneys. I'm proud of my project. We worked with this family for six months. What did we get? One month of diapers, one month of bus passes, and ten group behavior management classes, even with our help. That's all they got.

This story illustrates the Catch 22s, the runarounds, the denials that less privileged families experience in seeking regional center services. And if you don't believe that all of this happened to one real family, I brought the original documentation with me.

Unlike the more affluent family featured in the *LA Times*, Angelo's parents could not quit their jobs, search the internet, network with other parents, basically make it their fulltime occupation to get regional center services for their child. And yet, if you look at the *LA Times* article, the quotes from regional center directors, oh, *those* families, those minorities families. They only take minimal advantage of the services available. They can't come to terms with their child's diagnosis. Okay. So we're blaming the families for being in denial. Those families, they can't participate as required in orientations or therapy sessions. Again, the response from regional center officials really struck me as particularly insensitive, given our real experiences with these families, right? It is not their fault that they are put through this kind of runaround.

Even with our help, Angelo's family ended up with far less from regional center than a white middle-class child with the same disability would have received a few miles away in a more affluent part of Los Angeles. This is wrong. We in the special-needs network have submitted joint recommendations to change this tragic inequity in which children and families who are already disadvantaged by race and poverty get the least from the regional center service

system, and more privileged—I mean, it’s exactly the opposite of what it should be.

I’ve submitted copies of my testimony and copies of our joint recommendations to the committee. Thank you very much.

SENATOR STEINBERG: Thank you.

A follow-up question here again, focusing on what we might do as a legislature because this is a horrific story, and yet it doesn’t—it shocks and yet you can see how it occurs because people go in there. You don’t get involved until after there’s a problem. Public Counsel, you’re attorneys. You’re limited in, I’m sure, how many cases you can take and how many people you can see. But I’m thinking about the analogy, the analogy that I’m thinking about are the court—I think it’s called the CASA program, the special advocates in dependency court when it comes to a child’s status as a foster kid reuniting with family, et cetera.

Where there is an advocate, an ombudsperson, not necessarily an attorney, involved with that child throughout the “court process”, I just wonder whether—I know we’re not in a financial condition to be starting a bunch of new “programs” here, but whether there is a way or a model out there where somebody can help the family from the very beginning of this thing, of this whole process, can walk into the regional center with them, can help them fill out the paperwork if there are language issues, can sort of knock down some of the barriers and the doors that exist, is there any such model? Is there any such mentorship—volunteer program—like that?

MS. MATTHEWS: Senator Steinberg, I mean, that's what we try to do. That's what the Protection and Advocacy program, which is now Disability Rights California, has advocates, client advocates. Areva Martin's program provides parent-to-parent support. But you don't want to have a system that's built that way. You don't want to have a system where you have to have, you know, your own little personal army to get services.

The service coordinators at the regional center are supposed to not be the family's adversary. They're supposed to sit down with the family and work out an individual—it's an IPP—it's an individual service plan for each child. It's not supposed to be an adversarial process. So I would start by fixing the way the regional center treats people.

MS. BLAKEMORE: Well, yes, but...

MS. MATTHEWS: I'm not opposed to your idea. I'm just saying, you shouldn't have to have an advocate with you to get a basic, fair level of services from regional center.

SENATOR STEINBERG: Let's let my colleagues get into this a little bit because I think this is sort of the heart of the matter here.

Senator Leno, Senator de León, we'll go around the horn.

SENATOR LENO: Ms. Matthews, this is such a hellish nightmare. It's hard to imagine how anyone has the fortitude to carry on, and I just wondered if you could help us, through each of these juggernauts this family had to pass through. Where was the regional center either breaking current law, not

providing the service that they should have been, and where do we need to change state law to require that this should never happen again?

MS. MATTHEWS: Well, what is true, what is correct, as Ms. Delgadillo said, is that regional center is a provider of last resort. And so what are called *generic services*, services that are available, for example, through the special education system or from the family's health insurance—in this case, Medi-Cal, or through some other system—basically you're supposed to try to get services from those other places first and then come back. And so the fact that the regional center said, well, you know, if this is a medical issue, you know, you've got to have it taken care of by your doctors, That is not in itself wrong.

The reason I went into so much detail is it's the way you do that, you know, go away; don't come back until you have two doctors' letters proving that this is nonmedical. Go away; don't come back until you've switched from an HMO to a fee-for-service and found a provider and done all this stuff on your own, right, from no help from us, and then we'll still say, oh, well, it'll take three months, no funding in the interim. So it is true that it is lawful for regional center to work with the family, work with the family, not abandon them, to find generic resources first. But if the family, with proper help from their service coordinator, you know, can show, hey, you know, can't get this service, Our individual child needs this service, I can't get it from Medi-Cal, I can't get it from the school system, got to get it from you—and a good example would be those three months of diapers—then you give it to them, right?

SENATOR LENO: If that is the case, as the provider of last resort, even with your advocacy, why would the final resolution have been, one month's supply of the diapers and once month's supply of bus tokens?

MS. MATTHEWS: Because we were also exhausted. We've been around with it so many times.

SENATOR LENO: Clearly, you weren't able to get the diapers paid for anywhere else. You weren't able to get...

MS. MATTHEWS: I know.

SENATOR LENO: ...transportation paid for anywhere else. Doesn't that mean the provider of last resort would be the regional center?

MS. MATTHEWS: Yes. That issue, we chose not to appeal that specific issue because so many other things were going on. I mean, this is not a shining example of successful advocacy on our part.

SENATOR LENO: It shouldn't be on you to begin with. It should be on us.

MS. MATTHEWS: That's what we managed to get after months of wrangling.

MS. BLAKEMORE: I think one difference I might just note is, that prior to the recent budget deficits, I found regional centers, while they understood they had to be getting generic resources to backfill those services while the family was going through the process and the law regarding, as a result of the budget trailer bill, really changed that dynamic so that that flexibility of providing things in the meantime isn't as available. So if you were going to do

one thing, I think it's looking at the trailer bill that many of us worked on and, you know, you passed, et cetera, and sort of providing that kind of flexibility again so that regional centers can provide that gap funding while the family is pursuing the generic resources.

MS. MARTIN: Can I also—I'm sorry.

SENATOR STEINBERG: Please.

MS. MARTIN: Senator, I just wanted to add to this. I think what the story illustrates too is just the institutional bias that exists. And obviously through legislation, we can't change, you know, people's perceptions and oftentimes even their behaviors, but I think it also illustrates the need for greater oversight on the regional centers from the Department of Developmental Services that is funding these regional centers because, if I walk into that regional center as an educated parent consumer, I'm not going to even, I'm not going to hear that. That is not going to be—I'm not going to be told, go away; go check with your health insurance; go check with social security. I'm going to be told, okay. Let's sit down and figure out what your son needs. And that is how affluent families are treated in the system differently from this family who walks in, monolingual, uneducated. They get told no so, of course, then that sends them off on this path that takes six months to get resolution, and that's where we're saying, institutionally, we have to change this system and have greater oversight, so when regional centers are doing that, somebody at the top is saying that's not acceptable. You can't treat this parent differently simply because she has education or he

has education than this family that does not. That is the bias that we're seeking to change here.

SENATOR LENO: If I can, finally, a final comment. I don't want to lay this on the backs of the regional centers because I also recognize we are starving them right now, and so we have to finally take the responsibility.

SENATOR STEINBERG: Senator de León.

SENATOR KEVIN DE LEÓN: Thank you, Mr. Pro Tem, Ms. Blakemore, as well as Ms. Matthews and Martin. Thank you very much for your compelling testimony.

On one end, I'm not surprised about the content of your testimony, given insensitive bureaucracies, especially in Los Angeles and Los Angeles County government, especially what I've seen and witnessed in our foster care system, our CPS system, in Los Angeles County. But nonetheless, I will say this, I'm just, just alarmed and blown away by this individual case. And the question I have is an open-ended question, but specifically, is this an isolated case? Would you say this is an isolated or would you say is this systemic and it's pervasive?

MS. MATTHEWS: I can respond to that because, as I've said, we've helped hundreds of families from these specific disadvantaged areas of Los Angeles. We chose this case because it's typical. And I wanted to echo Ms. Martin's comments, Why do humans engage in behavior? Because it works. If you have a family without social and economic power and you give them a denial and runaround, most of them give up, right? Yeah, we get to

keep our budget, right? You know, it's easier on you if you if you have a limited budget and high caseloads, if a lot of people just go away. Whereas if I lived on the west side and I had more money and I was treated this way by any bureaucracy, you know, I have the social and economic power to raise hell and I would talk to the person's supervisor, supervisor's, supervisor and I'd get them in trouble and it wouldn't work.

SENATOR DE LEÓN: So let me ask the question.

MS. MATTHEWS: Yeah.

SENATOR DE LEÓN: So within this dynamic here—and I'm going to leave an open-ended question—I don't want to make my own conclusions or make conclusions for you all within regards to your testimony—if this is systemic and it's part of the culture and as elected officials here, we can move forward policy that dictates X, Y, and Z, but if it's culture, you know within the system itself, are we talking about the issue of race, power, and socioeconomic status, clearly, you know, within the regional centers and where is accountability? Where does the buck stop with regards to this, which I find to be just, you know, heartbreaking and just absolutely horrific? Where does the buck stop, in your opinion?

MS. MARTIN: I can say to that, Senator, that the buck can stop with the DDS. They provide the funding. These are independently operated regional centers, nonprofit organizations, that get their entire budget in some cases from the Department of Developmental Services which this body ultimately controls the governor, the state of California controls. So we can change

behavior because we control the purses strings. So those regional centers that are not complying, those regional centers that are not making these services available across the board and equally to families from underserved communities, can be dealt with. They can be dealt with because their contracts are dictated to by the Department of Developmental Services. So that's why a part of what we're asking for is greater oversight. We shouldn't allow those regional centers to continue to operate in the fashion at which they're operating. No family should have to go through that.

SENATOR DE LEÓN: And this is Terry Delgadillo? The buck should stop...

MS. MARTIN: Yes. Not her personally but her department. This is not an attack on her.

SENATOR DE LEÓN: It should be her personally if she's in charge. It should be her personally.

MS. MARTIN: Well, the department, absolutely.

SENATOR CAROL LIU: The department.

MS. MARTIN: Absolutely. This is about the Department of Developmental Services that controls the dollars that goes into these regional centers, and then the directors of the regional centers. There's accountability up and down the chain here because they, these regional centers are contracting with the department.

SENATOR DE LEÓN: You were going to say...

MS. BLAKEMORE: I was just going to say that I also think it's—two things with that.

One, we have to just come to grips with, there are disparities and we have to be willing to publish the data that shows that. That was a bill that Karen Bass introduced in 2005. It was not successful. And then it has to be everyone in the system looking at that data and figuring out what are the strategies to change that so that we can say we have a system where the color of your skin doesn't direct what services you receive.

SENATOR DE LEÓN: Mr. Pro Tem, just one last, not a question but a commentary per se is, this becomes so pronounce, is what we see every day in the communities that we represent, for example, those children who need the services, who do get them, regardless of the skin color and regardless of socioeconomic status or perhaps if their parents are educated, they should get those services. And those kids who obviously tragically don't get the services because you have a systemic culture that stops them, that does not want welcome them, many of these kids end up in our system nonetheless and they end up in CYA; they end up in juvenile hall, and they end up in LA County Jail in Vacaville or Folsom, Chino, and so forth, and we're paying the consequences because they never got the much-needed critical services that they needed from the get go.

SENATOR STEINBERG: And that's why we're here today and to dive into this difficult subject, a vital subject, and we'll hear from the regional centers in a few moments as well.

Senator Liu.

SENATOR LIU: I think I'll just wait until we hear from the regional centers, okay?

SENATOR STEINBERG: Senator Emmerson, any quick questions?

SENATOR BILL EMMERSON: I think I'll wait as well.

SENATOR STEINBERG: Okay.

Senator Alquist, are you going to go now?

SENATOR ALQUIST: I have to go to Approps, but if I can say about two things.

SENATOR STEINBERG: Sure, sure.

SENATOR ALQUIST: One, it does seem like this issue would be more prevalent in Los Angeles County. I would be surprised if it occurred, as an example, as much in Santa Clara County since I know a little more about that. But what we really need to do is build an accountability with DDS and include parent satisfaction. There ought to be a menu of services and there ought to be a sheet of paper saying how easy or difficult it was for parents to access these services.

MS. BLAKEMORE: And effective, particularly if all of that is in languages that those parents speak.

SENATOR ALQUIST: Exactly. Thank you.

MS. MATTHEWS: May I comment briefly in response? I mean, I don't want to sound like, you know, I'm attacking regional centers.

There's another thing about best practices. Some regional centers do not treat people this way, right? The ones that treat families appropriately can provide best-practice models for those that don't.

SENATOR STEINBERG: And maybe what needs to come out of this is a clear understanding of what those best-practice models are, you know, and the culture or the way people treat one another—attitude, et cetera—can't necessarily be legislated. But where there are elements of best practices that in fact can be put into law and required as the norm, we need to know that and we ought to incorporate that into our law.

Okay. Thank you.

Senators, I'm sorry. Senator Price, had a brief question.

SENATOR PRICE: Right, just briefly. I'm going to have to leave. I'm anxious to hear the response from the regional centers. I think it's a pretty damaging indictment if it occurs at one or however many. Certainly I think the best practices is a good idea as a roadmap, if you will, and there has to be greater transparency which is kind of amazing to learn the hurdles that, you know, have to be overcome to provide services, at least in this one instance. And as I said, if it's occurring in one family's experience, it obviously has occurred in other's so it's very troubling.

Thank you for your testimony.

ASSEMBLYMEMBER MITCHELL: I just wanted to comment very briefly.

A lot of what I, my early thoughts were already raised in terms of the notion of culture shift. I think it's what we do as legislators, to try to find a way to fix a problem by writing a new law. And based on what we're hearing today and what I heard over time, it may not be that. It really requires a culture shift. So what we have to figure out in our current economic climate, how to motivate the culture shift as well as the issue of accountability that the senator referenced and the accountability is spread across.

In 1998, the Bureau of State Audits released an audit entitled *Regional Center Budgets are Not Based on Needs, and Departmental Oversight Could be Improved*. The Department of Developmental Services' response to the Bureau of Audits basically denied that there was any correlation between differentiation in expenditures at regional centers, so the accountability starts with the governor; it starts with the legislature; it goes to the Department and to the regional center. So we need to have a real frank conversation about everybody whose hands are tainted by what has been going on for an extended period of time. And I would encourage us all to look back at this old audit to recognize what the audit found and to really look at what the department's response was, to begin to talk about accountability, and how do we create a culture shift even given the current fiscal climate. That's not going to change overnight. But recognizing the resources that we do make available, there is an expectation that Californians have access under current law, under current statute, to the programs and services that they're entitled to.

UNIDENTIFIED SPEAKER: What year is that?

ASSEMBLYMEMBER MITCHELL: Nineteen ninety-eight.

SENATOR STEINBERG: Nineteen ninety-eight.

Thank you very, very much. You might stick around. I know Ms. Martin is on the last panel. But we may go back and forth here a little bit, okay? Appreciate your testimony very much, okay?

Let's got to Panel IV, the Regional Centers & Their Systems of Care and invite Jim Burton, the executive director of the Regional Center of the East Bay; George Stevens, the executive director of the North Los Angeles County Regional Center; Dexter Henderson, the ED of the South Central Los Angeles Regional Center; and Robert Riddick, the ED for the Central Valley Regional Center.

There's one threshold question I have, thinking about the last panel and awaiting your response is, How are regional centers currently evaluated by either the state and/or outside organizations? Are you evaluated based on outcome measures? And if not, is that part of what we ought to drive towards as well to say this is what we seek, this is how we'll measure it, and this is how we'll report it? Go ahead.

MR. JIM BURTON: Good morning, Senator Steinberg and Members of the Senate Select Committee on Autism & Related Disorders. My name is Jim Burton. I'm executive director of the Regional Center of the East Bay.

I was asked to do something very different; but based on the testimony today, I want to tell you how difficult it was to hear that testimony. As someone who has worked at regional centers for 36 years, it's appalling that

situations like that exist in the regional center system and we have to make sure that they do not.

Regional centers, Senator, are monitored in a number of ways—by the Department of Developmental Services, in terms of contract compliance, compliance with the law. Every other year, we have a team of auditors from, monitors from, the Department of Developmental Services who review all of those issues.

SENATOR STEINBERG: Contract compliance, process, check in...

MR. BURTON: Yes.

SENATOR STEINBERG: ...the box? In the foster-care system, we moved at the county level to outcome-based reporting. Does that exist in the regional centers?

MR. BURTON: Not—no.

SENATOR STEINBERG: There you go. That's another way to begin to change culture, is to begin holding the centers accountable for outcomes. Go ahead.

MR. BURTON: We do have a performance contract process and goals and objectives. It is a summary process. It is not detailed enough or in depth enough.

SENATOR STEINBERG: Okay.

MR. BURTON: We also have reviews on an annual basis for Medicaid waiver funding. That can include both folks from the Department of Health

Services as well as the Department of Developmental Services as well as CMS. Those are the primary ways in which we're reviewed.

I want to speak to you today—I was asked to speak to you today—about regional centers, our system of services, for over 250,000 people with developmental disabilities. I was also asked to provide you with an overview of the funding streams, processes by which regional center budgets are established and purchase-of-service funds are allocated.

Ms. Delgadillo did a really thorough job, as she always does, of discussing funding streams. There are really two—federal funds and state general funds. About 40 percent of our budgets are federal funds, primarily Medicaid, Medicaid waiver, through the Medicaid waiver, and targeted case management, and then the balance through state general funds.

Each regional center has an individual budget and really two budgets—a budget for the services that we purchase in the community that represents about 89 percent of our total budget, and a budget for regional center services that are provided directly by the regional center known as the operations budget. They're very different budgets and there are two—in terms of the services provided, I did want to go back to the funding streams.

In particular in California, the funding streams are not a determinant of the type and amount of service that we provide to others. So in some states, for example, not California, thankfully, you have to be eligible for federal funding of services to be eligible for any services. So I just wanted to be clear,

that while we work hard to bring in federal funds, they don't play a part in the determination of services for the individuals.

SENATOR STEINBERG: They can determine the amount they have available, though, correct?

MR. BURTON: They determine the total amount. They're part of the total amount that we have available, yes, but not the individual amounts.

The purchase-of-service budget again is the largest portion of our budget and is the budget upon which we rely for the purchase of services for, again, over 250,000 people with developmental disabilities and their families. I think the most unique piece of the budget—and Ms. Delgadillo outlined how funds are allocated—what's important is that we receive one budget for purchase of service. Although a number of factors go into that budget, that budget—it does not include any significant line items or we don't have budgets for—by diagnosis, we don't have budgets for types of service. We have an overall budget for purchase of service.

We also have an entitlement in California and a requirement under law that we serve everyone who is eligible for services and individually determine the needs of each of those, each of the people that we serve and their families.

The purchase of service is extremely unique, the purchase-of-service budget is extremely unique because it is really based on the commitments made in all of the individual program plans, all of the individually determined plans for each family. It is really the sum of all of the services that are authorized and purchased through that individual program plan process, and

my colleagues are going to be discussing more specifically how that process works in California.

In summary, the POS budget is one budget for all services, for all consumers, based on individual needs. And I guess, as simple as I can say it, it is one large pot of money that is used to purchase all services that are determined individually. It is driven by the individual program plan for each person that we serve.

The regional center operations budget is the budget for services provided directly by regional centers. As Ms. Delgadillo indicated, it is allocated to us based on really a per-capita, per-person-served basis, no differentiation by diagnosis, by age, no differentiation based on needs, for underserved populations. Regional centers must live within those budgets, must absolutely not spend any more money than we have or allocated for that purpose, and must use that money to meet all of the requirements of federal and state law, federal and state regulation, our state contract, and most importantly, the service needs, the people that we serve and their families. The vast majority of the regional center operations budget are used for staffing costs, serving people and their families.

SENATOR STEINBERG: I think we get the basic picture.

MR. BURTON: Okay.

SENATOR STEINBERG: I've got a lot of pages left. We've got to kind of run...

MR. BURTON: I just skipped them.

SENATOR STEINBERG: That's okay. I appreciate it. We've just got to run through it and, really, I think what you described for us is maybe the way that the system is supposed to be. But what we really want to know is whether you believe the Angelo story, since that is the most poignant story we've heard today, is the exception, whether it's prevalent, whether the *LA Times* disparity numbers that have been spoken about here are true. And if so, what is systemic here that needs to be changed?

Let's get right into it. I know you came prepared to give us the big picture overview. We appreciate that because we need to know. What you told is valuable, but let's get into it here in the remaining minutes we have, all right?

MR. GEORGE STEVENS: Thank you, Senator. My name is George Stevens and I'm the executive director of the North Angeles County Regional Center.

We serve the northern part of Los Angeles County comprising the San Fernando, Antelope, and Santa Clarita Valleys. We serve around 18,000 individuals. Director Delgadillo's comments about the number of people coming into our system with autism are quite accurate and quite shocking when you look at the number of children that we are attempting to serve. I was asked to talk about the IPP process, and I think through my discussion here I will address some of the issues that have come up. And if I don't, just ask me. I'm not bashful about giving some answers you may want to hear or not hear.

The IPP process, as envisioned by its framers and enacted into law must be preserved and protected. The framers gave us a process where a team of individuals that knew the client and, as appropriate, his her family well, well enough, to have earned their trust and confidence. Regional center counselors had the time and expertise to be viable and necessary team members. Service provider representatives are well educated, fairly compensated, and also viable members of the team. In short, the client was surrounded by a team of individuals who had the time and expertise to engage in meaningful planning.

In addition, the planning process was not constrained by artificial limits. The framers intended for the process to be expansive, creative, innovative by identifying services and supports to meet the unique needs of each client. All needs were to be identified either through clinical assessment or discussion with the client or his or her family member. As envisioned, the IPP was to be a comprehensive document that contained goals, objectives to meet the immediate and long-term needs of clients.

Today the IPP process is very different from the one envisioned by its framers. The process now reflects a series of statutory changes, years of underfunding at both regional center case management, and service provider direct-support professionals who are vital members of the IPP team. Regional center counselors no longer have the time to spend searching for creative and innovative solutions due to high caseloads, Medicaid waiver compliance, and trailer-bill implementation. Service providers and staff turnover continues at a

less-than-acceptable rate. In short, the IPP process is not working as envisioned, especially for our most vulnerable clients and families.

As such, we must recommit ourselves to the vision. We must find ways to promote creativity, innovation, and most of all, commit financial resources that are necessary to ensure effective planning teams and the services necessary to implement the IPP.

I'm going to share with you, the committee, that my perspective on the IPP process is based upon experience as a regional center service coordinator. We were called counselors at one time. I was a regional center counselor when the IPP process was introduced, so my attitudes and perspective is generated from my personal experience. As a counselor, I simply wanted to help families and clients on my caseload. Trained as a social worker, I found the initial IPP process to be client and family friendly. I had the time to really get to know clients and families and served to help them. It's afforded me the opportunity to work for many of the issues that oftentimes separated clients from needed services.

The IPP served as a roadmap, we refer back to, throughout the year. We saw people more than every three years as we worked through goals and objectives contained in the document. I found that I had the time to develop true partnerships with clients and service providers, and each client's needs were served as the focus of our conversation.

I believe we have an opportunity here today, but first we need to put blame and excuses behind us and look to see how we can build on a conclusive

system. We need to recommit our financial resources and time to ensure that each client has an IPP that reflects his or her needs consistent with the initial intent of the framers. Today, we're at the end game of an IPP process that resembles a Jenga puzzle. At the bottom, it's a good foundation, but we've added and added and added and added. It will collapse.

Many statutes, requirements, regulations have stacked onto the initial process and now it no longer solely serves clients. However, the current heavily laden IPP process is slowly crashing down on clients it was intended to serve.

SENATOR STEINBERG: Well, that was provocative. And the follow-up obviously is, okay, what are the three things you would do to change the IPP process to make it what you experienced back when you started out in this business as a counselor?

MR. STEVENS: I think we need to adequately fund regional center case management services.

SENATOR STEINBERG: Okay. Funding.

MR. STEVENS: I think we need to adequately fund our provider community, and we need to educate our families. We need to be able to spend time with them.

SENATOR STEINBERG: So it's money. I mean, really.

MR. STEVENS: Yeah.

SENATOR STEINBERG: When it comes down to it.

MR. STEVENS: It's all about the money.

SENATOR STEINBERG: Yeah.

MR. STEVENS: However, if we were to get at these issues that we're hearing today, it takes time. All the things that were talked about here—the service coordinator—there was a time when service coordinators at regional centers went with families to the Social Security Office, went with the families to their doctors' appointments, went with families to visit programs to make sure that they had access, especially those families that were like the family you heard today had transportation issues. Our service coordinators oftentimes took them. We're talking about time and time is about money.

SENATOR STEINBERG: Thank you.

Next.

MR. DEXTER HENDERSON: Good morning, Senator and Members of the Panel. It seems like my topic that I was asked to speak on is a little mundane at this point and not really something that I need to go into.

SENATOR STEINBERG: Do like we do—just improvise on the spot.
(Laughter)

MR. HENDERSON: I didn't come here to refute the *LA Times* article; I didn't come here to refute or have a point/counterpart with any of the other speakers. That's the perspective that they have. I can answer your question very directly—is this a cultural issue with regional centers? My answer is very specifically no, it is not. I would like to think that this isn't that situation that was discussed earlier today is an exceptional situation, a circumstance that is egregious in a situation that we all are concerned about and should be

concerned about. But the realities of it, similar to what's been stated, is that regional centers are inundated with things that they used to do—they used to do things that they can't do any longer. We used to pay for diapers almost out of hand with most of our consumers and families. But because of the budget constraints that have occurred over the last number of years, we're looking at those kinds of things much more closely. We used to provide at our regional center transportation almost without thinking because most of the families in our community needed that transportation because they weren't and not in a situation where they could drive the individual to a day program because of a father or parent had to be at work at 7 o'clock or 8 o'clock early in the morning and wasn't able to transport to a program. Now, because of the increased trailer bill, trailer-bill language that we have placed on us from this last year, we have to go to a generic resource, even more so than what we did before, get a denial from them before we can provide that, and it's impacting the way we provide services to some of the folks in our community.

Yet, are we monitored by DDS? Quite distinct—yes, yes, we are. In a situation that was discussed earlier for a letter that had gone to DDS, you could be assured that we get from the director's office or to one of our chief counselors or one of our top members of our staff, we would have received a telephone call or a letter or some sort of an inquiry about what that situation, what it's about, and give more details and ask for information to further justify some of the actions that were being taken, that was taking place.

With respect to our regional center, I think outreach is one of the most important things that we could be doing. We are doing that now, but we're doing it with our own dime. We're robbing Peter to pay Paul in order to do that. And any of the research, any of the literature, that you see will indicate that one way of remediating or reducing the impact of a disparity in the receipt of services is to provide expanded outreach services. And many, many, many years ago in the core staff formerly, we all had an outreach person who could go out and provide outreach into the community. I don't think any regional center person hires a full-time outreach person at this point. What we've had to do is kind of pull a multiple interdisciplinary kind of a team taskforce to actually do outreach in our regional center but the pulling away from other prime responsibilities that they have in order to do that. We've had a lot of successes with that in reaching out to communities and reaching out to people who don't hear about the regional center.

Why don't they hear about the regional center? The regional center has zero dollars to advertise about our services. We have very few dollars to go into the community and actively work to pull people within the regional center to explain to them what we do to discuss the differences between our system and other systems. It really does again come back to funding. Do we have the dollars and resources to do all the things that everyone wants us to be within a regional center community? But again, back to that last situation, I would like to think that that is not the picture of a regional center and I think that is something that certainly we'd like to hear more about in terms of the other

side, of what was going on with that. But a lot of that also related back to some of the new trailer-bill language that's out there.

SENATOR STEINBERG: Senator Leno had question.

SENATOR LENO: Thank you, Mr. Chairman. I do have a question for Mr. Henderson.

Let me preface my comments by saying, I recognize that what we have done, not only to regional centers but to so much of our state infrastructure, is shameful and it's the result of, as our former governor put it, starving the beast of government, the government that provides...

MR. HENDERSON: True.

SENATOR LENO: ...all of these necessary services. But with that stated, I think it's important, if we've got a problem, we have to acknowledge it, understand it, so that we can begin to solve it.

I have to trust Ms. Matthews when she says that the reason she told us Angelo's story was not because it was exceptional but because it was far too common, from her office's experience.

You acknowledged, that due to funding constraints, that you no longer provide the diapers that Angelo would need, though you once had. You acknowledged that you don't provide the transportation that Angelo needed, though you once had, so at the same time, you said Angelo's situation was uncommon. It sounds like it in fact is common.

MR. HENDERSON: Pardon me, Senator. I didn't mean to say, if I did say, that we wouldn't provide that. I was simply saying that there are more

constraints and more of a review process that enters into the process at this point, more so than prior, in prior times. We all have POS guidelines, the purchase-of-service guidelines, that are approved by the Department of Developmental Services, and each regional center, while they may not, their guidelines may not be exactly the same, they're supposed to follow those specific guidelines, and we do give our guidelines out, if asked for, and we also have a summary of our guidelines in a little booklet form that we've developed that summarizes all of our services. And so a family could essentially go through that little booklet and look at all of the services that we provide and the general criteria, the general guidelines, that we use in order to provide those services, and we've made that book too available, in English and Spanish, to all of our families. That does help but it also creates a perception that, oh, I can get anything that's in this book here and I can go through and pick this, this, and this. But it's again based on the disability, based on the interdisciplinary team's conversation and collaborative conversation and partnership with the family and discussing the needs and the issues that that family or that consumer presents and we hash that around, sometimes back and forth. It should not be adversarial or disrespectful or done in a cavalier fashion.

But we do have staff to help facilitate the process and we hope that it's a collaborative, interactive kind of a process. But many, again, of our families within my service area are not as assertive, if you will. They're not as interactive with or feel as comfortable in the discussion that it takes to explain

what their needs are, and it's my thinking that our staff have been very sensitive and understanding of that and they try to work with and communicate with our families in a way that's open and in a way that encourages them to explain what they think they need and explain why and to discuss their desires and that's how we operate. Again, there may be some differences from center to center regarding that.

SENATOR LENO: Do you think public schools could do a better job of referring families of need to your regional center services?

MR. HENDERSON: You're not going to get me involved in that, are you, Senator? (Laughter)

SENATOR LENO: You don't have a budget to, as you say, advertise. It would seem to me a public school was a place where a family would learn of you.

MR. HENDERSON: We are very frustrated oftentimes in our interaction with public schools. There's no question about it.

SENATOR LENO: Thank you.

SENATOR STEINBERG: Thank you.

We have session beginning, at least in the Senate, in 25 minutes—same with the Assembly—so Senator de León.

SENATOR DE LEÓN: Just real quickly, and I appreciate your comments and I'm very sensitive to the long years that all of you have invested in the world of social service but in particular with these children.

Let me underscore the following: We've had a very strong, compelling testimony and I've heard your commentary and it doesn't equate, so something has to give. So I will venture to say the best-case scenario is the prism in which you view the world specifically as it pertains to, Is it systemic and cultural or not? And the world—and the prism in which they view it is dramatically different, for whatever reasons, because it doesn't jive. We're talking two different places right now.

Now I don't know enough about the South LA regional centers so I'm not going to make any commentary on that. It would be very unfair of me to do so and I wouldn't do that. I do not doubt at all whatsoever your professionalism and your commitment to these children, but Assemblywoman Mitchell just referred to a study—I should say 1998, 14 years ago—and I would venture to say that is pre-budget deficits or at least as Draconian as the cuts have been compounded on. So I will venture to say, you have empirical data there that clearly states that we've had some very severe, systemic problems previous to the Draconian cuts. I'm very sensitive because you guys are absolutely right with regards to the cuts that we have voted down collectively as a legislative body has severely impacted your ability to do what you need to do best by these children and these families. No doubt about it. No one's going to argue that.

The issue of money, obviously, that's always been an issue for us. What's going to happen in November is going to have a major impact on all of you specifically, but we know that money is not going to be the panacea in the

immediate short term, given the state of economy, and the challenges that we have that, Senator Pro Tem, I would say nicely outlined this with the San Francisco *Chronicle* today, John Diaz, and the article, editorial, with regards to ballot initiative reform, you know.

So kudos. That's going to be very difficult obviously and we're going to try our best. But I'll just leave it at that, that we have a study that's 14 years old that clearly states the data, that we have some systemic issues going on. Obviously we're not going to get into the stuff right now, but I would just say that we do have an issue and it has to be resolved in some form, way, or shape and obviously collectively, us doing it together is the best way to do it.

MR. HENDERSON: And, Senator, with all due respect, I was not trying to counterpoint what they were saying.

SENATOR STEINBERG: No, it's okay.

MR. HENDERSON: I'm sure that information is accurate. I think the key thing is that we are all willing to sit down and talk about those kinds of issues and come up with some sort of...

SENATOR STEINBERG: And we're doing so in a very public way here and will continue to, but it also is going to take some intensive, private conversations and I've got an idea at the end I'll share with you about a potential public policy response here that isn't a, not an overnight solution again but begins dealing with the culture issue that you and others have spoken about.

Sir.

MR. ROBERT RIDDICK: My name is Robert Riddick.

SENATOR STEINBERG: Thorough and brief, thorough and brief.

MR. RIDDICK: I can be so brief to say that I've provided written testimony, but I do want to mention that Central Valley covers Tulare, Kings, Fresno, Merced, and Mariposa, and Madera Counties, and I'll let my public testimony or written testimony...

SENATOR STEINBERG: Thank you very much.

Any other questions for this panel? If not, we'll move to the last panel.

Thank you very much. Again, tough spot to come on up but we appreciate it. We're all trying to solve the same problems here.

Last but not least, moving towards a solution here, we're privileged to have with us Dr. Sergio Aguilar-Gaxiola who's the director of the UC Davis Center for Reducing Health Disparities, who I've worked very closely with on the implementation of the Mental Health Services Act, Prop. 63, and he's an excellent resource; Dr. Barbara Wheeler, the associate director of the USC University Center for Excellence in Developmental Disabilities; Dr. Jan Blacher, distinguished professor of education, UC Riverside and founding director of SEARCH; Rocio de Mateo Smith, the executive director of the Area 5 Board, State Council on Developmental Disabilities; and Phil Bonnet, executive director of the Alta California Regional Center; and Areva Martin again to speak on this.

Would anyone else like to be on this panel? (Laughter) What the heck, we've got, you know, we've got room in the very front here but—guys, we have a

few minutes here and I apologize because you cannot encompass your life's work and what you do in a few minutes. But try to guide us a little bit here as briefly as possible.

Dr. Aguilar-Gaxiola, welcome, friend.

DR. SERGIO AGUILAR-GAXIOLA: Oh, thank you so much. I appreciate the opportunity to say a few words, and I'll try to be as brief as I can.

You asked a very important question at the beginning of the hearing, and the question was, What is happening with health developmental disorders that is happening in other mental disorders as well as physical health conditions? And my answer is that, unfortunately, it's not. We have, you know, in mental disorders, for example, even though the evidence shows that we need ___ to prevalence rates of various mental disorders tend to be a little bit lower in minority populations—Latinos, African Americans—with some exceptions.

The issue is really that these groups tend to have more persistent disorders and also with symptoms that tend to be more severe and disabling, something that is very much aligned with what we heard already. But the issue, to a great extent, is the treatment gap, that the people who is in need of services is not aggressive in the services.

Ms. Matthews gave an incredible testimony of, you know, illustrating what happens with one family. And I can capture that in what has been described as the five As, you know, issues of availability of services, accessibility, appropriateness that speaks about the culture and language,

affordability, and advocacy. Each of those are of critical importance to get the families and the individuals that need the services into the door of services. But getting them into the door of services is not enough. You know, the data, for example, that I can share with you with Latinos who make it into the door of services, up to 75 percent don't return for a second time. They just receive one session, so serious, serious issues about quality of care, that it should give us pause on what might be going on. And this has been going on for four years. And we have to face up to this information, this data, and to come up with specific solutions.

I have seven recommendations, in terms of moving forward:

SENATOR STEINBERG: Go real quick because we want to get to everybody. But list the seven and then we'll...

DR. AGUILAR-GAXIOLA: Yes.

SENATOR STEINBERG: Do you have them in writing?

DR. AGUILAR-GAXIOLA: I have them in writing.

SENATOR STEINBERG: I think for the record, the solutions, just boom, boom, boom—60 seconds.

DR. AGUILAR-GAXIOLA: Okay. Public spending should be consistent with the best available science. We spoke about best...

SENATOR STEINBERG: Evidence-based practices.

DR. AGUILAR-GAXIOLA: Community to find solutions as well.

SENATOR STEINBERG: Community and evidence-based practices.

Number 2.

DR. AGUILAR-GAXIOLA: Identify the issues and build on the strengths. We ought to be looking at the strengths of these communities as well, not just the deficits.

SENATOR STEINBERG: Okay. That's related to one.

DR. AGUILAR-GAXIOLA: Bring diverse partners to the table. We need to be a part and these families at the table.

SENATOR STEINBERG: We need stakeholders at all levels to represent diversity; we need to look back at that Jim Beall bill...

DR. AGUILAR-GAXIOLA: Yes.

SENATOR STEINBERG: ...again. I learned something.

DR. AGUILAR-GAXIOLA: Engaging chairs, strategic planning involving schools and communities. We heard about that.

SENATOR STEINBERG: Cooperating with schools and creating those linkages, now with the insurance industry as well, given 946 and its signature.

Next.

DR. AGUILAR-GAXIOLA: Okay. Interventions and implementation strategies that are culturally and linguistically appropriate. Senator [sic] Mitchell mentioned about the cultural shift. That really has to be a part of...

SENATOR STEINBERG: Obviously.

DR. AGUILAR-GAXIOLA: ...it. Two very important ones--_____ the effort and use of the data to continuously improve the strategies and inform all of us on—and this is on performance measures. This is accountability once again.

SENATOR STEINBERG: Performance measures. Just know you are previewing what I'm going to end this whole hearing with here. Very good.

DR. AGUILAR-GAXIOLA: Early identification and prevention are key.

SENATOR STEINBERG: (SB) 946, other strategies like it, early intervention.

DR. AGUILAR-GAXIOLA: Thank you so much.

SENATOR STEINBERG: Thank you as always, for all of your work, Doctor.

Okay. Let's go. Who's next? Go, go.

DR. JAN BLACHER: Okay. Thank you, Senator—oops—thank you. Thank you, Senator Steinberg, and those of your esteemed colleagues who are still left in the room. I'm Jan Blacher, professor in the graduate school of education at UC Riverside. I come to you here as the founder and director of the SEARCH Family Autism Resource Center at UCR, which stands for support, education advocacy, resources, community, hope. But I didn't always have my one leg out in the community, like I do now, and I think you will be receiving post-hoc, some information in your packet about the mental health of Latino women that I've studied in the last couple of decades. I did not come prepared to speak about that. But the short form is, that Latina mothers of children in the DDS system that we studied had a 49 percent—49 percent of them—had clinical symptoms of depression. And that was back in the late '90s, but what you need to know—and there's vast literature—that depressed mothers are less likely to seek services for their children, okay?

So let me talk today about something on...

SENATOR STEINBERG: You came all the way from—where did you come...

DR. BLACHER: All the way from the Inland Empire.

SENATOR STEINBERG: You know what? And so it's really not fair to you or to anybody to, you know, cut you off, but I don't know how we're going to do this. Maybe what we can do is—hold on—there's always a solution...

DR. BLACHER: I'm thinking.

SENATOR STEINBERG: I wonder if we could come back immediately after we have a relatively short session, you can come back and finish this. I don't know.

DR. BLACHER: Whatever. I mean...

SENATOR STEINBERG: I don't know, schedule-wise, and then we've got public testimony, et cetera. So give your testimony.

DR. BLACHER: You want me to do it? Well, I'm going to cut it short.

SENATOR STEINBERG: Thank you.

DR. BLACHER: Keep half of it out. But what I really want to do, and at Lou Vismara's suggestion, was to explain what we've done at SEARCH with mainly Latino families and how we might be able to leverage these efforts for greater impact statewide.

You have in your packet another case. I'm not going to review it here. It's a case of Mrs. Teladono and her child Val who were kind of left out of what I call the road race to autism diagnosis, and she came to us for SEARCH, and

let me tell you that what we do is target low-income and mainly Spanish-speaking families and we target their educational needs from diagnosis through adulthood. And beyond that, of course, we screen their children. And you mentioned this earlier, Senator. We actually teach these families what evidence based means so that they can make more informed choices with regional center and with their schools about the treatment that they have for their child and so that they don't waste a whole lot of valuable time on unsubstantiated treatments.

Now you also have evidence in your notebook that Latino children are often identified later, at older ages, than Anglo children. And that mere act puts them at risk because they lose valuable time for early intervention and that's the window during which you can make the most gains.

I have three points to make from data that I have in your packet and I don't know if you want me to show it but they are three points, something that hasn't been mentioned today, that we have been successful in reaching Latino families in our screening clinic and that's contrary to some of the information in your packet. And the Latino families coming to our clinic are not older on average than the Anglo children. But what's interesting—second point—is that these Latina mothers report fewer and less severe symptoms in their children than the Anglo mothers, and this underreporting of symptoms is most noticeable in key areas, like social development, which is a target for autism. And, three, when we actually do the screening and use gold-standard screening instruments, including the observational measure, the ADOS, we find that

among the children that do have autism, the Latino children are actually more severe in their symptoms.

SENATOR STEINBERG: It's begging the question, What are you doing so successfully to get more Latina(s) into your clinics for the screening in the first place?

DR. BLACHER: You know, out of 100, we have about 87 of them are Latina. We have made particular efforts to do that, which is what I'm about to tell you.

SENATOR STEINBERG: That's what we need to know. What is that model that gets the outreach and brings people in?

DR. BLACHER: Well, one of the implications of these data, though, the fact that Latina mothers underreport the symptoms, is that they are less aware of what autism is. And we really need autism campaigns to go beyond just materials written in Spanish—flyers in Spanish, red flags in Spanish. That's not it. We need personal outreach. Autism education is key.

SEARCH has bilingual, bicultural staff members who get off the grid, if you will. They go to community meetings; they go to parent groups; they get on Spanish radio stations; and they talk about autism and autism screening, as just a few examples. So, you know, I have a lot more to talk about in terms of the economic value to doing this. But I'm going to close by just reminding you that SEARCH is really a community outreach for UCR because, as you know, the UC system is a Ph.D.-granting institution so we provide a context for Ph.D.

students and school psych and special ed to really engage in research and learn about families and autism firsthand.

Our screening and follow-up services have been proven to be quite effective, and we would like to be involved in consolidating these kinds of efforts across the state. I'll leave it there and thank you for listening.

SENATOR STEINBERG: Very good. Thank you for shortening it but we got the essence of it and it was very good, all right? What we're going to do here—here's what we're going to do. At noon, we'll break. We have session that I think will be between half hour and 45 minutes on our side, and then we'll come back and we will conclude the hearing. All right. So I'm sorry for people who have flights and all that but we're doing the best we can.

MS. DE MATEO SMITH: Senator Steinberg, because we're going to break and you're not coming back for 45 minutes, I just want to acknowledge that a large group of Spanish-speaking families who came here and will have to go back to pick up their kids, and they are here because they are so interested...

SENATOR STEINBERG: Can you all, the families, stand up, raise your hands? Is there a particular—is there one person who might be a good spokesperson?

MS. DE MATEO SMITH: They have two pieces of written testimony.

SENATOR STEINBERG: I want the two people who are going to testify to come forward. We will take them out of order, without objection.

MS. DE MATEO SMITH: I am sorry.

SENATOR STEINBERG: That the families have—we hear from the families directly, okay? If we can make room at the table here, I'd appreciate it. Again, we will make this work. Let's hear from the families. We appreciate you. You're the real reason why you're here, you and your children. And please, we have a few minutes. Give us the essence of what you want us to take away today, please.

MS. MARIA RODRIGUEZ: We come to you to representing more than 80 families in the East Bay...

SENATOR STEINBERG: Your name is?

MS. RODRIGUEZ: Maria. Rodriguez.

SENATOR STEINBERG: I'm sorry, Ms. Rodriguez. Go ahead.

MS. RODRIGUEZ: ...who have a child with autism and who are active in small groups. We belong to a support group of Spanish-speaking families ___ to learn more, how help our families and children and to support each other in our challenges and our struggles. As we raise a child with autism ___ new future. We have a fantastic services system. That is so difficult to understand. That is why we're coming together to learn and to be informed.

We learn from professionals who's coming to speak to our group and for each other experience. English is a second language for most of us, and our master of English varies widely, though we are all committed to learn in order to help our families.

We find it very difficult to understand the service delivery system. Families who are new on the system find it very hard to understand how to

working with the system. We find it difficult to understand the concept and is challenged when the information is in English even when we are working _____ with the language. When information is translated, translation tends to be literal and poor quality. When families have request(ed) translation for report, it took a long time, a year sometimes, or we are told it is very expensive. It is very hard to get service for our children with autism. There are not enough bilingual providers. Specifically, if our child needs behavior intervention, it is critical for us to understand the concept and how to be able to follow up with intervention. When the providers cannot explain the concept, it is the way we can't understand.

We are not always able to follow up. If we request that the service to be provided in Spanish, we are told that our waiting list for the service, in Spanish. Sometimes we are offered service in English, but often we are left without services. Often we are unable to get the services for our families' needs. Unfortunately, some families had to have experience to bring _____ by the case manager that they should be grateful for the service, the service, and should not ask for more. And we are grateful and we are not, not assertive and our children miss out.

Sometimes it feels like social worker many times do not know information. Many of us did not find about support groups or other information from our case manager or from other parents. It feels like they don't want us to get information because we will demand more.

Thank you very much for holding this hearing. It is essential to _____ service for children and adult of color. Thank you.

SENATOR STEINBERG: Thank you very much for having the strength and the caring to come to Sacramento and to tell your story, Ms. Rodriguez.

MS. RODRIGUEZ: Thank you very much.

SENATOR STEINBERG: Go ahead.

MS. ROSA VALLEDOR: My name is Rosa Valledor. I'm here representing Congreso Familiar. I won't reiterate what she said today. I'm here to talk about maybe some solutions of maybe some best practices that Congreso has done but I concur with everything she says.

Okay. Congreso—I'll tell you a little bit about Congreso. Congreso Familiar is a grassroot organization whose mission is to provide education and develop leaderships in the Spanish-speaking community that have children with disabilities. We have been gathering Spanish-speaking families for over 20 years in Northern California through an annual conference that draws close to 1,000 participants.

This conference would not be possible without the partnership of the regional center of the East Bay. Maybe this is something that the other regional centers can copy so they can do an outreach properly, respecting the cultural.

SENATOR STEINBERG: So it's a one-day conference?

MS. VALLEDOR: Yes, sir. We provide daycare. There's 30 workshops. We have different services, different workshops, from education, rights,

responsibility, health, therapies, and we have, and also informational fair from different agencies in the Bay Area so parents can talk to them one on one. Our regional center executive director, Jim Burton, always attends. So a lot of parents are able to talk to him and even thank him.

SENATOR STEINBERG: Do we know, if I may, whether this occurs, this sort of outreach occurs, throughout the state in other centers or not, mixed, is what I'm told.

MS. VALLEDOR: I think it's different because we provide babysitting and we do transportation, and we invite the whole family. We don't just invite the parents. We invite the grandparents; we invite the uncles, aunts, caregivers, so they can all be educated.

SENATOR STEINBERG: Because I hope my district office isn't listening, but I think I want to do one of these in Sacramento.

MS. MARTIN: Special Needs Network does a similar conference in Los Angeles, and we draw approximately 2,000 families out and primarily African American and Latino Families, and it's two days of very similar informational conferences, workshops; childcare is provided. It started with a legislative breakfast where Assemblymember Mitchell and Senator Curren Price, amongst others, talked about what's happening in Sacramento. So it's happening in South LA. It seems like it's happening in...

SENATOR STEINBERG: But is it also a place where an individual family can actually open a door to getting the help that they need?

MS. MARTIN: Absolutely. Regional centers are invited as well as other service providers, so we get kids signed up for everything from preschool to get them connected with regional center representatives as well as other therapy agencies and providers in the community.

SENATOR STEINBERG: Okay. Very good.

UNIDENTIFIED SPEAKER: I will talk to it when I present later on.

SENATOR STEINBERG: Okay. Thank you. I cut you—did I cut you off too short?

MS. VALLEDOR: It's okay. I know we're limited in time, but I just wanted to talk about—that's one way of reaching other parents, not just the parent but the family, in order to support the child so the child can be successful.

SENATOR STEINBERG: Sure, sure. And it doesn't take legislation.

MS. VALLEDOR: No. And we're a mom-based organization and nobody pays us. We just do this because we see the need.

SENATOR STEINBERG: If it doesn't take legislation, it must not be a good idea. (Laughter) That's all I've got to say. So—just kidding—let us take a break here and we'll come back again, be flexible between 12:30 and 12:45. Apologies but we've got to get to session. We'll stand in recess. Thank you.

***** RECESS *****

SENATOR STEINBERG: The select committee will reconvene. I want to thank the panelists, the members of the public, the members. I want to welcome Senators Berryhill and Fuller to the dais. They've been consistent participants in the discussions—Senator de León, of course, for being here this morning and coming back—and I'm sure we'll have other members.

So we still are on a relatively tight timeline because we have full afternoons, but let us finish panel. We'll take the public testimony. We did hear from the parents from Southern California, and then we'll hear from others and then make a few suggestions and point some directions here, and we will then adjourn.

Please.

DR. BARBARA WHEELER: Good afternoon. My name is Barbara Wheeler. I'm the associate director for the USC, at the University of Southern California. A lot of things that were already said, I would repeat again but I won't do that, given the fact you have not a lot of time.

First of all, though, I would like to say that it's really gratifying that we are no longer debating that there really are racial disparities in regional center services. It seems like we have been going back and forth for a long time, so I'd like to commend the Senate Select Committee on Autism & Related Disorders to bring us to this place and so we can move forward.

I think you already know this, but the issue we're discussing about racial disparities is not just about individuals with autism. It actually impacts people with all types of disabilities within the regional center system. I don't have

permission from Terri to discuss this. But when you asked the question about the needs-based formula for producing budgets and how that addresses disparities, I was actually on a committee where they presented the data from the Stanford people, and what ends up happening is, if you use objective data, such as CDR ??, did you find the needs of the client, they have ways of looking at the severity of the needs. And then they looked at—they did an interesting study. They took a bunch of DDS data, applied that formula, saying that all the people who have this need should get this amount of money. And then when they plotted it, the mean level was what you should have gotten using the formula and nothing else.

There were a whole bunch of people below the mean who tended to be underrepresented minorities who were getting less than what would have been predicted if they had just used a needs-based formula, and there were fewer people above the mean getting considerably more. And these were, technically, if you use the formula and believed it, were all people with the same severity of needs. So it is a way to start addressing the issue of disparities so that the power of the advocacy of the parent isn't the major factor in getting services as well as expenditures. And if that's wrong, then I guess Terri is going to have to talk to you.

Okay. There are some quick myths I wanted to go through that I keep hearing when I'm on these committees. I hear sometimes that people who come from diverse cultures, they choose to take care of their own so that is a choice that they get, fewer services. I work with minority parent groups a lot,

have done it for decades, and I've never heard a single one say, I don't want services. They are really clear that they may not want a certain type of service or the way it's delivered or that they don't trust that the provider will respect the cultural values of their family. Some of them also worry about their kids. So if you hear that myth, I hope you just don't consider it really an issue. It gets messy when they say, well, it's really their choice. If you know the Lanterman Act, individual choice is a major factor. It's not a choice when you don't have a full array of acceptable options. So that one is a myth.

The other one that I'm hearing now is, we just need to train parents to be better advocates, so that when they're in the IPP process, they can speak up and get the services they need. Our system of the IPP—it's also in special education with the IEP—is built on a western model of advocacy which is their skills and behaviors that are not comfortable for some cultures. They don't question authority. By not questioning does not mean they agree with what they're being told.

So the notion of trying to train these families to be better advocates and somehow the disparities will go away, that is actually putting the onus on the client and I think it really belongs on the regional center. It's not that we don't need to treat people to be good advocates, but it shouldn't be the first solution, so that's another one that I hope we don't get caught in.

In terms of engaging and supporting underserved groups, we've had some luck, and there have been programs all over the country contracting with minority CBOs—I'm not a regional center. But where we've paid them to do

work, to reach underrepresented groups we have some grants trying to get more Latino families involved in biomedical research on autism, and we use a community-based organization as our representative, and we've used them in other ways as well. That is something that regional centers could do. They could vendorize CBOs. But my colleague, Areva, when we talked about this, she said, Uh, Barbara, double-edged sword. Once you start paying poor CBOs who are doing this for free to now do this work, they are less likely to criticize the regional center, even if they're not happy, because they are now a funding stream. So I think it's a great idea, but I encourage the legislature to figure out a way that they're not caught in a bind where they lose their primary goal, which is primarily to be advocates for groups that aren't currently well served by the mainstream system so that's something to think about as well.

In terms of best practices, I wanted to recommend the work that Rachel Guerrero has done. She's now retired from the California Department of Mental Health. Every time I mention that, people say, What are you talking about? Mental Health doesn't even exist anymore. But she was the chief of Multicultural Affairs. She had an incredible ability to come up with ways, to bring power back to communities. Her job was, people of color were not using the mental health service system, and she seemed to have control of her finances, but Dr. Gaxiola probably knows some of the programs. But they had a program where they actually put money into the community to address this issue, and I think it's a model potentially for regional centers.

Do you want to just mention that, Dr. Gaxiola? And then I have one more thing to mention.

DR. AGUILAR-GAXIOLA: Sure. The project that Dr. Wheeler is referring to is California for Reducing Disparities Project that is under the Prevention and Early Intervention, a statewide project, is one of four and...

SENATOR STEINBERG: Through the Mental Health Services Act?

DR. AGUILAR-GAXIOLA: Through the Mental Health Services Act, yeah.

SENATOR STEINBERG: Good to see some integration with the autism advocacy community and the mental health community and that the funding streams find some ways to link where appropriate are like that.

DR. AGUILAR-GAXIOLA: Yes, and the unique aspect of this particular program is that usually we tend to rely on interventions that are best practices based on the best evidence available. While this one specifically is on community-defined evidence, which is to go and, you know, in a very grassroots manner and speak with as many representatives from ethnic and racial groups, including LGBTQ groups is to learn from them what seems to be working at the community level, recognizing that what comprises best-evidence-based practices usually are created without the inclusion of minority populations into those trials, you know, or that research. So I think that one of the strengths of this particular project is that it is not more of the same. It is an innovative way of consulting with communities to see what the communities in their wisdom, you know, in community places, have identified as solutions, you know, coming from their own.

SENATOR STEINBERG: Thank you.

Let us, last point quickly, please.

DR. WHEELER: It is also important that stakeholder workgroups reflect the ethnic diversity of the population in their area. The boards of directors of regional centers must have good training and support so they can be active participants in the governance of the regional center.

SENATOR STEINBERG: Thank you very much for your testimony, good suggestions.

SENATOR STEINBERG: Who's next? Briefly, briefly. Go, go.

MS. DE MATEO SMITH: Thank you very much. And since the parents spoke and they have so much to say, I'm not going to speak about that. I'm just going to reiterate. The conference that they spoke about, what is unique about it is that parents took the leadership. A group of young parents came to us professionals who were putting on a conference and took it away from us, developed their own nonprofit, and have grown and developed.

How do you develop parent leadership? How do you develop information on education for families? You go to the families who are the key and learn from them and get a little bit humble and listen to them. So education and information is critical. It has to be in the language and in the culture of the family. This conference is not just a collaborative with a lot of organizations but it is the parents, and we invite everybody, as the mom said—grandparent, neighbors, anybody who has anything to do with that—because that makes a difference.

There are other conferences like that, and I needed to tell you that Fiesta Educativa here in Sacramento...

SENATOR STEINBERG: Right.

MS. DE MATEO SMITH: ...is an exemplary conference also that does very similar things, and there's Fiesta Educativa in Los Angeles, Fiesta Educativa in Monterey County, or something like that. That's important. It's not enough. It's not enough. It is important...

SENATOR STEINBERG: It's one strategy. It's one...

MS. DE MATEO SMITH: But it is critical. It is critical because, when you're participating in your language, you have a dialog that you cannot have through a translator or an interpreter. So that's—developing leadership is critical in the parents. There was a grant from the state council to develop parent leadership amongst Latino families. Twenty families came from all over Northern California and for six months, once a month, spent all day, and they have grown in providing educational opportunities for other parents in developing parent groups and in joining boards and committees. It is critical, but it is this whole thing about being amongst your own people that gives you the strength to bridge into the other culture.

So speaking of cultures, there is a real cultural issue because our culture—and now I consider myself American after more years here than I was ever in Mexico—our culture direct and assertive. Those two things are considered bad manners in many cultures; and therefore, we are asking people to come and ask for services in a way that is not of comfort to them that they

don't know. And it's not until they learn that that's why they have to do it that they may be able to assert the rights of their children.

So parent groups are critical for that because parent groups are a place where families talk to each other and learn from each other and get strength from each other, and that's why you had all of these parents that came today. They came from the Bay Area. They learn from each other. They are—they get strength from each other. But there is this unspoken belief that parent groups nurture discontent or at least nurture assertiveness and that's not good for the system because they'll come and ask for services. So that is a real thing.

I wanted to also talk about what you said about families, Latino families, not identifying their needs, as heavy as they really were. That's because our community is so used to carrying such heavy loads, that what would be considered *really heavy* to somebody else, it's just one more burden that they carry, and we have to be aware of that because sometimes they will come and speak in ways that we do not understand that it is as difficult as it is for them because it is a different language.

SENATOR STEINBERG: Senator de León had a quick comment.

MS. DE MATEO SMITH: Sure.

SENATOR STEINBERG: Then we're going to...

SENATOR DE LEÓN: Let me say something. I'm not a sociologist or a social worker, but on that issue it's interesting. I can say anecdotally, you know, obviously on the issue of mental health, which is such a critical issue and obviously it affects African Americans, Latinos, Asian Americans—everyone

on the spectrum. But I remember growing up when folks in our family or neighbors had some mental health issues, it would sort of be, like, you know, you didn't discuss it directly or it wasn't a diagnosis. They knew something was wrong but there was never no clinical diagnosis of individuals, kind of like, you just stayed quiet and you just put it to the side and you just lived with them and you just take care of them. And the funny thing about it—and again, this is anecdotal—when I go to Mexico, I used to see folks who have mental, developmental disabilities. They often—this is anecdotal, you know—but they often seemed more happier because the family wraps around tightly and there's no access to all the programs that have here. It's a very fascinating component I see, very fascinating component, in the way that interaction is, which is culture, you know.

DR. BLACHER: Do you want discussion or no?

SENATOR STEINBERG: No. I do. I want spend the next five days having discussions. But go ahead. Respond briefly.

DR. BLACHER: I want to respond briefly because there's such a tendency to point out needs, needs, needs in a session like this, but over the years our project has published a number of things that shows that the Latino families that have been in our studies report far higher positive impact of their child with disability, and disability can include autism, than do Anglo families. And that's been shown with young adults, adolescents, and little tykes and whether they have mild disorders or very severe impairments. So one of the things we've been grappling with is, despite lower socioeconomic income, lack

of education, unbelievably low income, more children, blah, blah, blah, they have resilience that no one else who has many, many resources has been able come up with.

So, you know, I'm just not saying ignore it. I'm saying, if we can harness the resilience and meet the needs of the child, we'd be...

SENATOR STEINBERG: The resilience is admirable obviously, but that's not necessarily a substitute for getting...

DR. BLACHER: Not at all.

SENATOR STEINBERG: ...getting the help that you need as well.

DR. BLACHER: But we should harness that and...

SENATOR STEINBERG: Of course.

DR. BLACHER: ...turn that toward...

SENATOR STEINBERG: Okay. We're going to move it on.

MS. DE MATEO SMITH: Okay. So let me just...

SENATOR STEINBERG: Conclude. (Laughter)

MS. DE MATEO SMITH: ...finish one thing because I think it's important and because the *LA Times* pointed out to one thing which was that parents, we don't serve minority parents because they cannot participate in orientations and whatever, you know. I think we need to be very aware that new initiatives do not harm people, underserved communities, more than the general population because they cannot be, take advantage of them, I mean, particularly worried about the Telehealth interventions for autism and how that could—we have to do it but we have to be very...

SENATOR STEINBERG: We have to be culturally ____.

MS. DE MATEO SMITH: ...careful and not to deny it because they cannot participate.

SENATOR STEINBERG: I understand, right. That's a very good ending point. Thank you. Thank you.

MS. DE MATEO SMITH: And let's do more bilingual case managers.

MR. PHIL BONNET: My name is Phil Bonnet. I'm the executive director of Alta California Regional Center. Thank you for allowing me to be here. I did bring written testimony so my testimony will be very brief this morning, or this afternoon, now.

With regard to cultural competency, I think that finding service coordinators and giving them the tools that they need to effectively work with families is incredibly important in this process, and I was just talking with some of the staff in my office, which is just down the street here in Sacramento, and asked about the different languages that are represented amongst our service coordinators. Right now the folks here at Alta speak 15 different languages in the service coordinators, and we hire people directly and give them pay incentives for bilingual abilities so that they can reach out to families. And I think service coordination is so, so critical.

The story that was told this morning—I think about that. If that were to happen at my regional center and I knew that it was true, the first thing that would happen is that that person wouldn't work for me anymore. And then the second thing that would happen is that I would look into the possibility that

that was going on in other places. Service coordinators got to have the time to connect with families. Caseloads have been rising and rising and rising and it's really, I think, hurting the relationship between families.

I started working in this field almost 30 years ago as the direct-care staff in a group home for kids with autism. And I remember, when the regional center would come to the group home, the parents were there; the child was there; the providers were there; and there was time, there was time to do it because the primary goal didn't escape people, and that is, treating our clients and taking care of their families. And that's still our primary goal, but we have so many other things going on. So there's a lot of different things that we could do, but I'm telling you, we've got to value the relationship between the service coordinators and the families.

The second thing is, I think we've got to take a look at different models of service for autism, and here in Sacramento we have a place called the Kendall School which is a center-based model where families who might not be able to bring people into their home for the amount of time and the intensity of services that is required with some in-home programs can go to a center, still get deeply involved and very much a part of the program but having it happen in outside areas. I think we've got to do more research about alternative types of programs that have good outcomes for our folks because, the way we've set it up is kind of an all-or-none program. So you buy in, you do this whole time, or you don't get much, and I think that that hurts kids and I think that we can do

more research about the effectiveness of other models. We've got lots of testimony in writing here for you. Thank you.

SENATOR STEINBERG: We'll read it.

Ms. Martin, last word.

MS. MARTIN: Thank you, Senator Steinberg, and all the senators that are here.

Again, I just want to thank you for convening this hearing. It's a very important first step towards addressing the issues of inequality for black and brown kids and kids in underserved communities.

One thing we didn't have time to delve into today was the actual disparities that that *LA Times* article revealed in terms of regional center services and funding, and I think that's an important issue that we have to remain mindful of. Those kids that are in that study, they're already in the system, so there's not an issue of outreach because we've heard a lot today about the need for more funding for outreach. We have to be clear on the fact that there are two issues. There is outreach issues, but there are also the kids who are already identified and are deemed eligible and the services that they get.

So I just want to end by saying, I think, what I've heard in terms of what's really, really critical here is, the issue of transparency and accountability. And when we started talking about this, Barbara said to me, Areva, there have already been bills about transparency and they haven't gone anywhere. And I said to her or I thought, well, Darrell Steinberg wasn't Senate

Pro Tem; and with Darrell Steinberg here leading the charge for autism, I think we have a real opportunity in this state to do something good for all of our kids and to say that all kids matter, not matter what your skin color is, no matter where you live geographically in the state of California, you deserve equal access to services and our kids should be getting those services, and I think we are all poised here to work collaboratively to make sure that happens. Thank you.

SENATOR STEINBERG: No pressure, no pressure. (Laughter)

You know what? Genuinely...

MS. MARTIN: Thank you, Senator Steinberg.

SENATOR STEINBERG: ...I'm so genuinely—this is, you're all incredible advocates, really, and it makes the difference. Areva, you're the best. But it's true, it's what makes a difference. It's speaking truth to power and holding people in these positions of power accountable, and I've got an idea that I want to close with.

I thank you all, panelists, for your time, your patience, and for all the work you do.

Let's hear from the public, those who have not spoken. And again, I'm going to ask you all to be very brief.

MS. LAUREEN FORMAN: Hi. My name is Lauren Forman. I'm from San Diego, California, and I was just coming up. I was excited to hear that you were having this, especially, specifically talking about the disparities and what I actually see and have witnessed in my own self is the disparity

based upon diagnosis. It has nothing to do with—and it's not within the autism spectrum. Just as Ms. Matthews did testify, doctors saying there's nothing we can do, especially for that family, my heart goes out to them when I hear that other families have heard that.

I'm a strong advocate. I didn't take no for an answer and I went out and sought treatment. In fact, in San Diego, at Rady Children's Hospital, if you call into the neurology clinic and say that your child has autism, they will not take an appointment. That's serious. Kids with autism, 25 to 40 percent, we know, do have seizures. They at least deserve to get a workup for an EEG, and so that's what I wanted to bring to your attention. If these children cannot get medical treatment, how can they get better? Thank you very much.

SENATOR STEINBERG: Thank you for coming from San Diego, and I know you're from San Diego. Very briefly.

MS. KRISTY NARDINI: My name is Kristy—thank you—Kristy Nardini—and I'm a parent. So seizures, ear infections, respiratory issues, limited food preferences, tummy troubles, rashes, ABA, RDI, IEP, IPP, IFSP, EEGs, MRIs, OT, ST, PT.

I have two master's degrees but neither prepared me for one of the toughest jobs in the world, and that is, parenting a beautiful child with autism. The illness part of my son's autism started appearing when he was around 15 months old and was in full force by 18 months. Yet, he was not diagnosed with autism until he was nearly three. A few months later, I attended my first parent support group and was fortunate enough that the speaker that night

had written a book about her son's recovery. I immediately made an appointment for my son to see her son's doctor and had to wait six months for our turn. I'm so grateful to say that with a lot of medical and therapeutic interventions, my now ten-year-old son is on the road to recovery.

I'm doing everything I can so he might attend college, have a fulfilling career, and a family of his own if he wants, and most importantly, contribute to our society, become a taxpayer, and be happy.

I've not felt compelled to speak out about autism until the CDC announced earlier this month, which happens to be Autism Awareness Month, that 1 in 88 are affected and that those figures are four years old. I want every doctor on every corner to recognize and treat the medical issues of autism so every child has the chance my son has.

We need an approach that treats medically and then provides rehabilitation. We need attention from both the medical community and the services that provide speech, occupational, and social therapies. The regional center is only one piece of this puzzle.

Thank you again...

SENATOR STEINBERG: Go ahead. Please, take your time.

MS. NARDINI: I'm done. Thank you very much.

SENATOR STEINBERG: Okay. Ms. Nardini, thank you. I commend all of you, really. I know we're hurly burly and rushed and all that jazz. And as Mr. ___ says, we need to have—I'll speak for myself—we need to have longer hearings during the interim and we will, okay? Thank you.

Who's next?

MR. ALI SADEGHI: My name is Ali Sadeghi, and I'm coming here on behalf of SCCABA, Southern California Consortium (for) Applied Behavior Analysis, in Los Angeles.

We heard a great deal of testimony. One of the things that I want to indicate regarding the disparity of services is that we might not need that much legislature [sic] to deal with this problem if, at the get-go, when the families, they come to the regional center for eligibility assessment, the psychologist will completes that assessment, connects the diagnostic assessment to a treatment protocol. My experience is that the psychologist makes the diagnostic assessment and there is no connectivity between that diagnosis and the treatment, so the parents are not educated at the get-go, what is available to them.

Parents then generally need to go and find on their own what treatment is available to them. There is some kind of Don't-Ask-Don't-Tell kind of policy. So if the parents are not asking what services are available, their service coordinator may not fully make them aware of what services are available.

SENATOR STEINBERG: Thank you, another good thing I didn't know.

MS. MICHELLE HEID: Yes. My name's Michelle Heid. Thank you for having me. I am also a member of the Southern California Consortium for Behavior Analysis. I'm also a parent of an 11-year-old consumer on the autism spectrum, so I've been through all of the same things that you, as a parent, have been through, finding it very challenging to navigate the system of

regional center and receive the help that my son desperately needed. And like this other mom that spoke before me, I didn't take no for an answer because I knew to speak up and I knew to continue asking for services that my son needed, and the challenges that parents have in navigating the regional center system are extreme. I also am highly educated, do not speak English as a second language, and find the challenges extreme.

One thing that was mentioned earlier is the IPP process, that the regional center comes together and a team wants to develop IPP goals that meet the best needs of the child. However, that IPP process is often rushed, parents will list multiple concerns with only two or three being written down on the IPP, and then the IPP is signed and never seen by the parents for months and months at a time. So they leave that IPP meeting thinking they're going to get great services. They leave and they don't get that IPP piece of paper for six to nine months afterward. And then for parents with English as a Second Language, it's often not translated so they can't—they can't even navigate it.

As a service provider, we also have the same struggles in getting those IPPs so that we can best meet the needs of the consumers that we serve. So I think that we really need to create a system for parents that works with parents. And like you mentioned, having somebody walk them through the process, that should be the service coordinator. There is a person designated to oversee the case management already, but their caseloads are so high, they just don't have the time to properly walk parents through that process, and I

think that their system's already in place. We just need to fix them. So thank you for having me.

SENATOR STEINBERG: Thank you. Very good.

MS. HEID: And we have written testimony as well.

SENATOR STEINBERG: Who's next?

Please submit it. We'll make it part of the record and endeavor to read as much of it as we can.

MS. EMILY BROBERG: Hello. My name is Emily Broberg. I'm a board certified behavior analyst and a clinical director of Foothill Child Development Services.

My personal, educational, and professional background all has prepared me to provide services to cultural background—culturally sensitive services—to bilingual families. I have currently many staff who are direct level and supervisor level who are bilingual in Spanish and Armenian, who serve the San Fernando Valley region, north of the county, and I have made efforts to specifically address the cultural needs of the culturally diverse population in our community and have been successfully been able to provide services.

I do have concerns, that while we are addressing the financial issues and all the regulations, I hope that they can continue to provide services because there are agencies like ourselves who are working hard to serve these families and are successful and do have a great relationship with the service coordinators and the regional center, and I do not want to be concerned every day due to financial reasons and sometimes lack of clarity in what the

regulations are. Our goal is to comply with the law and to be able to provide, continue to provide, quality services with program integrity as we have been in the last five years.

SENATOR STEINBERG: Good. Thank you.

You know I think Senator Leno said it earlier and bears repeating, you know, the people, the individuals, who work, in this system are dedicated people and help lots of people. And, you know, we're talking about the system here. We're not talking necessarily—and I'm sure there are some people who aren't so good working in the system, like in anything—but I'm talking about systems change here and how do we change culture and the macro ____.

MR. JIM LANTRY: Senator, Jim Lantry. I've got two hats today. One, ATPIAN, which works with treatment providers to help them get credentialed with insurance companies. And just to follow up with what you just said, I will tell you, that across the state, we have so many different kinds of treatment providers that we're working with that appeal to various cultural aspects.

We have one group that appeals to the Vietnamese; we have others that appeal to the Latino culture. They're out there. They just need the help that they need from the regional center.

My other hat today is the DIR/Floortime Coalition and I'd like to say, you know, we talked about evidence-based practices and evidence-based practices are three pronged—so clinical research, obviously, clinical expertise, another one, but the other one is the cultural and family values of the patient, and we need to take those into consideration. And what that means is, we

need to provide services that are appropriate for that particular individual, both from a family and cultural standpoint, and from their own individual disability.

There are seven regional centers in the Greater Los Angeles area. Some of those regional centers will offer one service; some of them will offer another. And unfortunately, many families find that they either have to forego a service or they have to move in order to get the services that they need. North Los Angeles Regional Center, for example, if you've decided that our children needs DIR Floortime, you're not going to get it. You have to move to East Los Angeles. And I don't say that to pick on North Los Angeles because about half of the regional centers don't offer it. Others disguise it as something else called adaptive skills training.

We need to have a list of services; they need to be consistent; and people shouldn't have to relocate. The people that are most affected by this are the ones that are subject to this hearing.

SENATOR STEINBERG: And what I want to put forward here in a few minutes, I think, goes towards exactly what you just said. Thank you.

Briefly.

MS. KAREN FESSEL: I'm Karen Fessel, with the Autism Health Insurance Project and help families make the transition to get insurance to pick up some of the interventions they need.

One of the things that I'm seeing is that families that have Medi-Cal are there also. Some of them are covered by a regional center but they've been cut back, just like everyone else, and there's nobody picking it up. And then also,

they have much longer wait lists for things like speech and occupational therapy. They were not included in the recent legislation, and so their services are just getting cut back and there's no—there's nothing in between; there's nothing to support them. And so they're getting cut back like everyone else, but there's nowhere else for them to go. That's essentially what I have to say.

SENATOR STEINBERG: Thank you, another gap.

Yes? Go ahead. Either one is fine.

MS. FAWN JIMENEZ: I'm Fawn Jimenez. I'm a board-certified behavior analyst from Southern California. I'm also the clinical director of an agency that provides behavioral services. I've worked with children from ages 2 to 56.

I just wanted to point out that the services that we provide are very cost-effective. When we work with the family, we want to teach them independence so that it won't take as much energy and emotional drain and finances in the future. For example, if you have a consumer that is 13-years-old and has been wearing diapers their entire life, if we go in and start working with them, one of the main things we want to target is to get them toilet trained, and it's going to decrease the financial stress on the family or the regional centers. It's going to help the families with, you know, decreasing the emotional frustration and just physically draining for them, so that's one example.

Another is, if a child has severe behaviors and they tantrum when they have to eat and their health suffers, we go in and we try to teach them to be able to tolerate sitting at the table and learning how to eat again so that they

can be more independent and the parents aren't stressed out also, and it's very cost-effective to provide these services now so that they don't have to do it later on.

UNIDENTIFIED SPEAKER: So medically necessary.

SENATOR STEINBERG: Yeah, and medically necessary. That's what 946 was about. We understand. Thank you.

MS. LAURA ROBERTS: Just so I don't forget everything, I'm going to look at my notes. My name is Laura Roberts. I'm from Southern California also. I have two hats also. I have a 17-year-old son with autism, and I have a behavior intervention company in Southern California. Most of our clients are in the South Bay, Orange County, and Inland Empire.

I have serviced over hundreds of kids and basically watched parents go through the navigation. And if it wasn't for the support groups in the South Bay and the things that I was able to tell parents and the parents I was able to reach, they wouldn't know what services were out there. My son got a behavior program, probably took about a year and a half before I knew there was such a thing, so he didn't start till close to five. It took about one month and he was potty trained, which just goes to what Fawn was saying.

These kids are going to be a huge burden to us in the future. My son, at 17, he cannot read, he cannot write, and he needs full care. Even with the best intervention, it doesn't always help. So I don't want to throw more into the bucket of list of things, but now it's all about like where are they going to live.

And listening to the spokesperson from DDS, it sounded like half the budget is going towards day programs and it's going towards living.

So what I've tried to do is get more informed on that also, and what I have found in sitting in two regional center meetings over the last three years—I sat in one two weeks ago in my regional center—and I've been to ___ again to the regional center twice to get services, and everybody in the room, English was a second language. The woman that was doing the training program, I'm sure she was dictated to do it by the regional center, and I couldn't understand anything she was telling me. All she kept saying is talking in circles and saying, we're going to evaluate your kid and we'll tell you where your kid goes.

And what I'm finding out for the first time, I called a group up here—Parents Helping Parents a month ago—that I get choices in living. I don't have to—the regional center doesn't have to tell me. I thought my son's going in a group home, no control. I thought that—and then they're telling me they're going to put my, they can put my son in a foster home. Now they have a brand new program that's going to save money that's called FHA where they're going to find a retired couple to take my son, and he's going to be in a house with just one couple and this is going to save them a lot of money. So I don't want to put more stuff out there for you, but I'm in the next phase of my life right now.

SENATOR STEINBERG: You've added—all of you have added—to the hearing in a very significant way because you remind us, just all the gaps that exist and, you know, part of the focus on early intervention, of course, is to

create better life outcomes and for more 17-year-olds to be ready to be completely independent, depending upon obviously the individual's circumstances, so you remind us that this agenda is a big one, a long one, and that we will chip away, chip away, chip away, chip away at this the very best we can, in these difficult times, okay?

MS. ROBERTS: Thank you.

SENATOR STEINBERG: Thank you. Thank you all very, very much. Appreciate it.

SENATOR LOU CORREA: Senator Steinberg.

SENATOR STEINBERG: Yes, Senator Correa.

SENATOR CORREA: I just wanted to add that on Thursday, we had a hearing in my district on this specific issue and let me say, not to add to the bucket but just a point to keep in mind, I had testimony from a parent, parents, whose 37-year-old, they actually got him to go out and live independently. He was doing great until he was lured into a financial scam. Because of the financial scam, he had to move back home. So my point is, as we try to strive to go independent with our children, let's just be aware that independence also carries a lot of risks out there for these folks.

SENATOR STEINBERG: Independence does not mean lack of support or the lack of need for support.

SENATOR CORREA: But I mean, this young man had actually gone out, consolidated all of his VISA cards to one card that carried some very

usurious rates that forced him to move back because he couldn't afford to pay all these new bills he had coming at him.

SENATOR STEINBERG: Thank you, Senator Correa and Senator Vargas. Welcome as well.

Do any of the members have a comment before I put out maybe a thought, an idea or two, to summarize this thing?

Yes, of course.

SENATOR JUAN VARGAS: I heard testimony, and I was here at the last one—I apologize not coming earlier--the service coordinator should walk the parents through the process. I thought that they did. How is that—I mean...

SENATOR STEINBERG: Hold on. Wait, wait, wait. Hold on.

SENATOR VARGAS: I thought that was sort of the duty of the service coordinator to do that.

SENATOR STEINBERG: It is. I think what we heard was some testimony, that whether it's the lack of resources or other reasons that the level of service is not what it should be when it comes to the service coordinator or when it...

SENATOR VARGAS: It is their mission.

SENATOR STEINBERG: It is their mission but we've got a frayed system here, which is not an excuse, but I think part of the reality here of what we're dealing with, with the increased caseloads, the decreases in funding, and that exacerbates, I think, a problem, in terms of disparities, that was already a problem, even with significant funding.

Senator Emmerson, you want to add anything?

SENATOR EMMERSON: No. I found the discussion to be very helpful today and I think there's a lot of work that we need to do. I think I was the one who spoke about interim hearings. I think we need to have some more hearings and work with all the stakeholders and looking forward to that process.

SENATOR STEINBERG: We will do that.

Senator Correa, anything?

So, you know, remember here what our jobs are, that is, to listen, of course. I hope we do well, even though we're harried. But to translate what it is we hear into public policy that can bring change, that's our job here, so I'm listening very carefully to—and there were some interesting bill ideas—certainly fixing the trailer bill to give flexibility to a lot of the centers, to provide gap services. I heard that. I heard a simple fix in the law that would require clear, written language appropriate, notices to parents to ensure that the parents understand the full array of services that are available for people because sometimes verbally they're told, well, you can only get this. I think the same would apply to housing options and placement options. I heard that.

But I want to get to what I think is—I heard a lot about autism outreach education. We heard about trying to standardize or at least build on these great community forums that occur where parents, especially from different cultures, can access providers who speak their language and understand their culture.

You know, we could spend our time on a lot of this stuff, and we probably should, but this is what I think. Back in 2003, I authored a bill when I was in the Assembly and it was Assembly Bill 636, and it did something that is fairly unique among Health and Human Services in California. It required the state and counties to develop outcome measures, outcome measures for child welfare. It has been an outstanding success. I am reading from a 2005 report, which has since been updated with similar, good information.

(AB) 636 said to counties, you have to report outcome measures around child welfare. You have to show the number of children percentagewise that are being protected from abuse and neglect. You need to show the percentage of kids that are being safely maintained in their own home, wherever possible, the percentage of kids that find permanency and stability in their living situations, the percentage of kids and families that find continuity within their family relationships. There are 14 different factors here. The counties report these; the state reports these now to the federal government.

And here's what, in 2005, they found that fewer children and youth were in foster care today than five years prior and that trend has continued. They report a bunch of positive information. They also say that in 2005 that California statewide was only doing slightly better at reducing the number of placements of children in care experience.

This system must be outcome based and outcome focused. If we're ever going to reduce disparities, if we're ever going to make a dent, we need to hold the centers and the state accountable for making progress here and then every

strategy which you've talked about here today can be the means by which we go about trying to accomplish those ends. But until there is that transparency and that accountability and the outcome focus, county by county or center by center and for the state as a whole, we will sit here a year or two from now and say, well, we're not sure if we made progress. We'll wait for the next exposé from a major newspaper and we'll hope that things are getting better as opposed to driving towards improving.

This information in the child welfare system is not just sat on websites, by the way, or on a piece of paper. It's driven change. It is driven change. It has forced counties to become more innovative, those that find themselves far behind the curve when it comes to abuse and neglect and the number of placements. It has forced the state to find some standard ways to improve the numbers, whether it be a standard safety evaluation for kids in the child welfare system. Make this system outcome driven, and that will drive change. It will drive cultural change. It will drive a reduction in these disparities if we hold ourselves and the centers hold themselves and the counties hold themselves accountable to better outcomes. That's my idea and I'm willing to work with my colleagues here to try to replicate 636 if you think that that is, that that would be useful. But the problem is the challenges.

It's one thing when we can all focus on a common goal like insurance reform, which we did. Without an outcome-based system and holding ourselves and each other accountable for outcomes, too many good advocates with their particular perspectives, specialty, idea, program, means of

intervention, et cetera—and you’re all doing a tremendous amount of work, and tremendous work on behalf of thousands of families—but systemic change? What are we driving towards and how do we measure it over time? County by county, center by center, and as a state.

So if those in the community, known advisor here, and the members think that this is a good, solid approach, I’m willing to work with you to take it on. That’s all.

Thank you very much. We’ll stand in adjournment.

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