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

ABBREVIATED AND EDITED TRANSCIPT OF THE HEARING
The following document represents selected excerpts that have been chosen and edited from the hearing. In some cases, testimonies (or portions thereof) have been deleted. Therefore, some of the comments may have been presented in a different context. The comments have been selected by the staff. For a complete transcript of the entire proceedings please select the following link: Transcript of Fair and Equal Access hearing – complete version

SENATOR DARRELL STEINBERG: 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. I'd like to give a warm welcome to Assemblymember Holly Mitchell who has taken great leadership on these issues and related issues.

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 CURREN D. PRICE, JR.: 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.

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.

ASSEMBLYMEMBER HOLLY J. MITCHELL: 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.

SENATOR MARK LENO: 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 EMMERSON: I will just say nothing and listen.

SENATOR STEINBERG: 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.

MS. TERRI DELGADILLO: 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 so that there would be services in the community so that individuals wouldn't need to go into state hospitals.

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. 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. 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 Department provides approximately $4 billion for community services and about 42 percent of that is now 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.

The other major funding obviously is to purchase services 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, 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.

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.

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: 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. 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?

ASSEMBLYMEMBER MITCHELL: 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: 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.

ASSEMBLYMEMBER MITCHELL: A second quick question, the client characteristics model you talk about, when will that happen?

MS. DELGADILLO: I really couldn't give you an answer today.

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

MS. DELGADILLO: Not indefinitely; 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 ALQUIST: I just wanted to mention 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.

SENATOR LENO: Ms. Delgadillo, you had mentioned that 45 percent of those coming into the system are on the spectrum. It's a dramatic increase, isn't it?

MS. DELGADILLO: Without a doubt, there's an increase, a very significant increase, in the number of diagnoses.

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

MS. CATHERINE BLAKEMORE: Good morning. Catherine Blakemore, Disability Rights California, which 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.

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.

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. Thank you.

MS. AREVA MARTIN: 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.

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.

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.

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.

The first point, 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 need regional centers to provide eligible clients with clear and accessible information about the range of services.

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.

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: 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.

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.

MS. MARTHA MATTHEWS: 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.

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.

Now imagine what it's like for Angelo's 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.

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.

SENATOR STEINBERG: 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.

I just wonder 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?

MS. MATTHEWS: That's what we try to do. 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.

SENATOR LENO: Ms. Matthews, this is such a hellish nightmare. 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: 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.

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.

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

MS. BLAKEMORE: 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.

MS. MARTIN: I think what the story illustrates too 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 hear that. Affluent families are treated in the system differently from this family who walks in, monolingual, uneducated. 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 KEVIN DE LEÓN: 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. Would you say this is an isolated or would you say is this systemic and it's pervasive?

MS. MATTHEWS: We chose this case because it's typical.

SENATOR DE LEÓN: 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, 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.

MS. BLAKEMORE: We have to just come to grips with, there are disparities and we have to be willing to publish the data that shows that. 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: 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 ALQUIST: 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.

MS. MATTHEWS: 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.

SENATOR PRICE: I think the best practices is a good idea as a roadmap, there has to be greater transparency; if it's occurring in one family's experience, it obviously has occurred in other's so it's very troubling.

ASSEMBLYMEMBER MITCHELL: 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.

SENATOR STEINBERG: 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?

MR. JIM BURTON: 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. We also have reviews on an annual basis for Medicaid waiver funding.

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. The funding streams are not a determinant.

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.

The regional center operations budget is the budget for services provided directly by regional centers, 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.

MR. GEORGE STEVENS: 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. The IPP process, as envisioned by its framers and enacted into law must be preserved and protected, 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, waiver compliance, and trailer-bill implementation. In short, the IPP process is not working as envisioned, especially for our most vulnerable clients and families. 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.

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: 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: We need to adequately fund regional center case management services, 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

MR. DEXTER 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. I can answer your question very directly—is this a cultural issue with regional centers? My answer is very specifically no, it is not. 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. 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.

With respect to our regional center, I think outreach is one of the most important things that we could be doing. 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.

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.

SENATOR LENO: 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: 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 purchase-of-service guidelines, that are approved by the Department of Developmental Services, and each regional center, is 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.

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

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

SENATOR DE LEÓN: 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. 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. ROBERT RIDDICK: I can be so brief to say that I've provided written testimony.

DR. SERGIO AGUILAR-GAXIOLA: The issue is really that minority populations tend to have more persistent disorders and also with symptoms that tend to be more severe and disabling. 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. For example, 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.

I have seven recommendations: Public spending should be consistent with the best available science and community-based solutions.

Identify the issues and build on the strengths.

Bring diverse partners to the table.

Strategic planning involving schools and communities.

Interventions and implementation strategies that are culturally and linguistically appropriate.

Performance measures.

Early identification and prevention are key.

DR. JAN BLACHER: I want 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.

What we do is target low-income and mainly Spanish-speaking families and we target their educational needs from diagnosis through adulthood.
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. Latino families coming to our clinic are not older on average than the Anglo children. 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.

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. 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. 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.

MS. ROCIO DE MATEO SMITH: I 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.

SENATOR STEINBERG: Let's hear from the families. You're the real reason why you're here, you and your children. Give us the essence of what you want us to take away today, please.

MS. MARIA RODRIGUEZ: We have a child with autism. 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. 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. We find it very difficult to understand the service delivery system. 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 grateful and not assertive and our children miss out. Sometimes it feels like social worker many times do not know information. It feels like they don't want us to get information because we will demand more.

MS. ROSA VALLEDOR: I'm here representing Congreso Familiar. 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. 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: 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.

SENATOR STEINBERG: We'll stand in recess. Thank you.

***** RECESS *****

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

DR. BARBARA WHEELER: 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. There are some quick myths I wanted to go through that I keep hearing. I hear sometimes that people who come from diverse cultures choose to take care of their own so that is a choice that they get, fewer 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. It's not a choice when you don't have a full array of acceptable options. 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. 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.

In terms of best practices, I wanted to recommend the work that Rachel Guerrero has done. 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, 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.

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

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.

MS. DE MATEO SMITH: But it is critical. 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.

SENATOR DE LEÓN: 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.

MR. PHIL BONNET: I'm the executive director of Alta California Regional Center. 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. 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.

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.

SENATOR STEINBERG: Let's hear from the public, those who have not spoken.

MS. LAUREEN FORMAN: 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.

MS. KRISTY NARDINI: 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'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 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.

MR. ALI SADEGHI: I'm here on behalf of Southern California Consortium for Applied Behavior Analysis, in Los Angeles. One of the things that I want to indicate regarding the disparity of services is that we might not need that much legislature to deal with this problem if, 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.

MS. MICHELLE HEID: I am also a member of the Southern California Consortium. I'm also a parent of an 11-year-old consumer on the autism spectrum. 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, 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. I think that we really need to create a system for parents that works with parents. 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.

MS. 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. 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.

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: 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.

MR. JIM LANTRY: I've got two hats today. One, ATPIAN, which works with treatment providers to help them get credentialed with insurance companies. 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. 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. 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.

MS. KAREN FESSEL: I'm 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 have 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.

MS. 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. If a child has severe behaviors and they tantrum when they have to eat and their health suffers, it's very cost-effective to provide these services now so that they don't have to do it later on.

MS. LAURA ROBERTS: I'm from Southern California also. I have a 17-year-old son with autism, and I have a behavior intervention company in Southern California. 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. 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.

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

SENATOR EMMERSON: 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: 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 a lot about autism outreach education. 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.

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.

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.

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.

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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