

**Senate Human Services Committee  
Oversight Hearing**

**Moving Toward Equity:  
Addressing Disparities In Services Provided by the Regional Center System**

March 14, 2017  
1:30 p.m.  
Room 2040

**Background**

**Overview**

Some 320,000 Californians are served by the state's Developmental Disabilities system. These children and adults have been diagnosed with conditions such as autism, cerebral palsy, Down syndrome or other serious disabilities that originated before 18 years of age and are expected to continue indefinitely. In California, a network of 21 nonprofit regional centers is tasked with evaluating the needs of individuals with developmental disabilities and coordinating services for these consumers. The regional centers are overseen through contracts with the state Department of Developmental Services (DDS) and services are funded with a combination of state and federal dollars.

The Lanterman Developmental Disabilities Services Act established an entitlement to services and supports for Californians with developmental disabilities who are living in their communities. The specifics of each consumer's care is dictated by an Individual Program Plan, which is updated annually and details the supports that will be provided and the goals attached to those services. For years there have been anecdotal reports of differences in access to services based on which regional center coordinates services for a consumer. Data recently made available confirms this. Average spending for all consumers statewide was \$12,270 in 2014-15, but average services purchased ranged from a low of \$9,198 at Harbor Regional Center in Torrance to a high of \$20,666 at Redwood Coast Regional Center in Eureka, which covers four rural northern counties.

Consistently, however, non-white consumers receive substantially fewer service dollars than their white counterparts. According to data provided by DDS, the average spending<sup>1</sup> on services for a white consumer was \$18,171 – more than double the average spent for a Latino consumer, which was \$8,356, and substantially above the average service cost for a Black consumer, of \$14,255. These stark differences in service funding remain consistent throughout the state and over time, with some local variations. Over the past five years, heightened Legislative scrutiny has prompted various changes to statute and forced DDS and the regional centers to collect data on purchase of service spending – categorized by race and ethnicity, language spoken, age, diagnosis, and other demographics. This has enabled the state, advocates and parents to more closely examine regional center spending patterns. At four public meetings conducted by DDS last summer for the purpose of identifying root causes of the disparities, consumers and family members identified systemic barriers such as a lack of understanding of the complex system and a lack of trust toward caseworkers.

Despite initial efforts by DDS and the regional centers, the disparities persist. The purpose of this hearing is to evaluate whether the state and regional centers have made progress in ensuring equal access to services in the past five years, and to consider the state’s plan to make progress in the coming months and years.

### **Developmental Disabilities System**

While there is some consistency in services statewide, there are local variations in rates, service types and access to services within each of the state’s 21 regional centers. The regional centers each are governed by a board of directors, and run by an executive director. While data and information is reported to DDS on each client’s purchased services, the state does not have ready access to client service information beyond billing codes. Even that information is somewhat unreliable as different regional centers may use different codes to provide similar services. A consumer’s regional center services may include assessment, diagnosis, individualized planning and case management, purchase of habilitative services from private vendors such as physical or speech therapy, supports for independent or supported living, day programs to help develop behavioral and other skills, behavioral therapies, vocational services, respite for family caregivers and residential care, and others. Before purchasing services, regional centers must use generic resources from other sources such as school districts and health providers.

In addition to the 320,000 consumers living in their communities, about 820 consumers live in three Developmental Centers, large institutions that once cared for the majority of the state’s consumers. DDS is in the process of shutting down the developmental centers, with the exception of 211 court-committed individuals in the state-run Porterville Developmental Center. Another 47 consumers live in a smaller, state-run facility.

### **Disparities in Accessing Care**

The issue of access to health care has been well studied by researchers, including the US Department of Health and Human Services, which publishes an annual disparities report. The

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<sup>1</sup> Department of Developmental Services, 2014-2015 Census and Consumer Population by Ethnicity/Race

Congressionally-mandated National Healthcare Disparities Report concluded in 2015 that “health care quality and access are suboptimal, especially for minority and low-income groups.” The findings show that, while overall access improved significantly under the Affordable Care Act, disparities to access persisted through 2013, especially among people in poor households, Latinos, and Blacks.<sup>2</sup>

Numerous studies have documented diminished use of medical care among ethnic groups, and particularly among Latino families. Medical journals have suggested that Latinos are less comfortable with the pace and relationships of Western medicine and therefore less trusting of practitioners.<sup>3</sup> Other studies, beginning with a 2003 report by the Institute of Medicine,<sup>4</sup> have focused on whether implicit racial bias in health care providers plays a role in decisions about care and could explain the disparities. Federal and private sector efforts have been underway to increase access to care of Latino families and other ethnic communities.

### *Regional Centers*

Within the DDS system, spending per consumer varies significantly from regional center to regional center. Similarly, there are wide variations in purchases of services to ethnic populations. The average spending statewide for services to a Latino consumer is \$8356 per month, as noted in the chart below. Notably, in neighboring Los Angeles-area regional centers Latino consumers receive \$5,828 in services and from Harbor Regional Center and \$11,238 annually from Westside Regional Center. These variations are reflected across all ethnic groups.

#### **Per Capita Expenditures in 2015**

<b>Race/Ethnicity</b>	<b>Number of RC Consumers</b>	<b>Share of RC Consumers</b>	<b>Per Capita Expenditures</b>
<b>White</b>	104,489	32.4%	\$18,171
<b>Native American</b>	1,095	0.3%	\$14,487
<b>Black/African American</b>	28,974	9.0%	\$14,255
<b>Asian</b>	27,663	8.6%	\$10,793
<b>Pacific Islander</b>	657	0.2%	\$9,999
<b>Hispanic/ Latino</b>	122,652	38%	\$8,356
<b>Other</b>	36,838	11.4%	\$8,084
<b>All Consumers</b>	322,368		\$12,270

*DDS table, March 10, 2017*

DDS has suggested that some ethnic disparities in per-consumer spending may relate to a cultural preference to keep family members at home, thereby reducing regional center costs. About 77 percent of all consumers live in the home of a parent or guardian or in their own home, and Latino consumers are more likely than other races to live in their own home, or the home of a family member while receiving services.

Yet, on average, regional centers spent 40 percent more on services for whites than Latinos living at home, and 49 percent more on Independent or Supported Living Services for whites

<sup>2</sup> <https://www.ahrq.gov/research/findings/nhqdr/nhqdr15/access.html>

<sup>3</sup> <https://www.theatlantic.com/health/archive/2014/05/why-many-latinos-dread-going-to-the-doctor/361547/>

<sup>4</sup> Smedley BD, Stith AY, Nelson AR, editors. Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare. Washington, DC: National Academy Press; 2003.

than Latinos. There were no significant differences in service costs for whites and Latinos in residential services.

### **Purchases of Services in Regional Centers per racial / ethnic group, 2014-15**

<b>Regional Center</b>	<b>Per Capita Spent White</b>	<b>White Consumer Population</b>	<b>Per Capita Spent Latino</b>	<b>Latino Consumer Population</b>	<b>Per Capita Expenditures Black or African American</b>	<b>Black Consumer Population</b>	<b>Per Capita Expenditures Asian</b>	<b>Asian* Consumer Population</b>
Alta California	\$15,264	50.2%	\$7,506	16.5%	\$11,136	12.2%	\$7,789	8.1%
Central Valley	\$15,462	29.4%	\$6,973	52.5%	\$11,555	5.8%	\$6,263	5.5%
East Los Angeles	\$28,530	10.3%	\$11,226	71.0%	\$24,691	1.5%	\$12,244	12.5%
Frank D. Lanterman	\$17,328	28.2%	\$7,868	45.0%	\$13,934	5.8%	\$11,205	11.6%
Far Northern	\$12,981	77.7%	\$8,027	10.3%	\$13,990	2.4%	\$7,294	2.2%
Golden Gate	\$30,591	34.1%	\$11,335	23.3%	\$28,198	8.2%	\$14,477	22.2%
Harbor	\$16,162	24.2%	\$5,828	40.7%	\$9,726	12.3%	\$9,377	11.7%
Inland	\$14,064	29.9%	\$7,479	41.1%	\$10,548	11.4%	\$9,115	3.7%
Kern	\$19,538	37.1%	\$9,604	44.0%	\$17,224	8.3%	\$15,835	2.5%
North Bay	\$20,371	49.7%	\$7,869	23.6%	\$19,035	9.1%	\$14,040	5.3%
North Los Angeles	\$16,528	32.9%	\$8,430	44.6%	\$10,882	10.3%	\$12,572	5.7%
Redwood Coast	\$23,378	73.9%	\$11,315	11.6%	\$13,695	2.0%	\$20,738	1.4%
RC of the East Bay	\$22,153	29.5%	\$9,260	22.0%	\$17,527	17.9%	\$10,083	17.6%
RC of Orange County	\$18,647	35.5%	\$8,828	32.6%	\$15,933	1.9%	\$11,456	15.9%
San Andreas	\$28,367	30.2%	\$11,875	37.2%	\$21,607	2.3%	\$11,479	18.4%
San Diego	\$16,181	27.9%	\$7,983	29.7%	\$12,436	5.0%	\$7,830	5.9%
San Gabriel / Pomona	\$20,252	19.9%	\$8,106	54.8%	\$15,497	6.1%	\$9,211	11.1%
South Central Los Angeles	\$28,697	3.5%	\$6,147	65.0%	\$15,650	26.2%	\$23,211	0.8%
Tri Counties	\$18,404	39.5%	\$8,926	40.3%	\$19,357	1.9%	\$14,109	2.8%
Valley Mountain	\$13,681	38.9%	\$6,721	34.0%	\$10,541	8.9%	\$8,108	7.1%
Westside	\$19,924	30.0%	\$11,238	32.5%	\$17,005	22.0%	\$15,873	4.5%

*Department of Developmental Services, January 23 and March 12 data charts  
\*Excludes Pacific Islander and Other populations*

Also worth noting is the disparity in rates of service utilization. This reflects services that have been authorized by the regional center, but are not being used by the consumer. In order to

receive authorized services, a consumer must have been assessed and given a diagnosis that qualifies for services within the regional center. After that, the consumer and his or her family must participate in a process to determine the consumer’s Individual Program Plan, and agree on a set of services that would benefit the consumer and achieve the goals of the plan. Advocates say low utilization rates may flag services that are inaccessible to consumers for reasons including language barriers with providers, transportation issues, or other reasons. Statewide data indicates that authorized services are more likely to be left unused by Latinos than whites, as shown in the table below.

**Service Utilization Rate**

<b>Race/Ethnicity</b>	<b>Statewide authorized services</b>	<b>Statewide expenditures</b>	<b>Utilized</b>
<b>White</b>	<b>\$2,295,218,622</b>	<b>\$1,898,695,734</b>	<b>82.7%</b>
<b>Hispanic / Latino</b>	<b>\$1,338,208,928</b>	<b>\$1,024,835,700</b>	<b>76.6%</b>
<b>Black / African American</b>	<b>\$505,652,876</b>	<b>\$413,033,759</b>	<b>81.7%</b>
<b>Asian</b>	<b>\$375,220,280</b>	<b>\$298,579,597</b>	<b>79.6%</b>
<b>Other ethnicity or race</b>	<b>\$401,565,923</b>	<b>\$297,792,299</b>	<b>74.2%</b>

*Department of Developmental Services*

Within the system, utilization rates vary by regional center. For example, Kern’s utilization rate among white families was 70 percent, while white consumers at Valley Mountain Regional Center used 97 percent of authorized services. However, in virtually every regional center, the usage rates by whites significantly exceeded the usage by Latinos, as exemplified by North Bay Regional Center, where whites used 88 percent of services at an average of \$20,371 per consumer and Latinos used 73 percent of services at an average cost of \$7,869 per consumer.

**Language access**

The Dymally-Alatorre Bilingual Services Act of 1973 (*GOV 7290, et. Seq.*) requires that state agencies that furnish information or services to the public must employ a sufficient number of bilingual staff or contractors to ensure provision of information and services to the public in the language of the non-English-speaking people. The Act also mandates that written materials be translated into non-English languages, particularly if the materials provide information to a consumer or affect that consumer’s rights, duties or privileges to services or benefits, and that the local office of the agency serves a “substantial number” of individuals who speak the same language.

The Lanterman Developmental Disabilities Act requires that a written copy of a consumer’s Individual Program Plan, and all communication during the planning process for services, be translated into a consumer or family’s preferred language, with specific timelines. (*WIC 4646*) The statute also requires that all intake services need to be conducted with the consumer and his or her family in their native language, and that those services include information and advice about the nature and availability of services provided by the regional center and by other agencies in the community. (*WIC 4642*)

California has the highest rate for non-English speakers among all 50 states. According to a 2016 report which analyzed California's Medi-Cal data, about 38 percent of Medi-Cal recipients, or 4.5 million people, reported having a language other than English as their primary language.<sup>5</sup> The same report, by the Department of Health Care Services, noted that 43.8% of Californians have reported that they speak a language other than English at home, compared with 20.8% of the U.S. population. Spanish, Vietnamese, Cantonese, Mandarin, and Armenian are the most frequently reported languages among Medi-Cal's non-English speakers.

Data from the DDS Client Master File indicates one-quarter of regional center consumers speak a primary language other than English.<sup>6</sup> Additional data provided by DDS shows the percentage of consumers whose primary language is other than English varies significantly by regional center: 43 percent of consumers speak Spanish primarily at South Central Regional Center, as well as one-quarter of consumers at San Gabriel / Pomona regional center and 22 percent of the consumers at San Andreas Regional Center.

Meanwhile, more than 6 percent of all consumers at Golden Gate Regional Center have Cantonese as a primary language, and a total of 7 percent – or about 800 consumers – at Frank D. Lanterman Regional Center have Korean, Armenian or Tagalog as their primary language.

DDS states on its website that it strives to reduce and/or eliminate any language barriers for persons who are non-English speaking or who have limited-English proficiency. The department's policy is to provide verbal interpretation and translation of written materials related to the DDS service delivery system in the languages that meet a 5 percent threshold of the persons served, as well as many of other non-threshold languages as possible by utilizing certified bilingual staff or contracted services.

However, it is unclear that all consumers with primary languages other than English are able to communicate effectively with their regional centers. DDS and the Association of Regional Center Agencies (ARCA) do not have information about how many caseworkers are bilingual, and anecdotal information suggests that the availability of bilingual caseworkers varies by regional center. Family members say they are occasionally called to interpret for other families if regional centers cannot find official bilingual interpreters.

## **Legislative responses**

Prompted by a Senate oversight hearing in 2012, a series of legislative requirements mandate DDS to document and analyze disparities in services provided to regional center consumers. At that time, the disparity gap was the same as it is today: Whites received \$15,817 in services to Blacks' \$12,270 and Latinos' \$7,247 – Latino's receive less than half the average purchase of services as whites.

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<sup>5</sup> [http://www.dhcs.ca.gov/dataandstats/statistics/Documents/Threshold\\_Language\\_Brief\\_Sept2016\\_ADA.pdf](http://www.dhcs.ca.gov/dataandstats/statistics/Documents/Threshold_Language_Brief_Sept2016_ADA.pdf)

<sup>6</sup> [http://www.dds.ca.gov/FactsStats/docs/QR/Dec2016\\_Quarterly.pdf](http://www.dds.ca.gov/FactsStats/docs/QR/Dec2016_Quarterly.pdf)

### *Select Committee hearing*

The Senate Select Committee on Autism and Related Disorders held a hearing in April 2012, to discuss questions surrounding equal access to regional center services for consumers with autism spectrum disorders (ASD). The hearing followed a series of articles in the Los Angeles Times in December 2011, which concluded that people of color, and from low income, and socio-economically disadvantaged communities receive fewer services compared to their white counterparts.

Often, the articles found, parents whose children receive services are wealthier, more sophisticated in navigating bureaucratic systems, and fluent in English. In contrast, parents who worked multiple jobs, single parents, immigrants, those who could not speak English, and those who have multiple children were less able to access services.

### *Task Force on Equity and Diversity for Regional Center Autism Services*

In response to the Select Committee on Autism hearing, a 20-member Taskforce on Equity and Diversity for Regional Center Autism Services was appointed by then-Senate President pro Tempore Darrell Steinberg. The group was charged with finding recommendations to ensure that consumers of regional center services receive appropriate and timely supports regardless of race, ethnicity, educational background and other socio-economic factors. The task force was co-chaired by Dr. Sergio Aguilar-Gaxiola, who leads the UC Davis Center for Reducing Health Disparities, and by Areva Martin, an attorney and parent of a child with autism who founded the Special Needs Network.

A 119-page report, “A Preliminary Report by the Taskforce on Equity and Diversity for Regional Center Autism Services,” was published in March 2013. It identified 19 recommendations, including:

- Ensure that consumers and family members receive information about their services and their IPP in their native languages and that key meetings be conducted in the consumer’s and family’s preferred language (page 16)
- All regional centers must establish a strategic plan to achieve equity and cultural competency (page 20)
- Specific statutory language should be included to require DDS and the regional centers to provide clear, linguistically appropriate versions of key documents and to post them on their websites. (page 31)
- DDS should serve as a clearinghouse for regional centers to share existing materials and to provide assistance in the development of materials and training. (page 32)
- DDS should establish an annual self-assessment for regional centers to evaluate cultural competency, including access to services, case management, staff training and others. DDS should use the information to design performance contract objectives (Page 35)

- There must be improved data collection, analysis, evaluation, transparency and oversight of regional center disparities. (page 44)
- DDS should establish effective accountability to the Legislature including quality assurance language to ensure specific goals, outcomes and results related to equity and diversity issues. (page 53)
- DDS should establish an Equity and Advisory Council with key stakeholders and that the council should provide a biennial report to the governor and Legislature on the status and progress of the regional centers in providing equitable and appropriate services to diverse and underserved communities. (page 59)

### *Legislation*

Members of the Legislature introduced a package of bills designed to ensure all consumers have access to appropriate services. Most of the bills reflected recommendations by the task force.

One requires a regional center to make every reasonable effort to communicate in the native language of a consumer's native or family member during the planning process for the individual program plan (IPP), to provide a copy of the IPP in the identified native language and to document the native language of the consumer or family member in the IPP. (*SB 555, Correa, Chapter 685, Statutes of 2013*).

Another bill requires a regional center's request for proposals for consumer services and supports to include a section on issues of equity and diversity (*SB 208, Lara, Chapter 656, Statutes of 2013*). Yet another requires the department's quality assurance tool to assess the provision of services in a linguistically and culturally competent manner and include outcome-based measures to evaluate the linguistic and cultural competency of regional center services that are provided to consumers across their lifetimes (*AB 1232, V. Manuel Perez, Chapter 679, Statutes of 2013*).

*SB 367 (Block, Chapter 682, Statutes of 2013)* mandates that annual training for regional center board members includes training on cultural competency and that the board annually reviews the regional center's executive director's performance in providing services that are culturally and linguistically appropriate. Another bill expanded the scope of data required to be compiled and annually posted on the regional centers' Internet Web sites, as well as requiring that annual regional center performance objectives include culturally and linguistically appropriate services and supports. (*SB 1093, Liu, Chapter 402, Statutes of 2014*)

In addition, several changes to statute were made in Budget Trailer Bill language. In 2012, *AB 1472 (Committee on Budget, Chapter 25)* established the requirement for regional centers to annually compile and post specified data about provided services along with related demographic information on their respective Internet Web sites. The next year, *AB 89 (Committee on Budget, Chapter 25, Statutes of 2013)*, required each regional center to notify DDS and the public about meetings being held to discuss local purchase of services data with stakeholders, as mandated.

The 2016-17 Budget trailer bill added a requirement for a regional center to offer a written copy of the IPP to a consumer or other representative in a threshold language, as defined, within 45 days of the request, and to document and provide to DDS the number of times a written copy is requested in a language other than a threshold language, and not provided within 60 days. (*SB 82, Budget and Fiscal Review, Chapter 23, Statutes of 2015*) It also mandated that DDS consult with stakeholders, establish objectives and report to the Legislature on the progress of those objectives during the 2016–17 annual legislative budget subcommittee hearing process.

Governor Brown issued a proclamation on June 19, 2015 convening the second extraordinary Legislative session to enact permanent and sustainable funding from a new managed care organization (MCO) tax and/or alternative funding sources. The effort focused on generating \$1.1 billion annually to stabilize state costs for the Medi-Cal program, provide funding to maintain In-Home Supportive Services hours and to increase payment rates for regional center service providers. The 2<sup>nd</sup> Extraordinary session bill package ultimately included \$11 million to reduce disparities in the purchase-of-service expenditures and to encourage the development and expansion of culturally and linguistically appropriate services. (*AB 2X1, Thurmond, Chapter 3, Statutes of 2016*)

#### *Addressing Disparities in Regional Centers*

DDS in January announced that it had approved projects for the \$11 million in grant proposals to address disparities. Each of the 21 regional centers submitted proposals, which included:

- Translating intake packet materials and providing orientation sessions in the various native languages of consumers
- Hiring bilingual service coordinators
- Providing cultural competency training for regional center staff and/or provider organizations
- Creation of social media platforms to communicate with consumers and families
- Establishment of services for monolingual consumers
- Purchasing headsets and other translation equipment for families
- Providing person-centered training to regional center staff, providers and/or families
- Establishing outreach services

#### *Cultural Navigators*

Many of the regional centers included proposals to contract with cultural navigators to help communicate more effectively with families who have language or cultural barriers and are not accessing authorized services. Most prominent among these navigator models is the promotora model, which gained prominence in the health field in the 1990s after recognition from the Centers for Disease Control.

Promotoras in the traditional model are well-respected women in their Latino communities who help navigate medical care for people in their own underserved communities. Because the

promotoras are leaders in their community, it is easier for them to deliver interventions in a culturally sensitive manner and to be perceived as having similar values and experiences. According to the Latino Health Access website in Los Angeles, promotoras “draw out residents who might not otherwise reach out for help. Our promotoras conceive unique and creative strategies to talk to our community about issues important to their health. Promotoras do not “target” the community. They join with neighbors to create relationships built on trust.”<sup>7</sup>

Originally, promotoras were volunteers, however increasingly they are becoming salaried. In this context, the promotoras will be contractors of the Regional Center tasked with helping underserved families navigate both regional center services and so-called “generic” services such as Medi-Cal or private insurance, that are required to be accessed prior to DDS providing services.

Another commonly used organization in Southern California is Fiesta Educativa, which helps parents to access services for children with disabilities. According to the organization’s website, it was founded in California in 1978 “by family members and professionals who recognized the need to provide assistance and advocacy to these Spanish-speaking families.” Regional center-based programs include Spanish-language orientation classes for parents who are mandated to take 16-hours of training prior to their children receiving behavioral services for Autism, parent-education classes, development of parent support groups, and others.

Some regional centers requested funding to hire navigators or “cultural brokers” to help communicate better with Korean, Hmong, Mandarin, Cantonese or Native American communities. The grants additionally target \$1 million in funding to create pay differentials supporting bilingual service coordinators at regional centers when fluency in the second language helps to address the language needs of the regional center’s catchment area.

### **Restrictions on services due to Budget Shortfall in 2009**

In July of 2009, DDS, its stakeholders and the Legislature restricted access to specific services in order to achieve savings that were needed in the face of massive budget shortfalls in the Great Recession. Advocates for consumers say these limitations have a disproportionate effect on those who are poor, have language barriers and difficulty navigating the complex regional center system, and may contribute to cultural and ethnic disparities in service provision.

#### *Suspended services*

Among the restrictions was the suspension of several regional center categories of services. These included the suspension of social recreation activities such as Special Olympics, art or music therapy, and limits on access to regional center-funded services while a consumer is between ages 18 and 22, during which time a consumer’s school district is supposed to be providing services. Additionally, there were limits placed on the number of hours that consumers can obtain for respite services. Since that time, some regional centers have imposed monthly limits on respite services.

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<sup>7</sup> <http://www.latinohhealthaccess.org/the-promotora-model/>

**Statewide use of Social / Recreational services in 2008-09**

<b>Race/Ethnicity</b>	<b>Total count</b>	<b>Percent of Total</b>	<b>Total Expenditures</b>	<b>Per Capita Expenditures</b>
<b>White</b>	5,835	48.1 %	\$5,831,385	\$999
<b>Latino</b>	3,444	28.4 %	\$6,672,431	\$1,937
<b>Other</b>	1,045	8.6 %	\$1,233,303	\$1,180
<b>Black / African American</b>	696	5.7 %	\$816,997	\$1,174
<b>Asian</b>	868	7.2 %	\$1,312,457	\$1,512
<b>Filipino</b>	182	1.5 %	\$213,953	\$1,176
<b>Native American</b>	48	0.4%	\$36,586	\$762

*Department of Developmental Services*

Advocates for consumers say that limitation on these services may disproportionately affect consumers from cultural minority communities who are less likely to utilize out-of-home services and therefore are more likely to use such supports. As the chart above indicates, Latino consumers were provided \$1,775 in these services prior to their suspension – significantly above the statewide average of \$1,376 and above the per capita average for white consumers of \$1,105.

The monthly respite cap reportedly also may affect families who need bilingual providers as in some areas there is a wait list, and the hours may expire prior to being able to access services.

*Group Orientation for Applied Behavioral Analysis*

Although Applied Behavioral Analysis (ABA) can be used with both children and adults, it is commonly associated with intensive treatment of young children who have autism. Through repetitive intervention, children are taught communication, social skills, play, self-care and other skills appropriate for school-based learning. Studies have demonstrated that many children with autism experience significant improvements in learning, reasoning, communication and adaptability when they participate in high-quality ABA programs. Studies also have shown that some children who participate in early, intensive ABA for two or more years before they are school aged may be able to acquire sufficient skills to participate in regular classrooms without support.

Prior to July 2009, ABA treatment included an in-home parental education and orientation component designed to familiarize families with autism spectrum disorder and ABA treatment. That was changed to instead require a regional center to “consider... the use of group training for parents on behavioral intervention techniques in lieu of some or all of the in-home parent training component of the behavioral intervention services.” (WIC 4685) Parents still need to be present during the in-home training for their children to ensure consistency of responses to the child between the trainer and parent. This change in statute has been applied variously by regional centers, and at least several have viewed the language as a mandate to provide orientation classes to parents as a prerequisite to providing services to children. At least one regional center mandates an 8-session, 16-hour training orientation prior to a child beginning ABA services at home.

Advocates for poor and minority families say this requirement can cause significant delays – or a loss of services – for families in accessing services if both parents work, or there are other children in the home who need care, or the transportation to the orientation classes is difficult, or

there are language barriers, among other challenges. This may be harmful as researchers have shown that younger children are significantly more responsive to ABA treatment, and specifically if treatment is begun at younger than 2 years of age.<sup>8</sup>

## **Self-Determination**

SB 468 (*Emmerson, Chapter 683, Statutes of 2013*) created a Self-Determination program, contingent upon obtaining a federal waiver, to provide consumers and their families with an individual budget and increased flexibility and choice in deciding what services and supports to use to implement their IPPs. The program will serve up to 2,500 consumers statewide for a three-year phase-in period, and becomes available to all regional center consumers after that. Advocates for self-determination say it can be especially effective for families who want or need more flexibility in planning services, including consumers who have language barriers to traditional services, or have other challenges in accessing services. DDS is in the process negotiating final waiver language with the federal government to implement the program.

## **Oversight of Regional Centers**

Each of the 21 nonprofit regional centers is funded through a contract with DDS, which provides the mechanism for the state to hold agencies accountable. DDS negotiates five-year contracts and monitors each regional center's compliance through an annual contract update. State law (*WIC 4629*) requires certain elements be included in each contract, including that services be rendered in accordance with state laws and regulation and that each contract includes annual performance objectives. Among the required objectives are the development of services and supports identified as necessary to meet identified needs, including culturally and linguistically appropriate services and supports, and to measure progress in reducing disparities and improving equity in purchase of service expenditures.

The role of DDS in overseeing regional center consistency, transparency and service provision was the subject of a 1985 California Supreme Court decision, the Association of Retarded Citizens (ARC) vs the Department of Developmental Services. The court, in considering whether the Director of DDS' had the authority to issue funding directives to prioritize certain categories of services, defined the roles of the regional centers and DDS as such:

“From our review of the provisions of the Act, we reach the following two conclusions. First, the regional centers and DDS have distinct responsibilities in the statutory scheme: that of the regional centers is to provide each developmentally disabled person with the services to which he is entitled under the Act; that of DDS is to promote the cost-effectiveness of the operations of the regional centers, but not to control the manner in which they provide services. Second, the Act defines a basic right and a corresponding basic obligation: the right which it grants to the developmentally disabled person is to be provided with services that enable him to live a more independent and productive life in the community; the obligation which it imposes on the state is to provide such services.

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<sup>8</sup> McDonald, Rebecca, et al, “Assessing progress and outcome of early intensive behavioral intervention for toddlers with autism,” *Research in Developmental Disabilities*, December 2014.

...As we have explained, DDS is without authority under the Lanterman Act to control the manner in which the regional centers provide services or to control their operations. Yet this is precisely what DDS attempted to do through the issuance of the Priorities, which directed the regional centers in effect to cut back on services by category, without regard to the individual client's IPP.”

Ultimately, the state Supreme Court ruled that DDS did not have authority to control the manner in which the regional centers provided services or to control their operations, and nullified the list of priorities for funding. Subsequent budget reductions have been enacted in statute. Since the ARC decision, DDS has interpreted the court’s ruling to mean that it cannot interfere or direct a regional center to provide specific services.

### *Special Contract Language*

If DDS determines that a regional center is not performing up to its contractual and statutory obligations, it may institute special contract language, which requires that a regional center take specific corrective action or risk losing funding. In the worst case scenario, DDS has authority to nullify the contract and replace regional center staff to ensure clients’ needs are met.

DDS could impose special contract language for a significant singular issue or concern; however, special contract language is most commonly utilized as a result of broader/systemic issues at a Regional Center. DDS will first attempt to work with Regional Centers by providing technical assistance on compliance and performance issues. According to DDS, special contract language would be used only when there are systemic and leadership issues that result in a lack of compliance with statute or regulation, and the regional center fails to ensure the adequate provision of services.

Use of special contract language is infrequent – currently two regional centers are under special contract language – however, it has not been used to enforce cultural disparity issues.

### **Next steps**

It is clear that disparities persist, despite initial efforts that are now underway. The question for the Legislature going forward is to identify whether the state has taken adequate steps to address inequities, and to hear from DDS and the regional centers what their intention are for making measurable progress, and what role the Legislature can play in assisting them.