

# POS Disparity

MAY 2013

EXPLORING EQUITY IN REGIONAL CENTER SERVICES



**This newsletter is in response to statewide inquiries regarding fair and equal access to services throughout the regional center system.**

As an agency, South Central Los Angeles Regional Center is charged with the critical tasks of raising awareness about the challenges that people with developmental disabilities face, the services that SCLARC provides and developing creative and innovative programs in order to realize our mission. Our mission is to provide quality services for our consumers and their families, enabling all to lead fuller, richer lives. SCLARC's goal is to educate the larger community about the issues impacting individuals with developmental disabilities.

Recently, the California Legislature, through Trailer Bill Language, determined that in order to allow for better statewide and local oversight of access and equity issues within the developmental services system, that all regional centers will display existing purchase of service utilization and expenditure data with respect to race and ethnicity, age of consumer, and disability on their websites' Transparency Portals. SCLARC's Transparency Portal is located at <http://www.sclarc.org/transparency-portal.php>.

The age of consumers are broken down by ages birth to two, three to twenty-one, and twenty-two and older. Disability detail is provided as well as information regarding race and ethnicity. The data is also publicly posted on DDS' website and regional centers are required to meet with their stakeholders regarding the data.

Throughout the following pages, SCLARC will present data regarding Purchase of Services spending trends within our regional center.

## THE PURCHASE OF SERVICES DATA

SCLARC's Purchase of Service (POS) data demonstrates why there seems to be a disparity in services

## INHERENT CHALLENGES IN SERVING COMMUNITIES OF COLOR

Groundbreaking Study from UC Davis' Center for Reducing Health Disparity shows cultural, social and language barriers impede services





# Purchase of Services

**If a generic or private resource initially denies a required service that SCLARC has determined to be the responsibility of that resource or agency, the denial will be appealed.**

SCLARC recognizes its responsibilities to assure that all consumers receive cost effective services that are designed to prevent or ameliorate (lessen) developmental disabilities, protect the individual's health and safety; and maintain the individual in the least restrictive residential setting. Services will only be purchased for needs associated with the consumer's developmental disability. SCLARC funds will not be used for those services categorized as activities of daily living that would be purchased by the average person such as routine medical and dental care, food, clothing and/or shelter.

- SCLARC will not fund any services that are considered experimental, optional or elective in nature.
- Prior to authorization of regional center funding, an exploration of the availability of private, personal or generic resources will be required.
- For individuals receiving early intervention services, consumers in public school programs and consumers who reside in health care facilities, services (health care

and/or therapies including behavior intervention) are expected to be provided as part of the individual's program, rather than as a separately funded service.

- SCLARC's eligibility team must determine that services are required as a direct consequence of the developmental disability.

- SCLARC may authorize funding for a service while a consumer or family member appeals a denial of service by a generic or private resource.

- SCLARC's clinical team will make the determination that the service is required to protect the consumer's health and safety, or that a prolonged wait for the service will have an irreversible impact on the consumer's health and safety.

- SCLARC will consider the consumer's risk for regression and the capacity of the consumer to regain any loss of function or ability if the service is not provided in a timely manner. The purchase of any service must be an effective use of public funds; both clinically and fiscally.

## SCLARC's Mission: To educate, advocate & empower

SCLARC will advocate for and work with consumers and their family members to ensure that generic and private therapy service providers adhere to their obligations in meeting the needs of persons with developmental disabilities.

- SCLARC will advocate for and work with consumers and their family members to ensure that generic and private therapy service providers discharge their obligations and meet the needs of persons with developmental disabilities.

**Exception Policy:** SCLARC recognizes that some individual needs are so unique that they may not be addressed in a service policy and may require an exception. Such requests for an exception to a service policy will be made through the Interdisciplinary Planning Team process.

# Challenges in Serving



In 2012, a ground breaking study conducted throughout California by UC Davis' Center for Reducing Health Disparities (<http://www.ucdmc.ucdavis.edu/publish/news/crhd/6705>) showed up to 75 percent of Latinos who sought mental health services opted against returning for a second appointment because cultural, social and language barriers are too high to surmount. SCLARC's intake coordinators and staff found this to be a similar trend with families seeking assessments for possible developmental disabilities. SCLARC has also found many challenges in serving communities of color. In addition to cultural, social and language barriers, the following also impede provision of service:

- Lack of access to information and technology
- Lack of exposure to medical professionals
- Few community outreach and awareness programs
- Lack of adequate health insurance
- Insufficient knowledge of advocacy strategies

Moreover, South Central Los Angeles Regional Center employees find that some of our stakeholders do not want strangers in their homes to provide LVN, behavioral and/or agency respite services.

The UC Davis comprehensive report, based on input from more than 550 Latinos in community forums in 13 California cities, including Sacramento, found that Western medicine's evidence-based best practices were ineffective at penetrating these barriers and bridging the cultural gulf. Still, efforts must be made to overcome barriers that make serving a large part of SCLARC's stakeholder population extremely difficult. Funding



is needed for bicultural and bilingual outreach and educational campaigns throughout South LA.

With more dollars from the Legislature and the Department of Developmental Services, SCLARC could provide culturally sensitive outreach and educational materials that detail where to receive free assessments regarding regional centers and school districts as well as handouts providing information on local support groups and organizations.

Over the last 25 years, SCLARC has created, instituted and modeled programs that focus on services, nutrition, wellness, substance abuse prevention, infant development, oral health care, and forensic support services. Our agency has a long history of developing programs that support and empower families. With appropriate funding, SCLARC is more than confident that we can continue our success in creating effective and supportive programs and an outreach campaign that will empower and educate families in our service area who are faced with the challenges that come along with a developmental disability

Below are three primary factors SCLARC believes impedes service provision within our service area.

## Just facts

### 1. Immigration Issues

Due to fear of deportation as well as a distrust in the government, many families want to remain anonymous and do not share household information or are told not to pursue services during the immigration process.

### 2. Privacy Issues

The Family Cost Participation Program and AFPF programs cause some families to decide not to secure services; not because they have to pay for a share of the cost, but because they must share household information but prefer to remain private.

### 3. Language Barriers

Service providers and non-Spanish speaking professionals have a hard time communicating with SCLARC consumers and families.



# Residential Homes & Living Arrangements

Out of home placement is the process that occurs when a regional center consumer leaves the home of their parents or legal guardian and moves into another living option such as a residential facility. Residential Direct Support Professionals provide services to children and adults who are unable to reside in the family home.

- A Level II residential home is similar to a home-like family setting where daily activities reflect the pattern of daily living for non-disabled persons of the same chronological age. These consumers generally have basic self-help skills and no significant behavior problems.
- A Level III residential home has a ratio of 1 staff member to every 3 consumers and provides a more structured environment. This is geared toward individuals who are non-ambulatory, present severe behavior deficits or have little self-help ability and require substantial supervision, support and training.
- A Level IV home has a ratio of 1 staff to every 2 consumers or 1 to 3. It meets the needs of consumers whose behavioral deficits and/or excesses prevent participation in activities of daily living and whose challenges are so significant that they are unable to be met in other residential facilities.

Historically, SCLARC's data demonstrates that Latino families tend to keep their loved ones in the home. Conversely, more of SCLARC's African American families opt for other living arrangements as the graphs to the right details. Across the board, economics seem to play a large factor in whether or not a family chooses out-of-home placement. Many families live below the national poverty level and rely heavily on the SSI benefits that SCLARC consumers receive in order to survive on a monthly basis. Thus, in those cases whether black or Latino, the SSI income seems to be a factor in deciding to place in a residential facility.

It should be noted that out-of-home placement drives the Purchase of Services budget per consumer up considerably which could, at first

glance, lead one to believe there is a disparity in services and equity. Residential placement on average can cost between \$5,000 and \$20,000 per month per consumer.



# What Do We Need to Know When Interpreting the Data?

- Everyone that SCLARC serves has unique needs, so services are going to be different for each consumer.
- Some services cost more than others.
- The differences in costs for services does not necessarily mean SCLARC stakeholders needs aren't met.
- The data presented does not provide an tell us why differences exist.
- We don't know why differences exist without looking at other information like age, living arrangements, etc.
- We don't know if the differences in costs are a problem without looking at other information.

South Central Los Angeles Regional Center  
POS Disparity Data

Consumers with no POS by Diagnosis			
Diagnosis	Total Eligible Consumers	Consumers w/No	% w/No
		Purchased Services	Purchased Services
Autism (Au)	2,782	888	31.9%
Intellectual Disability (MR)	6,772	1,762	26.0%
Cerebral Palsy (CP)	173	53	30.6%
Epilepsy (EP)	105	31	29.5%
Category 5 (CAT5)	213	74	34.7%
Other (NODX)	<u>2,524</u>	<u>249</u>	<u>9.9%</u>
<b>Total</b>	<b>12,569</b>	<b>3,057</b>	<b>24.3%</b>

**Explanation**

Under the Autism diagnosis, 888 consumers have no POS or 31.9% of total eligible consumers with the diagnosis. This is due mainly to the higher count of school age consumer in this group. Typically, these consumers get its services from the school district.

Consumers with no POS by Ethnicity			
Ethnicity	Total Eligible Consumers	Consumers w/No	% w/No
		Purchased Services	Purchased Services
Asian	58	11	19.0%
Black African-American	3,840	788	20.5%
Filipino	42	8	19.0%
Hispanic	7,730	2,075	26.8%
Native American	9	0	0.0%
Other Ethnicity or Race	339	87	25.7%
Polynesian	11	1	9.1%
White	<u>540</u>	<u>87</u>	<u>16.1%</u>
<b>Total</b>	<b>12,569</b>	<b>3,057</b>	<b>24.3%</b>

Under the Hispanic ethnicity, 2,075 consumers have no POS or 26.8% of total consumers under this ethnicity. The same reason applies as well, the a majority of the consumers are school aged. Additionally, the situation was exacerbated by the elimination of social recreation services as result of a Budget TBL.

POS Per Capita by Ethnicity		
Ethnicity	Consumer Count	SCLARC
		Per Capita Expenditures
Asian	58	\$10,232
Black African-American	3,840	\$13,182
Filipino	42	\$17,628
Hispanic	7,730	\$5,503
Native American	9	\$15,943
Other Ethnicity or Race	339	\$9,078
Polynesian	11	\$27,284
White	<u>540</u>	<u>\$24,768</u>
<b>Total</b>	<b>12,569</b>	<b>\$8,899</b>

The per capita spending per consumers under the hispanic ethnicity was below the State average because of the reasons mentioned in the previous charts.

POS per Capita by Language		
Ethnicity	Consumer Count	SCLARC
		Per Capita Expenditures
Asian	17	\$29,627
English	7,030	\$11,683
Other	41	\$16,857
Spanish	<u>5,481</u>	<u>\$5,203</u>
<b>Total</b>	<b>12,569</b>	<b>\$8,899</b>

The per capita spending per consumers under the spanish language was below the State average because of the reasons mentioned in the previous charts.

Per Capita Comparison			
Ethnicity	SCLARC	Statewide	Variance
Asian	\$10,232	\$12,576	-22.9%
Black African-American	\$13,182	\$15,667	-18.9%
Filipino	\$17,628	\$13,432	23.8%
Hispanic	\$5,503	\$9,704	-76.3%
Native American	\$15,943	\$17,597	-10.4%
Other Ethnicity or Race	\$9,078	\$9,688	-6.7%
Polynesian	\$27,284	\$13,773	49.5%
White	<u>\$24,768</u>	<u>\$19,632</u>	<u>20.7%</u>
	<b>\$8,899</b>	<b>\$11,323</b>	<b>-27.2%</b>

Centro Regional de Sur Centro de Los Angeles  
Disparidad de POS

Los consumidores que no tienen POS por Diagnóstico			
Diagnóstico	Total de los consumidores elegibles	Consumidores sin Servicios adquiridos	% sin ningunos Servicios adquiridos
Autismo (Au)	2,782	888	31.9%
Incapacidad Intelectual (RM)	6,772	1,762	26.0%
Parálisis Cerebral (PC)	173	53	30.6%
Epilepsia (EP)	105	31	29.5%
Categoría 5 (CAT5)	213	74	34.7%
Otro (NODX)	<u>2,524</u>	<u>249</u>	<u>9.9%</u>
<b>Total</b>	<b>12,569</b>	<b>3,057</b>	<b>24.3%</b>

**Explicación**

En el diagnóstico del autismo, 888 consumidores no tienen servicios adquiridos o el 31.9% del total de consumidores elegibles con el diagnóstico. Esto se debe principalmente al aumento en el recuento de los consumidores en edad escolar en este grupo. Por lo general, estos consumidores obtiene sus servicios del distrito escolar.

Los consumidores que no tienen POS según su origen étnico			
Origen étnico	Total de los consumidores elegibles	Consumidores sin Servicios adquiridos	% sin ningunos Servicios adquiridos
Asiático	58	11	19.0%
Afro-Americano	3,840	788	20.5%
Filipino	42	8	19.0%
Hispano	7,730	2,075	26.8%
Nativo Americano	9	0	0.0%
Otro Origen étnico o Raza	339	87	25.7%
Polinesio	11	1	9.1%
Blanco/Anglosajón	<u>540</u>	<u>87</u>	<u>16.1%</u>
<b>Total</b>	<b>12,569</b>	<b>3,057</b>	<b>24.3%</b>

En el origen étnico Hispano, 2,075 consumidores no tienen POS o el 26.8% del total de los consumidores en este grupo étnico. La misma razón se aplica, la mayoría de los consumidores están en edad escolar. Más aun, la situación se exacerbo por la eliminación de servicios de recreación social como resultado de un cambio del ley del presupuesto.

POS per cápita por origen étnico		
Origen étnico	Cuenta de Consumidor	Gastos per cápita de SCLARC
Asiático	58	\$10,232
Afro-Americano	3,840	\$13,182
Filipino	42	\$17,628
Hispano	7,730	\$5,503
Nativo Americano	9	\$15,943
Otro Origen étnico o Raza	339	\$9,078
Polinesio	11	\$27,284
Blanco/Anglosajón	<u>540</u>	<u>\$24,768</u>
<b>Total</b>	<b>12,569</b>	<b>\$8,899</b>

El gasto per cápita por los consumidores bajo el origen etnico hispano estaba por debajo de la media del Estado, debido a las razones mencionadas en las tablas anteriores.

POS per cápita por lenguaje		
Lenguaje	Cuenta de Consumidor	Gastos per cápita de SCLARC
Asiático	17	\$29,627
Inglés	7,030	\$11,683
Otro	41	\$16,857
Español	<u>5,481</u>	<u>\$5,203</u>
<b>Total</b>	<b>12,569</b>	<b>\$8,899</b>

El gasto per cápita de los consumidores de lenguaje español estaba por debajo de la media del Estado, debido a las razones mencionadas en las tablas anteriores.

Comparación Per Cápita			
Origen étnico	SCLARC	En todo el estado	Desacuerdo
Asiático	\$10,232	\$12,576	-22.9%
Afro-Americano	\$13,182	\$15,667	-18.9%
Filipino	\$17,628	\$13,432	23.8%
Hispano	\$5,503	\$9,704	-76.3%
Nativo Americano	\$15,943	\$17,597	-10.4%
Otro Origen étnico o Raza	\$9,078	\$9,688	-6.7%
Polinesio	\$27,284	\$13,773	49.5%
Blanco/Anglosajón	\$24,768	<u>\$19,632</u>	<u>20.7%</u>
	<b>\$8,899</b>	<b>\$11,323</b>	<b>-27.2%</b>

# Age Does Matter!



## Regional Centers are the Payor of Last Resort

By law, SCLARC cannot purchase services from any agency receiving public funds to serve members of the general public (generic agencies). In accordance with the Lanterman Act, consumers must first contact generic agencies and resources for services. An example of a generic agency or resource would be a public school, the Department of Children and Family Services (DCFS), Medi-cal, California Children's Services (CCS), County Mental Health, etc. If the consumer is denied services from the generic agency or resource, the agency or resource must provide consumers with a written denial for services before SCLARC can pay for any service listed.

SCLARC has always done its due diligence, as an agency in following the directives of the Department of Developmental Services (DDS) and the Lanterman Act to serve **only** after all generic resources have been contacted, consulted and denied. Regional Centers are the "payor of last resort." This means families should be served by generic resources (i.e. school districts etc.) first. Children from ages 3-22 should have needs met by the local school district. SCLARC can, and does, supplement those services.

As you can see, the majority of SCLARC's Latino consumers are between the ages of 3-21. Therefore, they receive most of their services, at this time, from generic resources. Conversely, most of SCLARC's African American consumers are **over** age 22. The law mandates that SCLARC **must** pay for their services. At

first glance, an assumption could be made that there is an inequity in service provision and funding. But, under further examination one can see that SCLARC's consumers are being served as the law mandates: generic services providing funding first and then SCLARC as the "payor of last resort."



### What Can SCLARC Do?

- 1) Modify orientation programs to ensure that families understand the regional center system and how it works with local agencies as well as state and federal government.
- 2) Educate our families on services, laws and regional center system

jargon (language) based on families educational level.

- 3) Train service coordinators to fully understand the regional center system so they can share information and educate families.
- 4) Create a "help" sheet for staff with generic agencies and contact information for other

community resources which can be readily shared with our families.

- 5) Review POS policy to see if, and where, SCLARC can make changes to ensure families are not going through unnecessary steps to receive services.
- 6) Create new service and supports that would

allow consumers to remain in the home; thereby reducing the number of African American stakeholders placed in residential homes.

- 7) Communicate more clearly with our families and consumers while referring them to generic services.





# Autism Legislation

## Autism Related Bills Being Considered in the 2013 California Legislative Session

**SB 126 (Steinberg D)** Health care coverage: pervasive developmental disorder or autism.

**Summary:** Existing law requires health care service plan contracts and health insurance policies to provide benefits for specified conditions, including coverage for behavioral health treatment, as defined, for pervasive developmental disorder or autism, except as specified. These provisions are inoperative on July 1, 2014, and are repealed on January 1, 2015. This bill would extend the operation of these provisions until July 1, 2019, and would repeal these provisions on January 1, 2020.

**SB 158 (Correa D)** Autism services: demonstration program.

**Summary:** Would establish, until January 1, 2019, a demonstration

program that would be known as the Regional Center Excellence in Community Autism Partnerships (RECAP) program to implement measures in underserved communities to promote awareness and reduce the stigma associated with autism or pervasive developmental spectrum disorders, improve the early screening, diagnosis, and assessment of those disorders, and increase access to evidence-based interventions and treatments, as specified. This bill contains other related provisions and other existing laws.

**SB 163 (Hueso D)** Developmental services: health insurance payments.

**Summary:** Would require a regional center to pay any applicable copayment, coinsurance, and deductible imposed by a health insurance policy or health care service plan for a service or support required by a consumer's IPP or IFSP, as specified. This bill would prohibit a regional center from imposing on the consumer or



his or her family a share of cost for, or income requirements relating to, those payments, and from seeking reimbursement for those payments. This bill would require a regional center to establish appropriate application and documentation forms to implement those provisions.

**SB 208 (Lara D)** Developmental services: request for proposals.

**Summary:** Would establish the Equity and Diversity in Developmental Services Act, and would require a request for

**SEE AUTISM BILLS ...**  
continued on page 7

## Watch your mail for SCLARC's Services Survey!

In an effort to assess and improve our customer service performance, South Central Los Angeles Regional Center has created a short survey regarding the services you receive from SCLARC. In the coming weeks, you will receive this survey in the mail. Please fill it out and, once completed, return it to SCLARC. The survey has prepaid postage. All you have to do is drop it back in the mail.



Your response will help the agency to determine how we can better serve our consumers and families and where we need to concentrate our efforts to make our service delivery process less frustrating for you. Additionally, we want to be more efficient. This is your opportunity to provide valuable input, shape the way services are delivered to you and your loved one as well as tell SCLARC what we could be doing better. Don't miss your chance to partner with your regional center and make your concerns known.

# Autism Bills ... Continued from page 6

proposals that is prepared by the State Department of Developmental Services or by a regional center and that relates to consumer programs or services and supports to include a section on issues of equity and diversity, as specified.

## SB 319 (Price D) Regional Center Data compilation.

**Summary:** Would require the State Department of Developmental Services to ensure that the regional centers collect, analyze, and report disability detail using uniform methodology and procedures that allow for comparisons across regional centers. The bill would require each regional center, commencing December 31, 2014, and each December 31 thereafter, to develop and post on its Internet Web site an annual report relating to whether the data indicates specified disparities and, if applicable, the regional center's recommendations and plans to reduce those disparities. This bill contains other related provisions.

## SB 367 (Block D) Regional Centers cultural and linguistic competency.

**Summary:** Would require the State Department of Developmental Services to require regional centers to develop a Regional Center Study and Planning Process for Equity and Cultural and Linguistic Competency (RESPECT) to address issues, outcomes, and monitoring relating to culturally and linguistically competent services and other factors that promote equity, fairness, and diversity for underserved populations. The bill would require RESPECT to be updated at least every 2 years, and include cultural and linguistic competency staff training and a requirement that providers include specified information in their vendor applications. This bill contains other related provisions and other existing laws.

## SB 555 (Correa D) Regional Centers: Individual Program Plans (IPPs) and Individualized Family Service Plans (IFSPs).

**Summary:** Current law states it is the intent of the Legislature to ensure that the individual program plan and provision of services and supports by the regional center system is centered on the individual and the family of the individual with developmental disabilities and takes into account the needs and preferences of the individual and the family, as specified. This bill would require those provisions to be implemented in a manner that meets the cultural preferences, values, lifestyle, and native language of the consumer and the consumer's family, and require the IPP or IFSP, and the services and supports provided under the IPP or IFSP, to be designed to meet the cultural preferences, values, and lifestyle of the consumer and the consumer's family, and provided in their native language, as defined. This bill contains provisions and other existing laws.



## SB 577 (Pavley D) Employment Pilot Program

**Summary:** Would require a job exploration and discovery plan, as specified, to be developed if job exploration and discovery services are determined to be a necessary step to achieve a supported employment outcome. The bill would establish an hourly rate for job exploration and discovery services of \$40 per hour for a maximum of 75 hours per calendar quarter for all services identified and provided in the plan. This bill contains other related provisions.

## SB 784 (Fuller R) Individual Program Plan (IPP) Planning process.

**Summary:** Would require the team developing the IPP or the IFSP to consider the consumer's, and his or her family's, needs related to issues that include nontraditional service hours, flexibility regarding treatment settings, parental participation requirements, and the scope of services available for adult consumers, and the use of treatment interventions, including, among others, center-based intensive behavioral interventions, as defined. This bill would provide that nothing in its provisions shall be construed to alter or impose requirements in addition to the requirements that currently exist under the act.



# Town Hall

## SCLARC to Host Community Meetings

In the coming weeks, South Central Los Angeles Regional Center will hold informal public meetings at various locations throughout its service area in order to give stakeholders an opportunity to discuss the disparity data detailed on our website ([www.sclarc.org](http://www.sclarc.org)) as well as other emerging trends and issues related to regional center services. Topics will include "How Can We Help You: Better Customer Service," "Understanding SCLARC's Service Delivery System," and "Team SCLARC: Working with Your Service Coordinator." Join us at:

**Where:** South Central Los Angeles Regional Center 650 W. Adams Blvd. Los Angeles, CA 90007

**Date:** Thursday, May 30, 2013

**Time:** 6 p.m. to 8 p.m.

**Where:** Keck Auditorium, Charles Drew University

**Date:** June 13, 2013

**Time:** 6 p.m. to 8 p.m.

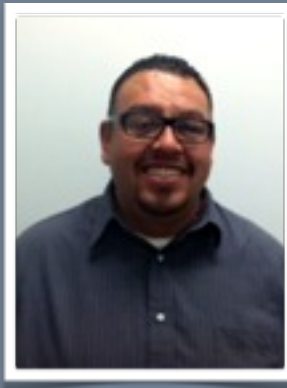
**Where:** Downey Rio Hondo Golf Course

**Date:** June 26, 2013

**Time:** 10 a.m. to Noon

## POS Disparity NEWSLETTER

So. Central LA Regional Center  
650 W. Adams Blvd.  
Los Angeles, CA 90007



Dear SCLARC,

First of all, thank you for allowing me to take part in this wonderful opportunity to do something that can be a blessing to so many people. I never saw myself (speaking to California's legislators about developmental disabilities). But now that I have, I couldn't see myself not doing it. The trip was such a great experience. It was very humbling at times because I never thought I would be in such a position to speak on behalf of so many. My son does not speak yet, but it felt so good to be his voice and a voice for all children [receiving services from] SCLARC. It is a privilege to be an advocate. I've learned that I must continue being a strong voice without hesitation because our children are counting on us.

Sincerely,

Alfredo Farfan SCLARC Parent