



North Los Angeles Regional Center

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May 30, 2018

Brian Winfield, Chief
Department of Developmental Services
Regional Center Operations Section
P.O. Box 944202, MS3-9
Sacramento, CA 94244-2020

Re: NLACRC's POS Expenditure Data and Public Stakeholder Meeting

Dear Mr. Winfield:

This letter will serve as NLACRC's report on the POS data compilation and NLACRC's POS Expenditure Data Community Meetings.

POS DATA COMPILATION

The POS data was posted on the NLACRC Transparency & Accountability page of our web site (www.nlacrc.org) on December 22, 2017. An announcement was placed on the home page of our web site with a link to the posted data.

ISSUES IDENTIFIED BY THE DATA

It is difficult to identify issues due to limitations of the data including POS costs, client count, contract POS expenditures, authorized services, utilized services and clients with multiple diagnoses. If we are going to look at why differences exist, other important factors that should be considered include geographic location, living situation, and individual consumer needs and choices.

POS PUBLIC STAKEHOLDER MEETING

Two public stakeholder meetings were held on March 20, 2018 at 6:30 p.m. at the NLACRC Lancaster office and March 27, 2018 at 6:30 p.m. at the NLACRC Chatsworth office. A presentation was also provided at the Cultivar y Crecer, Spanish-speaking parent support group meeting that was held on March 23, 2018.

COMMUNITY MEETING NOTIFICATION

The community meeting announcement was posted on the NLACRC web site calendar and home page at least four weeks prior to the March 20, 2018 meeting date. Flyers were mailed to promote the meetings to consumers and families, an announcement was posted on the NLACRC Facebook English and Spanish pages, and e-mail blasts were sent on February 16, March 1, March 8, and March 16 to a list of over 10,000 individuals that includes Family Focus Resource Centers, Statewide Council, service providers, and others.

COMMUNITY MEETING PARTICIPATION

Thirty (30) people registered to attend the Chatsworth meeting and fifteen (15) registered to attend the Lancaster meeting. Twenty-seven (27) individuals attended the Chatsworth meeting, seventeen (17) individuals attended the Lancaster meeting and twenty-seven (27) attended the

Cultivar y Crecer parent support group meeting. Spanish language interpreters were present at all three meetings. We did not receive requests for interpretation in any other language.

A total of 71 individuals attended the three meetings which included consumers, parents, vendors, and at least one representative from the Office of Clients' Rights Advocacy, the Statewide Council on Developmental Disabilities, and the Department of Developmental Services.

RESULTS OF THE PUBLIC STAKEHOLDER MEETING

The meetings that were held in Lancaster and Chatsworth were conducted by executive director, George Stevens, and the meeting for Cultivar y Crecer was conducted by deputy director, Ruth Janka. The POS expenditure data and information were presented using a PowerPoint presentation. All attendees received a hard copy of the presentation, which was available in English or Spanish.

QUESTIONS AND COMMENTS

These are the questions and comments raised by those in attendance at the meetings held on March 20, 2018 at NLACRC Lancaster, March 23, 2018 at the Cultivar y Crecer Parent Support Group, and March 27, 2018 at NLACRC Chatsworth.

Questions or Comments	Response
At what age does NLACRC define a child as an adult? What about if the child is conserved?	Age 18.
Are emergency applications clearly defined?	It depends on where the individual is situated. We still occasionally get the person who has lived at home all of his or her life, never opened a regional center case, the parent passes away and that's the emergency. In the main for Early Start and under age 21, for intake cases we take a real aggressive approach on getting those people in. The adults frequently have longstanding issues so it's a different challenge.
Who is on the IPP team?	The IPP team includes the Consumer Services Coordinator (CSC), consumer or consumer's legal representative and anyone the consumer wants to invite. For a child, it's the parent or guardian and the regional center service coordinator, and you can invite as many people as you want.

Questions or Comments	Response
What if the consumer doesn't speak the family's language?	NLACRC assigns the case based upon the language of the decision maker.
Do you think it's fair that more money is spent on consumers who need residential services compared to consumers who live at home?	It's based on people's Individual Program Plans.
Why would the State pay that kind of money for residential services?	That's a decision that the State made. We probably need a better statistic for the types of individuals who need this assistance. It's a greater need to have a family member to take care of their own children. We should come up with a service category to pay parents to help support their adult children. A residential rate has board and care (food, electricity, etc.) paid for by SSI. The part that goes beyond SSI is the support needs of the consumer (teaching, training, etc.). Regional centers can help with respite, personal assistance, independent living and skill development.
Why do other regional centers pay for camps?	NLACRC buys things that consumers need. We have the highest deficit amongst regional centers, but we follow the Lanterman Act. There are certain ways we can do camp but it has to be in the IPP. We can't buy it just for the sake of buying.
Is it an exemption?	It can be done with an exemption but it should be far and few between. We are still fighting to get camp and social/recreation back.
Does a parent have to file a 4731 against a vendor or can NLA file a 4731?	It has to come from the parent.
For per capita by diagnosis, why is Cerebral Palsy so high?	The number of cases coming in is very low. Existing consumers with Cerebral Palsy are aging. The cost factor is the aging population. They require more support than ever before. No one thought they would live and thrive in the community. Consumers are living longer and being supported costs more.
Is there a change in law regarding staff educational requirements?	It depends on who's providing the service. It depends on the service type, too.
What's the difference between autism and intellectual disability?	Intellectual disability is dependent on IQ. 100 is the mean, less than 70, is two standard deviations below mean. Autism is a clinical diagnosis based on a collective number of symptoms – language, social, eye contact. Many people with autism have very high skills in certain areas.

Questions or Comments	Response
For consumers who live on their own, would that give them more of an advantage for support?	Individuals living on their own create more cost. Regional center pays for support to make sure you're eating, cooking, going to functions, etc. For adults, they receive Supplemental Security Income to help with room and board. It's the amount of support that goes into people living independently.
If you have more than one diagnosis, what category do you fall under?	You would potentially be in both categories. In an autism bucket, there can be people with intellectual disabilities.
For families participating in the FETA program, how do they get services?	The services are authorized on your IPP. If you're not using them, we want to know why. FETA is a program that is looking at underserved families. FETA goes into the community. It's not a program at CSUN.
How can I get information about FETA?	Dr. Jesse Weller can provide you with more information. He's here tonight if you have questions for him.
How can my child be involved? I'm not understanding the Lanterman Act. The system is voluminous.	We're coming out with three brochures by age. The Lanterman Act is based on need. The brochures will give people an idea about available services.
Have you reduced the CSC's caseloads?	We need 145 CSC's to meet the ratios and that would cost \$12M.
Is it the money or the ability of funding qualified CSCs that presents a challenge?	It's the money. The State doesn't pay us enough money. It's something we're advocating for. The multiplier hasn't changed since the late 90s, early 2000s. Every year we go forward, the money we receive doesn't go as far.
What is the caseload for a CSC?	For Early Start CSCs it's 1 to 63 or 64. For non Early Start they range between 1 to 85 or 1 to 95 and there are a few instances where it's over 100.
What is the turnaround on translated IPPs?	45 days

Questions or Comments	Response
For FETA you say you have 31 families participating. What are you doing to look for more families? How many families don't have POS?	To look for more families we are having our self-determination specialist go to support groups but it's been a struggle to get people connected to the program. It's a trust factor but it's the economic climate that makes people feel suspicious. The data for families that do not have POS is available on our web site.
How are you measuring your success in the FETA program?	Success means that we've increased POS for these families.
Are you tracking the families?	We make initial contact with families and they seem interested. We try to contact them again but they don't respond. It's been a challenge. ELARC is doing something similar. Once they have them invested they're finding a bit of success.
Does the regional center have anything to do with IHSS?	Our Clients' Rights Advocate, Bebo Saab can help you with IHSS and provide information.
Do your CSC's have one type of clientele?	Our CSCs have caseloads that are determined by age. We've learned over time that age determines the types of services more so than diagnosis.
If your child is going through a transitional phase and your IPP is not sufficient, can you call a meeting?	Yes.
How many of your staff are bilingual?	We can get you that number. When a caseload gets to 50% we build another caseload. A person has 50% of whatever language they speak and the other half is English.
If a regional center CSC authorizes a service in December and the provider can't provide the service until March, when do they start paying the provider?	In March. The provider can only bill for the services they deliver.
Why is it that the Caucasian group has a greater amount of funds expended then other groups?	We seek to understand if there are obstacles to accessing regional center services. We are looking at where are they if any, and how do we remove them.
A parent from the Cultivar y Crecer support group comments that more information is needed for new children.	

Questions or Comments	Response
<p>What is it that the Whites are receiving that the Hispanics haven't asked for?</p>	<p>We don't have the analysis to show what constitutes the amounts Whites receive vs. what Hispanics receive. The types of services are available to anyone whether it's respite, adaptive skills training, previously behavior intervention, social skills training, independent living skills training, personal attendance services, nursing services it not available from Medi-Cal. All of these services are available to everyone. It's utilization and access. The dollar amount represents how much a family accessed on average in a given year.</p>
<p>Is what's on the screen (slide 24) what they receive at home?</p>	<p>Yes, in contract to individuals living in a residential program.</p>
<p>An individual comments that parents might not ask for services due to fear. If they tell you "No" one time, you think "I'm not going to ask again." Or perhaps they don't feel comfortable because they don't speak English.</p>	<p>What is important is to make sure everyone has information about what services are available. If you ask for a service and your CSC says it is denied, you can question this by appealing it. Appeals are intended to give you an opportunity to have someone else look at an issue to decide if the service should be provided.</p>
<p>People are afraid because they are undocumented.</p>	<p>Know that the individual's status has no bearing on our provision of service. We do not communicate with immigration. We don't provide information to immigration and your regional center records are confidential. We don't release records.</p>
<p>Do you offer singing as an activity?</p>	<p>Your CSC can help you find resources in the community such as LA County Parks and Recreation.</p>
<p>Why do some people receive 30 hours of respite and not others?</p>	<p>It depends on the supervision needs of the child based on their disability and the family support needs. There's a correlation between the amount of respite we provide and the severity of the supervision needs of the child. The 30 hour a month respite limitation has been removed. Respite is assessed based on the individualized need for every family. Before January 1st of this year, respite was limited to 90 hours a quarter or 30 hours a month, unless you had an extraordinary circumstance. Since the law changed, regional centers have the ability to provide more than 30 hours per month if needed.</p>

Questions or Comments	Response
My son is 20 years old. I've never applied for respite. In what cases can that service be denied?	If the individual does not have care and supervision needs that exceed that of someone of the same age without a disability. In our young ones that may be the case. When individuals are older the impact of the disability becomes more significant. Another circumstance is when the child has another government paid service providing supervision throughout the week and there's not an opportunity for another regional center service. If there are enough of other entities providing support, there might not be an opportunity for respite.
More efforts are needed to ensure inclusion and embracing individuals with developmental disabilities to prevent abuse, prevent bullying and victimization. Our community needs to be educated.	

How is NLACRC addressing the POS disparities?

- Continue FETA (Family Empowerment Team in Action), a two-year pilot program in partnership with California State University Northridge. FETA is currently working with families from underserved communities to help bring them a better understanding of the services provided by Regional Center and Family Focus Resource Center and how to access them.
- NLACRC hired social media consultant RG Pacific for a second year to set up a Facebook page in Spanish and improve and expand our English Facebook page. As of May 2018, we have over 3,200 English followers and over 800 Spanish followers. We will continue to work with RG Pacific in FY 2018-19 by adding other social media tools including Twitter and YouTube in order to amplify and diversify our audience reach.
- Our community legislative and education consultants conducted a Community Needs Assessment Survey in the fall of 2017. A "Stakeholders' Priorities Report" was published based on survey results, and a Community Town Hall was held on April 5, 2018 to share the survey feedback with several of our elected representatives including Assemblymembers Chris Holden and Adrin Nazarian, Board of Supervisor Kathryn Barger, and City Councilmembers Mitch Englander and Bob Blumenfield. The event drew more than 300 people. We are scheduling follow-up meetings with all of the representatives who participated to continue discussions on how we can work together to address areas of concern expressed by consumers, families and service providers including healthcare, affordable housing, transportation and safety.

The consultants provided 7 legislative advocacy trainings to the community in the San Fernando, Santa Clarita and Antelope Valleys, as well as providing trainings to board members, staff, and vendors. In January 2018, the consultants provided a legislative advocacy training at Festival Educativo, an event for our Spanish-speaking families. Eighty-three (83) individuals attended the event. A Candidates' Forum is being held for

Assembly Districts 39 and 45 on May 29, 2018.

We are looking to extend the contract with our consultants into FY 2018-19 to offer more educational trainings in the community, host another Candidates' Forum in the fall, and we are looking at adding a legislative advocacy tool on the NLACRC web site before the end of 2018

- NLACRC's deputy director will schedule meetings out in the community with organized groups in order to have conversations with consumers, family members, and providers to ask for feedback and suggestions.
- NLACRC is developing a "Commonly Coordinated Services" brochure for School Age, Transition, and Adult consumers and their families. Draft copies of these brochures in English and Spanish were made available at the meetings for attendees to review and provide feedback. We are also developing a Consumer & Family Services Guide.
- NLACRC has been meeting with community-based organizations that have been awarded ABX2_1 funding for FY 2018-19 to discuss how we can partner with them and provide support in their efforts to reduce disparities.
- NLACRC plans to do an analysis for individuals who receive in-home respite care and individuals who do not receive services in order to determine where disparities might exist and how we can address them.
- NLACRC will meet with the Valley Industry and Commerce Association ("VICA") to learn about how our staff can participate on VICA's committee and become more involved in their legislative advocacy efforts.
- NLACRC is considering adding a new bilingual position for a regional center "conciierge" or "cultural broker" who will reach out to families that are not utilizing authorized services and who can be available to provide assistance to consumers and families that are having difficulty obtaining the services that they need.

Copies of the following documents are enclosed with this report:

- Flyer to announce NLACRC's POS Expenditure Data Community Meeting held on March 20, 2018 at NLACRC Lancaster and March 27, 2018 at NLACRC Chatsworth
- Sign-in sheets from the two community meetings and the Cultivar y Crecer parent support group meeting.
- PowerPoint presentation distributed at the community meetings.
- Meeting minutes

Questions?

Please do not hesitate to contact me at (818) 756-6200 should you have any questions.

Sincerely,

A handwritten signature in black ink, appearing to read "George Stevens". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

George Stevens
Executive Director

Attachments: POS Expenditure Data Meeting flyers
Meeting sign-in sheets
Meeting minutes
PowerPoint presentations

c: Debra Newman, Board President, NLACRC
Association of Regional Center Agencies

