



North Los Angeles County Regional Center

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May 25, 2017

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 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 28, 2016. An announcement was also 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 23, 2017 at 6:30 p.m. at the NLACRC Chatsworth office and March 30, 2017 at 6:30 p.m. at the NLACRC Lancaster office. The information was also presented to Cultivar y Crecer, NLACRC's Spanish-speaking parent support group, at their monthly meeting that was held on March 24, 2017.

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 3/23/17 meeting date. Postcards were mailed to promote the meetings to consumers and families and an e-mail blast was sent on 2/23/2017 to a list of over 7,000 individuals which includes Family Focus Resource Centers, Statewide Council, service providers and many others.

COMMUNITY MEETING PARTICIPATION

- Forty (40) people registered to attend the Chatsworth meeting and fourteen (14) registered to attend the Lancaster meeting. Twenty-one (21) individuals attended the Chatsworth meeting, ten (10) individuals attended the Lancaster meeting and thirty-two

- (32) people attended the Cultivar y Crecer parent support group meeting. Spanish language interpreters were present at all three meetings. We did not receive any requests for interpretation in any other languages although one family attended the meeting on 3/23 in Chatsworth who were monolingual in Arabic. Unfortunately we did not receive notification ahead of time that they required language interpretation. They did end up staying for the meeting.

This year the Chatsworth meeting was held in the evening and an additional evening meeting was held at the Lancaster office with the hopes that more people might attend.

- A total of 64 individuals attended the three meetings (59 family members, 1 vendor, 2 people from the Office of Clients' Rights Advocacy, 1 from DDS, and 1 from the Statewide Council).

RESULTS OF THE PUBLIC STAKEHOLDER MEETING

The meeting was conducted by executive director, George Stevens. 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.

These are the questions and comments raised by those in attendance at the meetings held on 3/23/17 at NLACRC Chatsworth, 3/24/17 at the Cultivar y Crecer Parent Support Group, and 3/30/17 at NLACRC Lancaster.

Questions/Comments	Response
Does birth to 5 years of age have a different funding stream?	No. For DDS there's \$19 million for maintenance of effort. Whatever a person needs is funded through the general fund and they get matching Medicaid dollars but it's invisible to the family. If you're eligible there's an entitlement and you get the service.
What is managed care?	Health insurance. The legislature took money out of the budget but it's not taken out of your IPP. It was taken out of the DDS budget. For the individual it's invisible because we did a smooth transition. It's no longer factored into the budget estimate because regional centers in the main shouldn't be providing it. It's like a generic resource.
On Slide 25 (Per capita expenses by ethnicity/race, 3-21 years), a parent says she sees a disparity.	There's a difference but we don't know what's causing the difference. It's something that would have to be analyzed. Is it a difference in diagnosis or access?

Questions/Comments	Response
<p>Parent comment – In the Harrington and Kane? article it says that Asians, Blacks and Hispanic families receive less.</p>	<p>They looked at need but some of the needs were outside of the scope or regional center. We need to ask as our demographics change, what do we need to do to make services more culturally sensitive. We still look at services from 50 years ago. Even if I give you a list of all the services, is that the menu you want to shop from? The legislature needs to ask the population what they really need.</p>
<p>The Cerebral Palsy Research Network has patient recorded outcomes. Some organizations have national outreach. Couldn't something like this help to address data issues? Maybe your staff can look into this?</p>	<p>Data issues are a reflection of a software system that was developed in the 1980s. Until there's an investment in software, we can't retrieve the data that we need. All regional centers seem to be doing something different – more collaboration is needed.</p>
<p>What is AB 279? Is that only for vendors?</p>	<p>It allows regional centers and DDS to pay the city and local minimum wage increases in Los Angeles. It slows the bleeding a little bit. Providers will have a difficult time serving people without this funding.</p>
<p>Annual reviews are conducted over the phone. Does that have an impact? If you're not seeing them in person it's just not the same. This is what the Clients' Rights Advocate hears. What are your thoughts?</p>	<p>You don't see the facial prompts if you're speaking over the phone. You only hear their tone. Families might not know that they have the right to ask for a face-to-face meeting. We should let them know that's an option.</p>
<p>How many Hispanic consumers do you have compared to White consumers?</p>	<p>(In reference to Slide 61 – Per capita expenses by ethnicity or race for residence type: residential all ages) This is only for Hispanic consumers in residential. It's a snapshot of how many of our consumers live in that residential code. On slide 56 you have more expenditures for Whites vs. Hispanics. It's based on the actual number of people who receive that service. It could be an issue but also when we isolate where people live, it seems that where people live at home is where the big variance exists. Residential services are about choice. Where people live drives costs. It's clear there's a difference between White people who live at home and Hispanic people who live at home. You can't compare people who live at home vs. people who live in residential settings. The rate system takes away variances. When people live at home there's more subjectivity.</p>

Questions/Comments	Response
Do you have that information separated by the 3 valleys?	No we do not.
In reference to Slide 78 (Consumers without POS by Ethnicity ages 3 to 21), for ages 3 to 21, there's a difference here that is concerning for the Hispanic population. Out of the 24,000 how many are Hispanic?	We need to look at people who live at home. Seems like a difficult barrier. It's over the age of 3 who live at home. Those are the families we need to reach out to.
I work with Down Syndrome LA and Cultivar y y Crecer. I hear that when people call NLACRC, their CSCs are not informed about what's available. Families who have babies with Down syndrome are told they can't receive services until they reach age 2.5 or 3 and by that time school districts will pick up services. Families have not been offered a Notice of Action, they don't know that they've been denied a service and don't know how to appeal a decision.	Give us a list of names of these individuals and we will look into it. It sounds like a combination of system problems and individual problems. It's important that people have access.
There are parents who are waiting to get their children into programs. What are we supposed to do? What's going to happen when our children turn 22? We parents have to start all over again. We're tired going through IEPs, therapies, etc. We're told it's going to get better but it's still so hard.	This is where we need your legislative advocacy. It's a rate problem – providers can't expand their services when they're losing money. There are programs that have to raise over a million dollars to keep their programs in business. They can't expand enough to meet growing needs.
For ages 3 to 21, do we still have vendors? Is that why there's a difference between Whites and Hispanics?	Suspended services probably impact this age category. It's not quite clear if adaptive skills services will stay at regional center. They may go to health care.
Do you have a plan to address these issues?	We need more staff trainings and we need to bring down our caseloads. We are working with CSUN but we still have more research to do to pinpoint the problem.
For people who don't receive services, are they still assigned a service coordinator?	Yes, we pull up everyone's caseload on a regular basis. We have people who have been authorized services but they're not using them. We try to determine why they're not used. We're approaching it from a number of ways.
Are you saying there are a lot of Hispanic families who have authorized services but don't receive them?	We are looking at all cases.

Questions/Comments	Response
I hear that a lot of service coordinators work four 10-hour days and one of the days they don't come to the office. How do you know they're doing work?	They have to turn in a TCM sheet to track their work and it's the supervisor's role to oversee.
What's the difference in caseload ratios?	Our board made a decision that we would have the lowest ratios in Early Start. We made the ratios of 1 to 62 in Early Start but this year it's at 1 to 67 but we are committed to keeping our ratios lower in Early Start
Do consumers who receive ILS or SLS end up returning home?	No. The majority of adult consumers live at home. Our strategy is people need to choose where they live and they need to be supported through and documented in the IPP.
(Slide 47 – Consumers without POS by Residence, 3 to 21 years) Are these the people who fell out of behavioral services?	School is the primary service for this age. The variance is from people who live at home.
How do you plan to help determine the types of services to help reflect demographic of the communities that are served?	DDS and ARCA will be doing a research project with Children's Hospital. We have also have our community educators to help get people more politically active. It's important that people have a voice and speak up. Nothing has been added to the Lanterman Act for a while. The Lanterman Act gives flexibility to add services that are needed, but we don't know what is needed.
What percentage of your staff are bilingual?	Probably 50% or more. We're one of the few regional centers that looks at competency – you have to be able to speak and write the language.
What is the total number of Early Start consumers?	Around 3200 or 3300.
What age group with the CSUN FETA project serve?	All ages, but the primary focus will be on ages 0 to 18 as those are the families that are struggling the most. There are more resources for adult consumers.
How does one obtain social skill services?	It depends on need. It has to be assessed through the IPP process.
How many days does it take to make a decision about a service?	15 days.

What are some of the ways that NLACRC is addressing the POS disparities?

- NLACRC is collaborating in a two-year pilot program that we are doing in conjunction with California State University, Northridge called the “Family Empowerment Team in Action” or FETA. The project involves statistical analysis based on services

authorized but not being used. There are two interns who will carry ten cases each. They will assist people who might have immigration, work, housing, and transportation concerns. The belief is that if a mentor or support person can assist them in accessing resources, this will help reduce stress and they will have more time to spend with family. In the second year, a minimum of 60 families will be served. We have identified 100 families and our CSCs will begin talking to them to determine who is at the highest risk. The first year will focus on the San Fernando Valley and the second year will be all three valleys.

- NLACRC has been working with social media consultant RG Pacific. A Facebook page was launched in August 2016 and we currently have more than 1,700 followers. The Facebook page has enabled us to promote many of our events, including the POS expenditure data meetings. We will continue to work with RG Pacific and we plan to add other social media tools including a Facebook page in Spanish, Twitter, and YouTube so that we may continue to reach more diverse audiences in the future.
- NLACRC hired a Community and Legislative Educator consultant in August 2016. The consultant has provided legislative advocacy trainings to the community in the San Fernando and Santa Clarita Valleys and is scheduled for the Antelope Valley in June. They also provided training at our event for Spanish-speaking parents, Festival Educacional, on February 25, 2017. The consultants worked with NLACRC to organize two very well attended Candidates Forums in October 2016 which helped introduce our agency to three new legislators: Assemblyman Dante Acosta and State Senators Anthony Portantino and Henry Stern.
- NLACRC plans to increase the number of staff to provide subject matter experts in the areas of parent or caregiver education programs, cultural competency training, outreach to underserved populations or additional culturally appropriate service types or service delivery models. We are in the process of looking for a cultural diversity specialist but we are having a difficult time finding someone.
- ARCA, DDS and regional centers will be working with Children's Hospital of Los Angeles to conduct more research. CHLA will interview families and service coordinators to ask them what they want and need.

Recommendations made by meeting attendees:

- Look into how the Cerebral Palsy Research Network is recording their patient outcomes. Maybe it will provide ideas on how to address data issues.

Copies of the following documents are enclosed with this report:

- Flyer to announce NLACRC's POS Expenditure Data Community Meeting held on March 23, 2017 at NLACRC Chatsworth and March 30, 2017 at NLACRC Lancaster
- Sign-in sheets from the two public 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 presentation

c: Lou Paparozzi, Board President, NLACRC
Association of Regional Center Agencies