Serving individuals with developmental disabilities
2241 Harvard Street, Suite 100 Sacramento CA 95815

ALTA CALIFORNIA
REGIONAL CENTER

April 30, 2019
Revised: July 30, 2019

Brian Winfield
Deputy Director
Department of Developmental Services
1600 Ninth Street
Sacramento, CA 95814

Dear Mr. Winfield:

This letter is written in accordance with Article VII, section 6(b) (i) of the contract regarding data compilation. Alta California Regional Center (ACRC) held two public meetings: Wednesday, March 13, 2019 at 6:00 p.m., and Wednesday, March 20, 2019 at 10:00 a.m. Both meetings were held at ACRC's main office, located at 2241 Harvard Street, in Sacramento. In the past, ACRC has held meetings in our branch office locations, however attendance in those venues was low. Hosting the meetings at our main office in Sacramento has been the most successful in terms of gathering stakeholders. The meeting notice was translated in several languages and posted in all ACRC offices and on the agency's website. The translated notices were also distributed to service coordinators (SCs) to share with clients/families. The notices were widely distributed across our community partners, including Family Resource Centers, State Council on Developmental Disabilities (SCDD), Disability Rights of California (DRC), Hmong Youth Parents United (HYPU), Southeast Asian Assistance Center (SAAC), Health Education Council (HEC) of the Mexican Consulate, and the MIND Institute. These partner organizations distributed the flyers to members of their organizations via email distribution and mailing lists. Attendance at the March13th meeting included 4 members of the general public (vendors and Family Resource Center staff) and 6 ACRC staff. Attendance at the second meeting included 12 members of the general public (parents, advocates, and vendors) and 14 ACRC staff. Two professional Spanish interpreters were available during both meetings.

The following items were presented at each meeting:

- ACRC's client demographics across ethnicity/race
- ACRC's employee demographics, including languages spoken

- ACRC outreach efforts in 2018 compared to previous years efforts (56 documented outreach events in 2018 compared to 44 in 2017). The total outreach to diverse communities was 12 in 2018.
- ACRC reported on Diversity Grant Funding projects: Fiscal Year 2016/17; Fiscal Year 2017/18 and approved projects proposals for current Fiscal Year (2018/19).
- ACRC presented the 58-page Purchase of Service Expenditures and Demographic Data, which included considerations of data limitations (purchase of service costs, client count, contract purchase of service expenditures, authorized services, clients with multiple diagnoses, category 5 clients, individual program plan, ethnicity, residence type, insurance copayments, coinsurance and deductibles and languages).
- ACRC's per capita expenditures by ethnicity or race for all ages showed that the Caucasian populations utilized services at the same rate as the African-American populations at 77.3% and 77.2% respectively. The American Indian or Alaska Native utilized POSs at the rate of 74.7% while Asians and Other ethnicity/multicultural are at an almost similar rate of 70.9% and 70.1% respectively. The Hispanic populations reflect a 69.3% rate of utilization.
- Additionally, ACRC queried its POS data on respite services which is attached to this letter. The respite POS data does not show disparity in utilization among the culturally diverse populations of ACRC. However, ACRC continues to work on implementing focused activities through its Fiscal Year (FY)18-19 Enhanced Respite services grant to increase vendor capacity in the areas of language, cultural competency/sensitivity, and availability of translated materials with the end goal of increasing the utilization of respite services among its ethnically diverse communities.
- ACRC has targeted the Hispanic, Asian, Slavic, and African-American communities in the diversity grant proposal.
- Discussion with the attendees ensued with feedback and proposed strategies.

Feedback/Proposed Strategies from the stakeholders:

- Respite agencies would like to better understand how respite is to be used and when it would be best to refer back to the Service Coordinator when the usage of respite falls under another service code (i.e. day care)
- Training service coordinators in client and family needs assessment to determine appropriate service based on the age of client, needs. Understanding generic and natural resources.
- A suggestion was made for ACRC to explore a survey on its website for people to provide feedback on outreach activities.
- A suggestion was made that ACRC should find a way to present case management data that are not reflected in the POS Expenditures table, such as service coordination, time spent on the phone connecting families to generic agencies, assisting clients and families in dealing with crisis, advocating for clients and families during individualized education plans (IEPs), and assisting with consents and medical appointments
- A member of the public also suggested documenting the economic benefit of the help extended to the client and his/her family as these are services that are not reflected in the POS Expenditures table

- The information below was submitted to ACRC by a member of the audience who attended the second meeting on March 20, 2019:
  - I continue to advocate for creation of an archived website of the Annual POS meetings, and others, to broaden the audience to include consumers and their family members who cannot make it the meeting physically
  - According to the Pew Research, 77% of US adults own a smartphone, with remarkably similar ownership amongst white, black, and Hispanic populations ranging from 75-77%. The link to the research was provided as http://www.pewinternet.org/fact-sheet/mobile/
  - Alta has two different pages on its websites on POS data: one at https://www.altaregional.org/pos-data which is more recent, but lacks letters sent from ACRC to DDS on the POS meeting summary reports, and another at https://www.altaregional.org/post/w-i-code-section-45195f2-reports which include the meeting summary report letters to DDS up until 2016.
    - Please consider consolidating these two website pages and posting the meeting summary report letters for meetings held from 2017 and after on the ACRC website.
  - Thank you for the slide presentation delivered by Lori Banales. It was impressive to see data showing how ACRC's outreach to Hmong and Hispanic communities has resulted in an increase in utilization of services over the last few years.
    - Please post your slide presentation on the ACRC website.
    - Though the numbers may be too small to draw a statistically significant conclusion, ACRC is gaining important insights from its efforts. Possible special factors affecting service utilization should be identified, and input solicited on potential methods to improve utilization of services vital to improving long term consumer outcomes. For example, sidebar conversations indicated that in some cultures, children with I/DD may be hidden within their families due to fears that the extended family will be somehow tarnished. I've personally heard similar input directly from an affected family member. The problems that result from such issues cannot begin to be solved unless they are clearly identified.
    - All regional centers must work to straightforwardly address how to respect cultural differences while protecting the rights of regional center consumers to live their best possible life. This is a budgetary issue as well, as every child that could have received timely services at an earlier age, particularly BIS, and does not, can end up costing the regional center and the state decades of higher cost care in the long run.

  - The following comments may be statewide in nature and more appropriately directed to DDS:
    - It would be helpful if regional centers would provide additional data to understand whether the percentage breakdown of consumers by ethnicity/race and by age group is representative of the general population in a regional center's catchment area. This is really step #1 to identifying racial and ethnic disparities - figuring out if there is a disparity in the initial assessment process that qualifies an applicant for regional center services.

		%	Catchment Area % total Population
American Indian	124	0.49%	?
Asian	2256	8.96%	?
Black	3015	11.97%	?
Hispanic	4311	17.12%	?
Pacific Islander	89	0.35%	?
Other/Multicultural	3139	12.46%	?
White	12250	48.64%	?
Total	25184	100.00%	

- By the same token, now that regional centers have been compiling POS data for several years, we need to see data on how expenditures per capita and % zero service utilization have been changing over time. It would be helpful to graphically present how the statistics have changed over prior years, to identify what strategies appear to be working and where issues like funding shortfalls or inadequate rates may be having an adverse effect. In future years, with such data, we can show the legislature how increased rates are helping.
- There is no gender data in the POS data, but there should be. We are beginning to learn that females with autism are under diagnosed, or are diagnosed late. We know that in the general population, many medical issues are under diagnosed in females, partially because the symptoms present differently (i.e. heart attacks), and also because the medical literature is in general biased towards males (because females have often been excluded in studies to control for hormonal cycles.) On the other hand, we know that males with autism are likely to be significantly taller than average when full grown, which may be a factor in service utilization, particularly if behaviors are present. None of this can be discerned unless the gender data is made available.
- Current POS data does not show the presence or absence of behaviors (or a behavior plan), but should. During a family/consumer DDS rate study meeting in Sacramento, many families spoke up to advocate for more training and higher

reimbursement for care providers of consumers with behaviors, as families were often unable to obtain direct care services that were authorized in the IPP for their children with behaviors.

- For the first time, DDS asked regional centers to identify spending by residential setting, shown on p. 21. This is helpful data. However, as was discussed, ILS is delivered in both a family home setting as well as an independent consumer home setting, so this category should be footnoted as a mixture of both.
- There was a discussion about why for people with an autism diagnosis, there is a relatively high percentage (29.1%) of consumers with no purchased services (see p. 29 and p.32). The ACRC input is that this arises at least in part from the ability of people with autism to secure insurance-funded services which are used in lieu of ACRC funded services. However, among the 1313 consumers with a diagnosis of both ID and Autism, who would also have access to insurance funded services, the rate of zero purchased ACRC services is far lower at 16.8%. Please consider whether another factor may be at least partially responsible.
- It would be worthwhile for ACRC to examine whether people with autism deemed eligible for ACRC services yet not intellectually disabled have a higher incidence of behaviors.
- As noted above, DDS has received rate study input from families that direct care providers who care for consumers with behaviors need more training and more pay, as today services are often unavailable. If ACRC can examine the autism-only data to determine the presence of behaviors and any correlation with low utilization of authorized services, it may help DDS to support an increase in training and compensation for staff who care for them.
- Please consider a footnote to the Epilepsy diagnosis as the regional center definition of an epilepsy diagnosis does not conform to the medical definition; specifically, a regional center diagnosis requires that the consumer take at least 2 different daily medications for control of epilepsy in order to be listed with an epilepsy diagnosis. Notably, this definition excludes a prescription for rescue medication (emergency anti-seizure meds) from consideration. I think this is important because consumers with a prescribed need for assistance with any emergency medication, including epilepsy rescue medication, are usually deemed ineligible for non-medical care services such as agency respite, yet ironically these same consumers do not even qualify for an epilepsy diagnosis in the regional center system, which will surely confuse the POS analysis.

- On p. 50, the Residence Type is noted as "Residential" but I believe these are residential facilities or CCFs. Please label this less confusingly.
- CCF service expenditures are extraordinarily skewed towards white consumers, away from consumers of color, especially among 22 years and older. It may be that there are cultural reasons among some ethnicities that favor keeping consumers in the family home; however, the family home residence should be verified to be the adult consumer's choice. Consider surveying community interest in Spanish speaking CCFs and if appropriate, issuing RFPs for them, or exploring other CCF approaches that would better serve nonwhite consumers.

- This is a particular concern for consumers still awaiting a housing choice voucher, because CCFs are usually the only viable community housing option for consumers wishing to move away from the family home.
- On p. 54, for ILS/SLS residences, the dollar expenditures are skewed even more heavily towards white consumers. I assume the dollar figures are dominated by SLS expenditures. It may be worthwhile to meet with some of ACRC's larger SLS agencies to explore approaches that would make SLS more appealing or accessible to nonwhite and/or non-English speaking consumers.
- However, given that SLS services are only available to consumers who have a rare Housing Choice voucher or who can afford to privately fund a separate home (because SSI is insufficient), it is more likely that that family wealth and income, which we know are racially and Ethnically skewed, are gating factors to gain access to SLS.
- This would in turn highlight the need for more CCFs for consumers lacking the family financial resources required to finance the housing costs in Supported or Independent Living, which would in turn endorse the DDS rate study which identifies a need for a significant rise in CCF reimbursement rates.

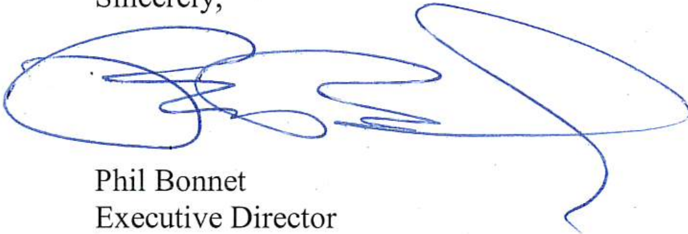
ACRCs Recommendations and Plans to Promote Equity and Reduce Disparities

- ACRC will investigate website enhancements.
- ACRC will continue to train service coordinators in needs assessment and person centered planning.
- ACRC will continue to provide community outreach, targeting diverse populations and communities.
- ACRC will continue to strengthen existing partnership with the Hispanic, Hmong, Slavic, and other Asian communities through non-profit organizations such as HEC, HYPU, SAAC, ARI (Asian Resources Inc.,) and YANA (You Are Not Alone) to facilitate mutual trainings and orientation to services.
- ACRC will continue to track and monitor POS expenditure data through the DDS grant projects.
    - ACRC's service navigation program continues to provide intensive assistance to transition-age clients needing to explore services as adults
    - Ancillary materials such as conservatorships information, Medicaid Waiver information, and transfer letters will be translated to languages appropriate to a larger ethnic composition of ACRC clients
    - Workshops will be provided in the clients' native language on topics such as organizing, understanding and advocating during IEPs, access and utilization of generic agencies such as Medi-Cal, IHSS, and regional center services as they relate to generic and natural resources
    - Enhancement of respite services and dialogue with the target populations to make the service culturally and linguistically responsive
- ACRC will collect success stories from the families impacted by its outreach efforts, service navigation, and collaboration with partner agencies and include these stories in its reporting to DDS, other stakeholders, and during Annual POS meetings

- ACRC will continue to explore innovative activities and partnerships geared towards enhancement of the diverse populations' participation in the greater developmental disability community, that could be funded under future grants from DDS

Should you have any questions or require additional information please contact Lori Banales at 916-978-6424 or lbanales@altaregional.org.

Sincerely,



Phil Bonnet
Executive Director

Attachment: Power Point: ACRC POS Public Meeting
Attachment2: Fiscal Year 17-18 POS on Respite services