



May 31, 2019

LeeAnn Christian, Deputy Director
Community Services Division
Department of Developmental Services
1600 Ninth Street, Room 320, MS 3-9
Sacramento, California 95814

Re: Expenditure and Demographic Data per W&I Code §4519.5 and DDS/Regional Center Contract

Dear LeeAnn:

In December, 2018, Harbor Regional Center posted a report, "Purchase of Services Expenditure and Demographic Data: Fiscal Year 2017-18," on our website as required pursuant to W&I Code §4519.5 as well as our contract with DDS. This report includes data related to purchase of service authorization, utilization, and expenditures, with respect to age, race and ethnicity, language, living arrangement and disability. Two public meetings were scheduled to be held regarding the data - one on March 20, 2019 during regular business hours and the other on March 28, 2019 in the evening.

At the monthly HRC Board meetings in January, February and March, the scheduled dates for the public meetings were announced. Notification of these meetings was posted in January, February and March on Harbor Regional Center's website and notice was also sent several times during these months to the more than 10,000 clients, families, service providers and other subscribers to the HRC electronic news bulletin as well as members of all Harbor Regional Center committees including the Client Advisory Committee, Service Provider Advisory Committee, Client Services Committee, Planning Committee, Community Relations Committee, Audit Committee, and the Self-Determination Advisory Committee, the HRC parent-to-parent mentors and all HRC parent support groups.

On March 20 and March 28, 2019 public meetings were held as scheduled (one at the HRC Torrance Office and the other at the HRC site in Long Beach) and the demographic and expenditure information were presented. A Spanish language interpreter provided translation at both meetings. In addition to our community partner presenters, HRC staff and Board members in attendance at the meetings there was a combined total of thirty-five (35) others present: thirty (30) HRC parents; one (1) service provider; one (1) representative from Disability Rights California; one (1) representative from SCDD; one (1) person who identified himself as a database and process management specialist; and one (1) representative from DDS.

English and Spanish copies of the presentation were posted on our website at www.harborrc.org. A summary of the data presented is as follows:

- The great majority of Harbor Regional Center clients are children – only about a third are adults;
- The substantial majority – 76% - of all authorized expenditures are for adults
- *Per capita* authorized expenditures for adults are 6 times greater than per capita authorized expenditures for children
- The vast majority of HRC clients live with *families* – 84%
- 63% of all HRC expenditures for all HRC clients are to cover the cost of services for those clients residing in *out of home living* arrangements
- *Per capita* authorized expenditures for clients who live in group homes are nearly 13 times greater than those for clients who live with families;
- Per capita authorized expenditures for clients who live with their families and are *birth to age three* are highest for Asian clients and lowest for African American clients
- Per capita authorized expenditures for clients who live with their families and are *age three to twenty-two* are highest for non-Hispanic White clients and lowest for Hispanic clients
- Per capita authorized expenditures for clients who live with their families and are *over the age of twenty-two* are highest for Asian clients and lowest for Hispanic clients

Following the presentation of the data, the HRC Director of Information & Development, Nancy Spiegel, who oversees HRC's "Diversity Initiative" provided an update as to the various activities in which HRC has been engaging to reach out to our Hispanic, African-American and Asian communities. She then introduced Patricia Herrera from 211 L.A. County who presented those in the audience with final data gathered as part of our highly successful DDS-funded "parents as partners" promotora program. Ms. Spiegel then introduced four of the HRC community partners who have received DDS funding to promote disparity initiatives in the HRC service area and representatives from each organization shared information about their projects and their partnership with HRC in these efforts. The four community-based organizations (CBO's) which had received DDS disparity funding and presented at our meetings are as follows: Learning Rights Law Center, Pediatric Therapy Network, Carolyn Kordich Family Resource Center and the Korean American Special Education Center.

At both public meetings most of those parents present were Spanish speaking. Several parents expressed their appreciation for HRC services and some thanked and acknowledged specific HRC staff. Several parents thanked HRC for the "Parents as Partners" promotora program and told their stories describing the help they received through this program. Some who communicated their appreciation for HRC support indicated that they would like to have more interaction with their service coordinators and with some of the various specialists at HRC. Several parents shared their concerns about the schools and stated they believe the regional center should pay the cost of legal representation for educational advocacy. Some parents requested that more parent groups and parent training be provided in the Long Beach area as well as other communities in the HRC service area.

Recommendations:

- The regional center system has severe data limitations which restrict the depth of analysis which can be conducted using the data available. The Department of Developmental

Services should *make the matter of upgrading regional center hardware and software a priority* as it is apparent to us that data limitations constitute a barrier to our understanding of the dynamics of expenditure differences.

- HRC appreciates that DDS has created a “research” unit and has been hopeful this team would make relevant and necessary data gathering and analysis a priority. It should be noted that it is not enough to identify differences if we do not understand fully why these differences exist. We do know that many of the differences in expenditures can be explained by adjusting the data for age and living arrangement. But there is no doubt that *socioeconomic differences* as well as the *availability of other publicly funded services* for some clients also have a significant influence on expenditures. **In the absence of data based upon these criteria, we cannot produce scientifically sound analyses and we look to the “research team” to spearhead an initiative which might result in the collection of this important data (if only for a sample but statistically significant subset).** *At this time, though the DDS research team has been in place for nearly two years, we have not been advised as to any projects initiated by the research team that might result in a better understanding of disparities and the factors that influence these.*
- The Department of Developmental Services needs to provide necessary financial support for regional centers to ensure that they are in a position to recruit, train and retain qualified staff, especially case management staff. **It is vital that caseloads are as low as possible for English as a second language or non-English speakers** so that sufficient attention can be given to those who need more support than others in navigating generic service systems as well as in helping to understand the regional center constellation of services and supports.
- *The Department of Developmental Services needs to develop an understanding of,* and ensure that our elected officials are educated, concerning *the real-life priorities of those living in poverty*...notwithstanding the personal agenda of others purporting to represent and advocate for these “underserved” families. It is clear to us, at least, that those who are homeless or living with several additional families in the same dwelling, who are jobless and with food insecurities are not in a position to place accessing behavior intervention for their family member with a developmental disability in a conspicuous place on their list of priorities.
- The Department of Developmental Services should support efforts underway to **reverse the damaging changes to the Lanterman Act** that were put into place during the Great Recession and that **disproportionately impact families who care for their developmentally disabled family members at home.**
- The Department of Developmental Services needs to recognize that *resource development for all clients is essential* (not just clients residing in state developmental centers and IMD’s or those who are specified as “difficult to serve” or in “crisis”). There must be a portion of each annual budget provided to regional centers for this purpose in order for there to be sufficient ongoing resources to meet the demand for such going forward. Attention to affordable housing issues is critical.
- We applaud the DDS efforts to make targeted funds available to regional centers in order to promote local initiatives aimed at increasing access to services for underserved populations. At HRC we have already taken action to implement those initiatives for which we have been funded. We are already learning about needs and barriers through

the implementation of our “promotora” program. We recommend that this funding continue to be available for this purpose on an ongoing basis but *we have serious concerns about the equitable distribution of these limited resources. Assuming there are disparities in all 21 regions of the state, it occurs to us that whatever resources are made available to address disparities should be equitably distributed.*

- We appreciate that for two years DDS provided “disparity funding” for the HRC promotora program we identified as “Parents as Partners”. This program was highly successful in connecting 79 families with no or low POS expenditures to stabilize their lives in such a way as to make accessing developmental services for their family members possible. We were exceedingly disappointed that, notwithstanding the clear success of our program, DDS failed to provide continuation funding in the current year. We recommend that DDS reconsider this decision going forward as to Harbor Regional Center. In fact **we recommend that DDS ensure each regional center has sufficient funding to put such a program into place, targeting a specified fraction of their client population for “promotora” intervention, on an on-going basis each year. Programs utilizing the promotora model are evidence-based and the single most definitively proven successful intervention to engage low-incidence populations and assist them with accessing needed services.**
- We are grateful that DDS and the legislature have recognized the need to provide funding for regional center staff who can be dedicated to the creation and promotion of activities that will enhance cultural competency and eliminate barriers to services based upon ethnicity. We expect the work of our Manager of Diversity and Inclusion (aka “cultural specialist”) will contribute immeasurably to the successful implementation of our disparity plans. Nonetheless, we must advise that **the biggest “juice for the squeeze” is repeatedly ignored: lower caseloads result in more time for service coordinators to ensure that each family is fully informed and adequately assisted to access needed services.** While we appreciate the funding for a specific staff member to manage our diversity initiative, **adequate funding for sufficient service coordinators has the highest likelihood of achieving the intended results for families.**
- Harbor Regional Center has heard from families that the reasons for the differences in expenditures among the various ethnic groups may be related to certain specified access problems. Based upon the input that we have received we are offering **child care** at more of our training and other service venues and we are making **transportation services** available if needed to ensure that access issues will not interfere with participation.
- In recent years Harbor Regional Center heard from families that having **lists of the various service and supports** that are available through the regional center would be important tools for ensuring that all groups are informed and knowledgeable. We have since created several such lists focusing on those services and supports typically available for clients of specified age groups. These materials have been translated and are now available in multiple languages.
- Harbor Regional Center will continue to maintain **parent groups that are specific to ethnicity and disability** and to seek input from those who participate about purchase of service access issues. We have sponsored parent support groups for Korean and Spanish speaking families for many years. We have offered long-standing parent support groups for those with children with autism and Down syndrome. A few years ago we initiated a Japanese speaking parent support group and more recently we developed a Cambodian

and a Chinese speaking support group. We will continue to reach out to some parent groups that are not affiliated with HRC in order to gather input from a wider base.

- HRC has challenged our **service providers to make increased efforts to recruit direct service staff whose ethnicity is reflective of the clients they serve** and who have appropriate language capacity to enable effective communication with the clients they serve. We have developed and are maintaining a data base of those service providers with bi-lingual capacity and will continue to encourage others to add multi-cultural/multi-lingual capacity.
- Harbor Regional Center will continue to **maintain a multi-cultural, multi-lingual staff** and will continue to provide them, our service providers and our Board with cultural competency training on a regular basis to the end that both HRC staff, service providers and Board members will remain accessible by language and sensitive to cultural differences.

We hope this information is helpful to you.

Sincerely,

A handwritten signature in black ink, appearing to read 'Patricia Del Monico', written in a cursive style.

Patricia Del Monico
Executive Director