



May 25, 2017

Brian Winfield, 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 Brian:

In December, 2016, Harbor Regional Center posted a report, "Purchase of Services Expenditure and Demographic Data: Fiscal Year 2015-16," 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 23, 2017 during regular business hours and the other on March 30, 2017 in the evening. In addition, presentations of the data were made at the regularly scheduled meetings of one of the Spanish speaking parent supports groups in the HRC service area on March 22, 2017 and at the HRC Japanese support group on March 27, 2017.

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 9,000 clients, families, service providers and other subscribers to the HRC electronic news bulletin; 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 23 and March 30, 2017 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 the HRC staff in attendance at the meetings there was a combined total of forty-six (46) others present: thirty-two (32) HRC parents; four (4) parents from other regional centers; two (2) service providers; one (1) representative from the State DD Council; two (2) representatives from Disability Rights California; two (2) representatives from the USC UCEDD; one (1) representative from DDS; and two (2) who signed in as "other".

English and Spanish copies of the presentation were made available at each public meeting and are also posted on our website at www.harborrc.org. A summary of the data presented is as follows:

- Nearly half of all HRC clients have “intellectual disability” as their primary diagnosis, while “autism spectrum disorder” constitutes the primary diagnosis for only a third of all HRC clients;
- The great majority of Harbor Regional Center clients are children – only about a third are adults;
- The vast majority of HRC clients live with families – only 14% of all HRC clients live in other types of living arrangements;
- The ethnic distribution of HRC’s client population is substantially similar to that of the population living in the HRC service area;
- The ethnic distribution of HRC’s staff is substantially similar to that of the HRC client population
- The HRC staff language capacity is sufficient to enable communication with virtually all HRC clients;
- The substantial majority of all HRC authorized expenditures are for adults;
- Per capita authorized expenditures for adults are 5 times greater than per capita authorized expenditures for children;
- A significant portion of all HRC authorized expenditures -38%- are to support out of home living arrangements;
- Per capita authorized expenditures for clients who live in group homes are 11 times greater than those for clients who live with families;
- *Per capita* authorized expenditures for all HRC clients who **live with families** are highest for our Asian clients birth to three and those over twenty-two; they are highest for our non-Hispanic White clients who are school aged; they are lowest for African American clients from birth to three and for Hispanic clients who are over the age of three;
- Per capita authorizations for HRC adult clients who **live outside the family home** are highest for our Hispanic clients and lowest for our African American clients;
- Authorized expenditures are highest for clients with a primary diagnosis of epilepsy and lowest for those with a primary diagnosis of ASD

At our meetings we responded to a few questions related to the demographic or expenditure data but most questions were asked by parents in the audience who were concerned about their individual services and supports. At both public meetings most of those parents present were Spanish speaking. A parent from another regional center asked whether HRC believes there are disparities in the purchase of services and whether the HRC senior management team reflects the ethnic diversity of our client population. He also expressed concern about the fact that the HRC cultural specialist is African-American as opposed to Hispanic. Several HRC Spanish speaking parents echoed the view that the HRC cultural specialist should be Hispanic. Several parents complained about the quality and quantity of their respite services. A few expressed dissatisfaction with HRC service coordination services. One parent advised that her sixteen-year-old son has been waiting for a wheelchair for many years and that he also needs IBI services. The representative from the SCDD corrected some errors on one of the slides and recommended that the HRC Board change its service policies to allow for service coordinators to make POS decisions. A representative from OCRA expressed concern that HRC did not include

data about the 5th category of eligibility in the material that was presented. One parent expressed dissatisfaction about the “promotora” program that HRC has received DDS funding to implement. One parent requested that we provide data regarding how POS authorized services by ethnicity changes from one year to the next. Some parents requested that more parent groups and parent training be provided in the Long Beach area. Several parents indicated concern about the fact that ethnic distribution for the general population was available based only upon the 2010 census. One parent questioned how she could get a budget of \$75,000 to care for her son at home (noting that this is the average cost for a similar client living in an out-of-home setting). One parent complained that her child was assessed very briefly by an HRC psychologist and HRC decided that he was not eligible but the schools are serving him as a child with autism. A number of parents had prepared letters which they provided to the DDS representative and to the HRC Executive Director.

Recommendations:

- The regional center system has severe data limitations which restrict the depth of analysis which can be done 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.
- The Association of Regional Center Agencies has hoped to engage assistance in further analysis of the expenditure data statewide. Understanding differences in expenditures is essential going forward and DDS support, including financial support, for such a pursuit would help to accelerate this effort.
- 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 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 or those who are specified as “difficult to serve”). 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 especially optimistic about the implementation of

our “promotora” program. We recommend that this funding continue to be available for this purpose on an ongoing basis.

- We are also 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.
- 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.
- Last year Harbor Regional Center heard from families that having a list of the various service and supports that are available through the regional center would be an important tool 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. Two years ago we initiated a Japanese speaking parent support group and in the past year we developed a Cambodian parent 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,



Patricia Del Monico
Executive Director