



April 11, 2016

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, 2015, Harbor Regional Center posted a report, "Purchase of Services Expenditure and Demographic Data: Fiscal Year 2014-15," 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, 2016 during regular business hours and the other on March 29, 2016 in the evening.

At the monthly HRC Board meetings in January, February and March, the scheduled date for the public meetings was 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 8,000 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 and Financial Development Committee, Audit Committee, Self-Determination Advisory Committee; the HRC parent-to-parent mentors and HRC parent support groups.

On March 23 and March 29, 2016 public meetings were held as scheduled (one at the HRC Torrance Office and the other at a community center 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 and Board members in attendance at the meetings there was a combined total of thirty-five (35) others present: twenty-eight (28) HRC parents; one (1) service provider; one (1) representative from the State DD Council; two (2) representatives from Disability Rights California; and, three (3) representatives from the USC UCEDD.

English and Spanish copies of the presentation from our public meetings are posted on our website at [www.harborrc.org](http://www.harborrc.org). A summary of the data presented is as follows:

- The ethnic makeup of HRC’s client population is substantially similar to that of the population living in the HRC service area;
- The ethnic makeup 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;
- Nearly half of all HRC clients have “intellectual disability” as their primary diagnosis, while “autism spectrum disorder” constitutes the primary diagnosis for about 30% of all HRC clients;
- Authorized expenditures are highest for clients with a primary diagnosis of epilepsy and lowest for those with a primary diagnosis of ASD
- The great majority of Harbor Regional Center clients are children – only about a third are adults;
  - It is worth noting that 75% of Hispanic clients are children while less than 50% of White clients are children
- 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;
- The vast majority of HRC clients live with families – only 15% of all HRC clients live in other types of living arrangements;
  - It is worth noting that 93% of Hispanic clients live with their families while only 67% of non-Hispanic White clients live with their families
- 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 12 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 across all age groups; they are lowest for African American clients from birth to three and for Hispanic clients age three and older;
- 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;

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 the meeting held in our Torrance office all of the parents present were members of our Japanese speaking parent support group. These parents requested that there be more information available from the regional center in Japanese. At the meeting in Long Beach most of those parents present were Spanish speaking. One parent asked questions about how service providers are authorized and selected to provide services for clients. There were several comments from parents who felt they were not getting needed services and others who indicated they are not getting timely responses from their service coordinators. There were quite a few questions about ABA services and co-payment issues and there were requests for clarification concerning respite, IHSS and Medi-Cal.

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 consider reversing 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.
- 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.
- 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. This past year we initiated a Japanese speaking parent support group and in the coming year we hope to develop 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 concerning barriers to service access from a wider base.
- Harbor Regional Center will review our written materials and will make every effort to translate as many as possible, funds permitting, into threshold languages.

- 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 are developing 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', with a stylized flourish at the end.

Patricia Del Monico  
Executive Director