



November 5, 2020

Ernie Cruz, Assistant Director
Office of Community Operations
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 Ernie:

In December, 2019, Harbor Regional Center posted a report, “Purchase of Services Expenditure and Demographic Data: Fiscal Year 2018-19,” 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.

Meetings Scheduled

Two public meetings were originally scheduled to be held regarding the data - one on March 26, 2020, in the evening in Long Beach, and other on March 31, 20120 in the morning in Torrance. When the need arose to close our offices to the public, for everyone’s safety in response to the coronavirus, we found it necessary to postpone these March meetings. We later scheduled two virtual meetings on Zoom, on June 12, 2020, and on August 27, 2020.

Public Notice

The dates for these public meetings were announced at our public HRC Board Meetings in January, May and July, in the months prior to each of the scheduled meetings. Public notification of each of these scheduled meetings was also posted at least one month in advance, on Harbor Regional Center’s website. Public notice was also sent several times during these months to the more than 20,000 clients, families, service providers and other subscribers to the HRC electronic news bulletin, and was provided to members of Harbor Regional Center advisory committees.

Meeting Outcomes

On June 12 and August 27, 2020, public meetings were held as scheduled, on the virtual platform Zoom, and the demographic and expenditure information were presented. A Spanish language interpreter was scheduled and was present to provide translation at both meetings, but unfortunately, we experienced technical problems with the Zoom interpreter channel at the June 12th meeting. During that meeting, we announced to all participants that unfortunately, due to the technical issues, the meeting would only be able to be presented in English on that date, and that we would notify our community of a new date in which Spanish interpretation would be made available, as soon as our technical issues were resolved. We later announced the follow-up meeting, with Spanish interpretation would take place on August 27th.

Attendance

In addition to our community partner presenters, HRC staff, and Board members, participant attendance was as follows:

- On June 12, 2020, there was a combined total of seventy-five others present: sixty-seven (67) HRC parents; two (2) service providers; four (4) representatives from Disability Rights California; and two (2) representative from DDS;
- On August 27, 2020, there were a total of seventy-seven (77) HRC parents; six (6) service providers; two (2) representatives from Disability Rights California, and three (3) representatives from DDS.

Presentation of Data

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 – 78% - 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* – 87%
- 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, we presented overviews of the various activities in which HRC has been engaging to reach out to our underserved communities, including collaboration with community-based partner organizations such as the Carolyn Kordich Family Resource Center, and Pediatric Therapy Network.

Public comments

We invited comments both in advance, in writing for those who preferred, as well as at the end of each online meeting.

- Several parents expressed their appreciation for HRC services and some thanked and acknowledged specific HRC staff.
- Some expressed appreciation for keeping families informed and providing help in self-advocacy and navigation of different programs that could help the client and family. Some expressed their feeling that HRC was not doing enough in this regard, and questioned why the data still reflects disparity for Hispanic families.
- Several parents, along with an attorney for Disability Rights California, expressed frustration with the technical failure in offering Spanish interpretation at the first meeting.
- Some expressed appreciation for the more frequent distribution of vital community resource information during the pandemic, through our electronic newsletter and social media.

- Some expressed appreciation for assistance they received from their service coordinator to work with the school district for development of their Individual Education Plan, while others expressed more recent concerns about their difficulties obtaining adequate support from their school district, and the additional challenges they experienced while having their children at home for distance learning during the pandemic.

Recommendations:

- 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 sufficient 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. 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.
- 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. 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, whatever resources available to address disparities should be equitably distributed.
- The regional center system has severe data limitations that 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. 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 that might result in the collection of this important data (if only for a sample but statistically significant subset).
- The Department of Developmental Services needs to acknowledge, and ensure that our elected officials are informed, concerning the real-life priorities of those living in poverty. We have seen that those who are experiencing unemployment, home and food insecurity are often not in a position to place priority upon accessing services for their family member with a developmental disability. We have seen that the added challenges of a worldwide pandemic have only added to these barriers.
- 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 recommend that DDS ensure each regional center

has sufficient funding to put a Promotora-type program into place, targeting a specified portion of their client population for promotora-type intervention, on an on-going basis each year. HRC implemented a very successful parent mentor program in 2016-18, but unfortunately did not receive funding for this program for 2018-19. After a one-year interruption, we are currently working to resume this program in 2019-20, and we hope to receive funding to expand this to more families in the upcoming grant cycle.

- Prior to the onset of the pandemic, based upon the input that we have received, Our family support and training calendar included many trainings targeted specifically to underserved non-english speaking families. We offered childcare at training events, collaborated with community partners to offer training and events in our more community locations, and made transportation services available if needed to ensure that access issues will not interfere with participation. Since the onset of the pandemic, these family support and training activities have been offered on virtual platforms.
- We are continuing to expand our library of publications in simple language, translated into multiple languages, informing families of the services available for each age group and providing information to support access to services.
- 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. Some of these groups have elected to go on hiatus during the pandemic, but some are beginning to resume meetings on virtual platforms. We have sponsored parent support groups for Korean and Spanish speaking families for many years and in recent years established support group offerings for Chinese, Japanese and Cambodian speaking families. We have offered long-standing parent support groups for those with children with autism and Down syndrome. 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.
- Harbor Regional Center will continue to maintain a multi-cultural, multi-lingual staff, and will continue to challenge 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.

Harbor Regional Center will continue to implement all of the above efforts to reduce barriers and to improve equitable access to services for all clients and families. We hope this information is helpful to you.

Sincerely,

Patrick Ruppe
Executive Director