

Harbor Regional Center
Positioning Paper on Constituency Concerns and Issues
January 2017

We respect how much work goes into the administration of running a regional center and are thankful for the hard work of the volunteer board of directors. But we need to add our voice. We are here to work together toward ensuring the best possible regional center. We want to collaborate with you on ensuring that the voices of families and consumers are heard and their concerns are addressed.

Background:

Harbor Regional Center (HRC) consumers and family members have expressed concern over their current and historical service provided by, and their relationship with, HRC. The issues include a lack of collaboration with families who seek guidance and best outcomes for their HRC consumers, lack of funding options, lack of support to provide recommendations on service options, long waiting lists for service and lack of provider options.

Consumers and family members have expressed these concerns at Fall/Winter 2016 DDS disparity sessions and HRC Board meetings during public comment in an attempt to illuminate DDS and the Board on trends, themes and examples of issues that exist. The response by the HRC Board did not reflect openness nor demonstrate willingness to listen with an ear toward collaboration with the attendees.

Objectives:

We are not here to merely represent individual consumer issues; instead we are here to illustrate a pattern of “no” – presenting personal stories only to demonstrate the bigger picture. Parents here are not attempting to solve family issues with the HRC Board. They are instead here to show the Board we are a coalition of many families, far beyond those present, who are no longer willing to accept what is not acceptable. Families and consumers are organizing to demand the rights of consumers be followed according to the spirit and the letter of the Lanterman Act, the law. The Regional Center system was started by families, for families, and that is coming full circle. We won't be silenced by what is built by, designed for and meant to serve our constituency.

Facts and feedback:

- DDS data shows a severe pattern of geographic disparity whereby HRC funds their consumers at a level far below other Regional Centers. (See attached tables)
- There is a pattern of denial by HRC for funding to consumers based on feedback from consumers and families. Parents report being “in the dark” about available services for their loved ones. When they ask for input by HRC, they are not given guidance. Instead they are often told “we don't do that” when asked to provide a service requested by a consumer or family member, although we know that these services are provided by other Regional Centers throughout California.
- Many families report a pattern of administrative neglect. Most families have never or rarely received annual statements of services provided. Many families do not receive a written account of their IFSP meeting or ever sign an agreement of services of any kind.

- HRC claims that the IFSP meeting is ‘person centered’ but the meetings recounted by families do not follow any Person Centered Plan, in which goals are listed and accounted for in future meetings. If such a plan exists it is not shared with families.
 - Many families when requesting services are not given a denial letter but told that the service is not available or depends on their coordinator finding another client needing the same service, a policy which runs counter to the individualization of the IFSP model. Often the request is not written into the IFSP.
 - This paperwork is very important because families need the written evidence of their requests being denied for fair hearing and for the future (i.e. under Self-Determination they need to extend their budget).
- Too few service providers are offered for funded services. In fact, there is often a “take it or leave it” provision when one provider is being offered. Service providers who are not on the “short list” meet roadblocks to get vendored, and the stalls can last months or years.
 - Many authorized services go unused because the vendor is unable to serve the family in an appropriate way. For example Respite services that send a different worker every time or “have no one available for a Tuesday”. The low quality and experience of professionals working with individuals, for example in behavior services with families having no control over who is working with their child, leads many families to underutilize even the few services that are authorized. But again, if there are not alternative vendors offered, it becomes a “take it or leave it” empty offering.
 - Families with children and adults with Developmental Disabilities are under a great deal of stress and have many problems to juggle in their busy lives: the school, medical and community. For many families in the Harbor Regional catchment area, dealing with the Regional Center is one problem too many, with little or no prospect of any help forthcoming. There is a pattern of giving up by many families, as they know the wall is too high to climb without collaboration or cooperation from HRC.
 - The Regional Center offers only reactive rather than proactive case management. Families report that in their experience services are received only when initiated by them. No one was able or willing to neither give guidance nor explain which services are provided to provide support to the consumer’s needs. Families end up reaching out for training and education from other organizations in order to then come back educated and prepared to “battle” for Regional Center services.
 - Despite the many denials of funding/services to consumers, HRC has systematically “returned” budgeted funds at year end (2016 amount was over \$2M) to DDS.

Our ask of the Board (not the HRC staff):

(While we respect and appreciate the efforts of HRC staff, this message is specifically for the Board, to whom the staff reports and is accountable.)

1. Listen to the requests of consumers and families as a priority. Don’t dismiss what you don’t understand. Seek understanding.

2. Collaborate with consumers/families and other HRC community members to create a better HRC for the future that serves with equity. Recognize that those of us making precious time to come to these Board meetings are doing so for the betterment of all HRC consumers, not just our personal loved ones. We represent the voices of many families, and have not taken this effort lightly. Our constituent families from many disability organizations have similar challenges that we are documenting and representing.
3. The board needs to better understand,
 - a. There is a pervasive dissatisfaction by HRC consumers/parents as to the level of support and services provided.
 - b. The geographic disparity issues that persist with HRC funding vs. other LA County RCs.
 - c. The limited offerings of provider options and waiting lists that are out of compliance with the Lanterman Act.
 - d. There are services and categories that are not being offered/funded by HRC that are entitled services (by the Lanterman Act), and are being provided by other Regionals Centers.
4. The board needs to find systems of accountability that ensure that the staff working on their behalf are competent and compliant with the Lanterman Act, systems as simple as recording paperwork completion, to adequately fulfil their oversight role.
5. Have an open mind and be willing to ask questions and probe at board meetings; seek to understand what you don't know and seek input from constituents beyond HRC staff. Do not simply listen and "rubber stamp" what you hear and read. Have the courage to stand up for what does not appear right.
6. Communicate your understanding of the above issues with consumers and families that are making the time and effort to collaborate with the Board. Seek to collaborate and understand we want to be on the same team for excellence in our community. Find specific and mutually satisfying methods of communication to gain valuable input from consumers and family members who have spend years and decades in this system, only to be turned away empty-handed, discouraged and demoralized.

Attachments:

Regional Center Disparity Data: graphs (courtesy data via DDS)

Response letter to HRC parents from HRC Board/president

Chart 1

LA County Per Capita Expenditures by Race/Ethnicity- Ages 3-21 (2014-2015)

Asian Black/Af.Am Hispanic White

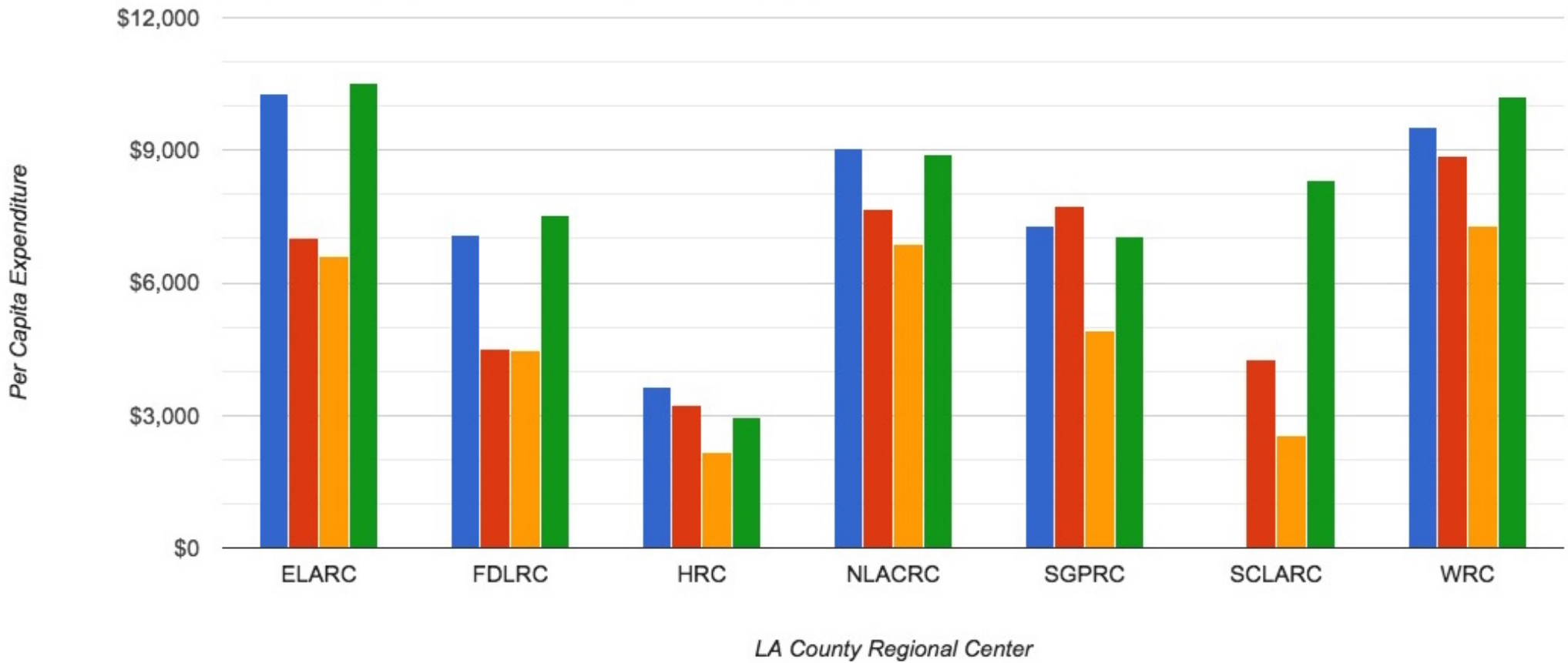
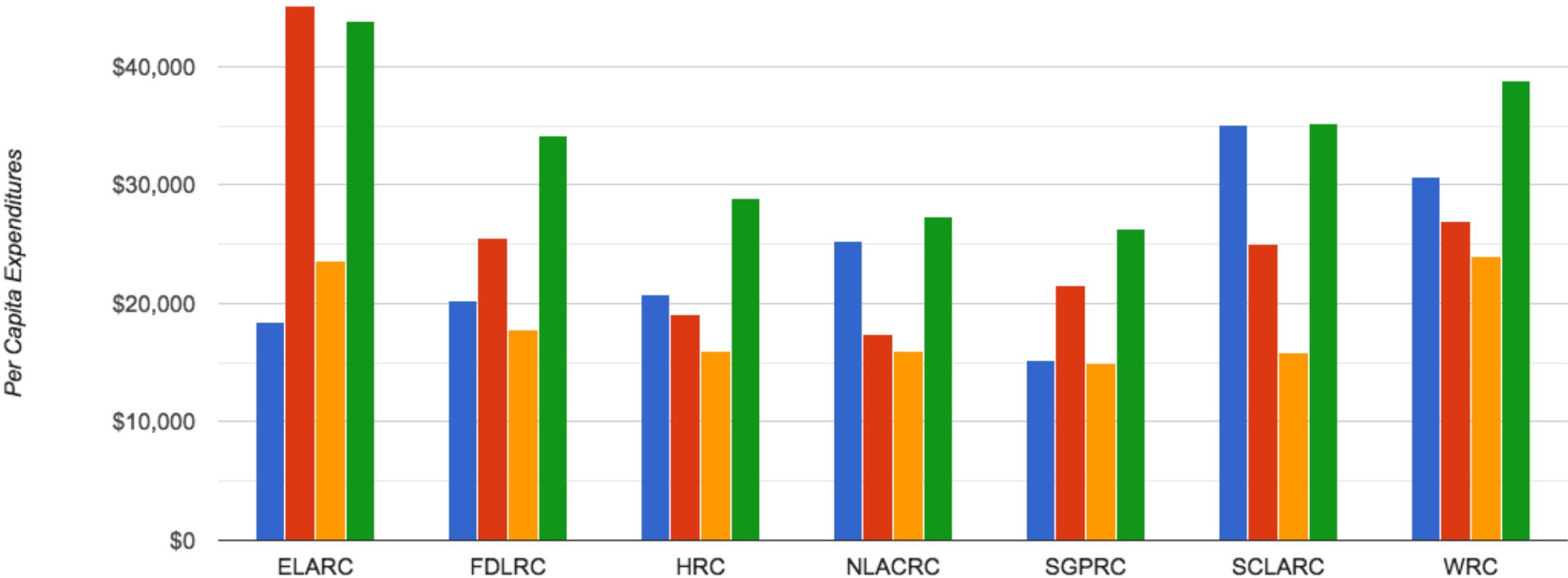


Chart 2

LA County Per Capita Expenditures by Race/Ethnicity Ages 22+ (2014-2015)

Asian Black/Af.Am Hispanic White



Los Angeles County Regional Center

Chart 3

LA County No Purchase of Services- Ages 3-21 (2014-2015)

Asian Black/Af.Am Hispanic White

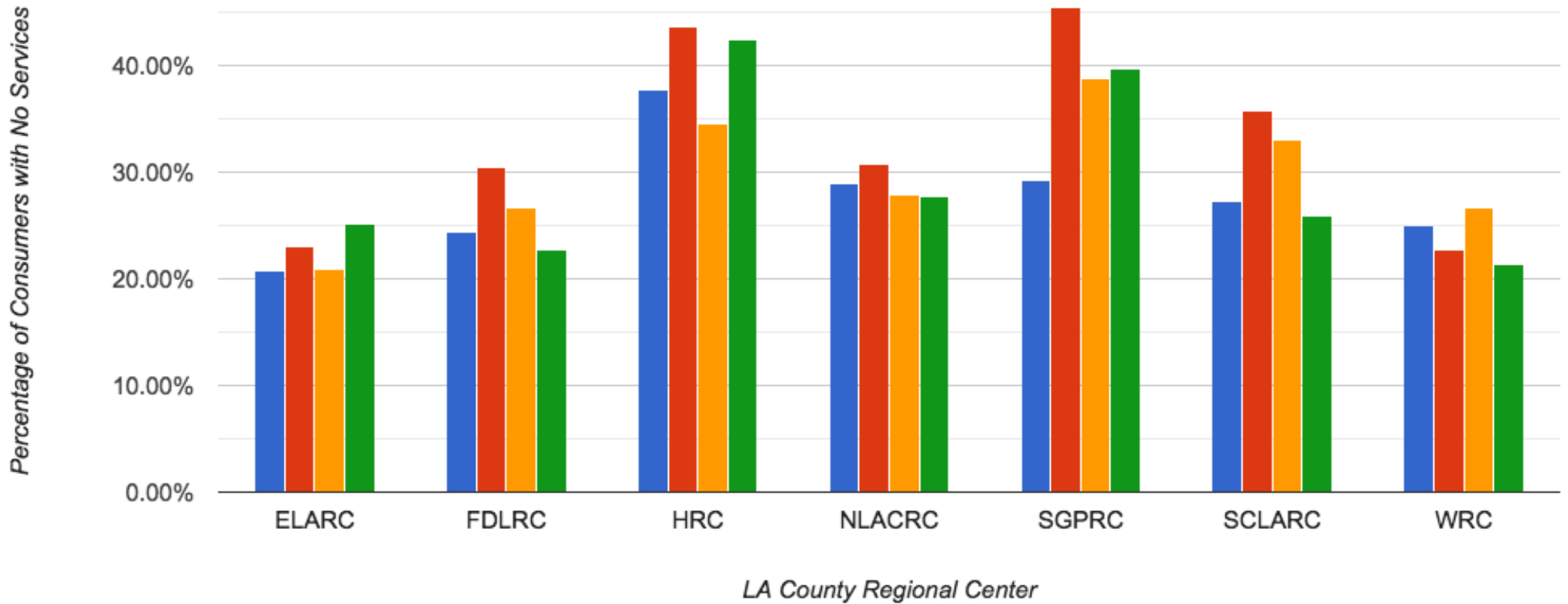


Chart 4

LA County No Purchase of Services by Ethnicity/Race Ages 22+ (2014-2015)

Asian Black/Af.Am Hispanic White

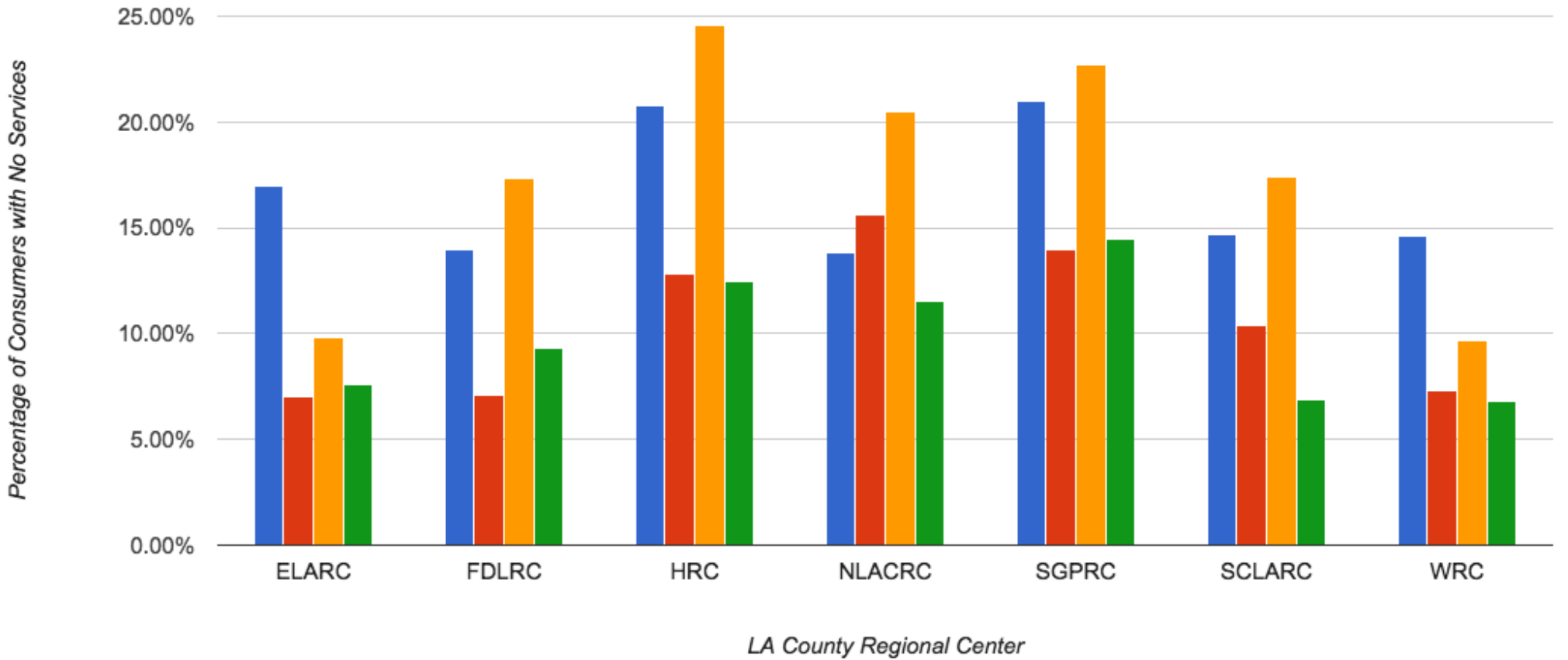


Chart 5

Per Capita Expenditures: White, Hispanic, and Spanish-Speaking (2014-2015)

White Hispanic Spanish-Speaking

