DISABILITY VOICES UNITED

REALITY CHECK

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Despite $22 Million in Grants, Racial and Ethnic Disparities Have Increased

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EXECUTIVE SUMMARY

In the past three years, California's legislature has invested a total of $33 million to reduce, and eventually eliminate, the vast racial and ethnic disparities that exist in the developmental disability system. The Department of Developmental Services (DDS) is distributing these funds to regional centers and community-based organizations who submitted proposals outlining how their projects would reduce disparities. Despite these significant investments, after reviewing the most recently available data, **Disability Voices United has found that no regional center successfully utilized the grant money to reduce disparities, and racial and ethnic disparities have actually increased over the past two years.**

The first two cycles of grants, equaling $22 million, have been disseminated, and the third installment of $11 million in grants was recently announced. These funds continue to be dispersed, however, without any thorough investigation into whether any of the previous grants had any effect. To continue to throw money at this problem, without having a clue as to what's working, makes no sense for the state – and more importantly, makes no difference for the long-underserved individuals and their families.

All of these efforts may end up being efforts around the margins. Many regional centers have not meaningfully included the affected communities in their equity grant planning and implementation. Many still attribute the disparities to the ethnic cultures of their clients and families rather than committing to self-reflection and exploring the culture within their own organizations. The grants have not proportionately targeted regional centers with the largest disparities. They have not utilized decades of evidence on how to reduce health disparities. They have not tied funds to actual reductions in disparities. They have not required rigorous independent evaluation of their programs. They have not required regional centers to provide easy-to-understand information on services or disparities.

We call on the Legislature to hold DDS and the regional centers accountable for reducing disparities and creating a long-term plan to eradicate disparities. A set of specific recommendations follows at the end of this report.

Disability Voices United recently analyzed the purchase of service data that regional centers are legally required to make available on their websites, as well as the recent grants announced by DDS. Below are the major findings from the data.

BY FAR, HISPANICS FACE THE GREATEST DISPARITIES

- **Disparities are felt most profoundly by Hispanic individuals with developmental disabilities and their families**. While in most regional centers, African-American and Asian individuals receive fewer services than whites, Hispanics face disparities at a greater level across all regional centers.
- **Hispanics receive half or less of the amount of services than whites at every single regional center**. In fact, at five regional centers, Hispanics receive 1/3 or less of what whites receive.
- These statistics are particularly concerning because Hispanics make up the largest ethnic group served by regional centers, comprising over 39.3% of consumers. (Whites comprise 31.6%.)

DISPARITIES HAVE INCREASED OVER PAST TWO YEARS FOR HISPANICS

- **Despite the investment of $22 million over Fiscal Years 2016 and 2017, there has been no progress in reducing disparities for Hispanics.** While expenditures for Hispanics rose in many regional centers, they actually increased at a greater pace for whites, thus widening the disparities.
- **In 20 out of 21 regional centers, disparities of Hispanics actually increased over the past two years.** Only in one regional center did the disparities remain the same, although Hispanics still face great disparities there.
- **Statewide, and in every regional center but two, whites had a greater percentage increase in purchase of service expenses than Hispanics.** While not intentional, one could make an argument that the racial/ethnic group that benefited most from these disparity grants was whites.

Service Expenses for Hispanics as a Percentage of Service Expenses for Whites Over First Two Years of Disparity Grants

Red - Disparities increased. Yellow – Disparities stayed the same.

Regional Center	2015-16	2017-18
Alta	**48%**	**45%**
Central Valley	**44%**	**40%**
East Los Angeles	**39%**	**34%**
Far Northern	**59%**	**53%**
Frank D. Lanterman	**47%**	**47%**
Golden Gate	**35%**	**32%**
Harbor	**34%**	**32%**
Inland	**53%**	**49%**
Kern	**49%**	**45%**
North Bay	**37%**	**33%**
North Los Angeles County	**51%**	**43%**
Redwood Coast	**46%**	**41%**
East Bay	**39%**	**33%**
Orange County	**45%**	**39%**
San Andreas	**41%**	**40%**
San Diego	**50%**	**46%**
San Gabriel/Pomona	**40%**	**39%**
South Central Los Angeles	**20%**	**18%**
Tri-Counties	**49%**	**46%**
Valley Mountain	**48%**	**47%**
Westside	**53%**	**50%**

EFFORTS SHOULD PRIORITIZE REGIONAL CENTERS WITH LARGE HISPANIC POPULATIONS

While Hispanics at all regional centers face significant disparities, attention should be focused on those centers with the largest Hispanic populations in order to have the most impact. Below, we shine a light on the disparities at the five regional centers with the highest numbers of Hispanics:

Inland Regional Center - Hispanic population of 15,321 (40% of all clients)

- The largest regional center in the state, with the largest population of Hispanics, has lost ground in the effort to reduce disparities over the past two years. Expenditures on whites actually increased at twice the rate as Hispanics.

North Los Angeles County Regional Center – Hispanic population of 13,642 (46% of all clients)

- Average annual expenditures on Hispanic clients barely budged in the past two years, moving only from $8,732 to $8,819, or only 1%. During the same time period, services to whites jumped 19%.

South Central Los Angeles Regional Center – Hispanic population of 13,494 (68% of all clients)

- This regional center has the widest disparities in the state, by far. In FY 2016, Hispanics received 20% of what whites received in services. And the situation has only worsened in the past couple of years as Hispanic expenditures lowered to only 18% of white expenditures in FY 2018.

San Diego Regional Center – Hispanic population of 11,864 (39% of all clients)

- Over the two years that disparity grants were distributed, per capita expenditures for Hispanics actually decreased from $7,763 to $7,622. In the same time period, SDRC spent $1,146 *more* on average for white clients.

Central Valley Regional Center – Hispanic population of 11,623 (54% of all clients)

- Hispanics make up 54% of the clients at this mostly rural regional center, while they receive only 40% of what whites receive in service dollars. Yet, relatively little of the disparity grants have been focused on this community. The regional center received a grant only in the first year and community-based organizations in the area have barely been funded to target Hispanics.

DISPARITY GRANTS SEEM RANDOM AND UNTARGETED

- **The disparity funds were not allocated based on numbers of underserved community members.** In fact, we found that some regional centers with significant numbers of underserved families have obtained less funding than might be needed to develop strategies to reduce disparities. For example, Regional Center of Orange County, with a very large Hispanic population who get only 39% of what whites receive, have a relatively small amount of DDS funding targeted directly at Hispanics. None of their projects include parent-to-parent navigation assistance, which has been proven to be very effective in training and reducing disparities.
- **DDS doesn't utilize independent experts to assist in the screening and selection of grants as well as determining evaluation standards.** There are experts in the field of eradicating disparities in California and around the nation who have experience in targeting communities of color, program design, and program evaluation.
- **It is unclear how some of the disparity funds are intended to directly reduce disparities.** Some of the funded projects may have great value, as long as they are connected clearly to getting underserved consumers the services they need. For example, in FY 17-18, DDS funded seven regional centers to provide person-centered thinking training for staff and vendors. We agree that this training is vital for staff to serve all clients. But these trainings were paid for entirely by disparity funds, yet it is unclear whether the trainings focused on equity and disparity reduction at all.
- Lastly, with the new disparity funds, many of the regional centers hired staff to manage their efforts to reduce disparities. **It is important to monitor the work of these managers to ensure that the positions directly reduce disparities.** Because these new hires work for the regional centers, the community needs to be confident that the disparity managers' priorities, which may naturally be influenced by their employers, will not prevent them from recognizing and pointing out barriers that may exist within their own organizations. For example, it has been recently reported that disparity managers are attending IPPs and representing the regional centers instead of the client and family. We must also ensure that they are meaningfully engaging underserved consumers, parents, and communities as opposed to creating more obstacles. We must ensure that these managers are engaging underserved consumers, parents, and communities in a meaningful way, as opposed to maintaining the same obstacles.

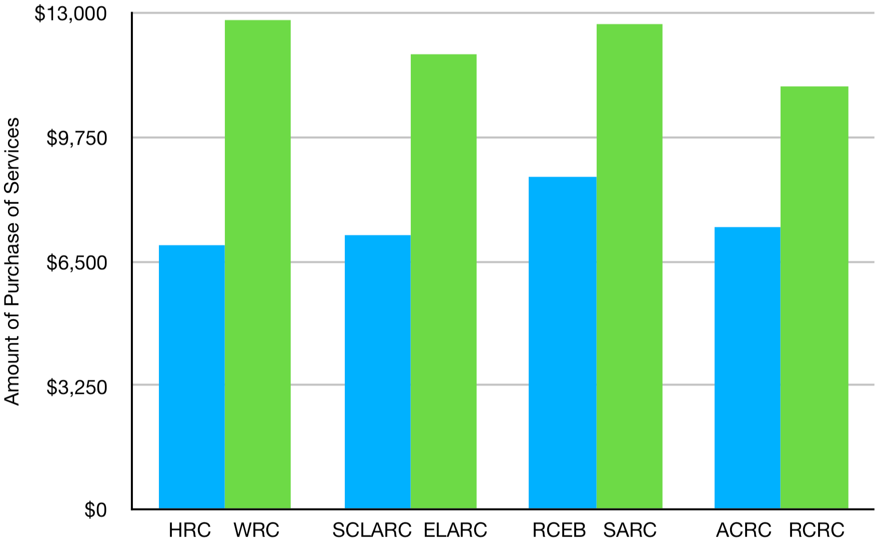
FUNDED PROJECTS NOT PROVEN OR INDEPENDENTLY EVALUATED

- **Funds have been allocated to projects without evidence that they will reduce disparities.** We are concerned that the state has invested $33 million in projects to reduce disparities, but with no data to support the efficacy of these projects. DDS and regional centers have not required their grant recipients to understand and follow evidence-based practices in improving disparities. Decades of work in significantly reducing health disparities could be utilized, and yet none of this information is provided to grantees or regional centers.
- **DDS is not requiring an independent analysis of the projects to ensure effective reduction of disparities.** Funded projects are only required to conduct internal evaluations that are not subject to any standardized quality metrics. They are not required to have formalized evaluations of their processes and outcomes. Furthermore, grant recipients are not required to rigorously evaluate and report family experiences with the intervention in the context of disparities.
- **Grant funds are not linked to increases in service funding for individual clients or for groups as a whole.** The goals and objectives of the projects do not have to be measurable directly in terms of purchase of service improvements. Projects are not incentivized to track reductions in disparities, and there are no disincentives for projects that make little progress toward the goal of equity.

DISPARITIES BETWEEN REGIONAL CENTERS A SIGNIFICANT FACTOR

- What is often overlooked in the discussion on racial and ethnic disparities is the equally significant differences in the level of services between regional centers. We shouldn't have a system in which where you live and which regional center serves you determines your ability to access needed services. These "geographic disparities" must be addressed if we ever hope to create true equity in our system.
- The chart below provides examples of regional centers that neighbor each other, often with similar demographics, yet offer dramatically different amounts of purchase of services for Hispanics.

Average Per Capita Expenses for Hispanics in Neighboring Regional Centers – FY 17-18



HRC – Harbor Regional Center
WRC – Westside Regional Center
SCLARC – South Central LA Regional Center
ELARC – East LA Regional Center

RCEB – Regional Center of the East Bay
SARC – San Andreas Regional Center
ACRC – Alta California Regional Center
RCRC – Redwood Coast Regional Center

MORE CLARITY AND TRANSPARENCY IS NEEDED

- **The "Other Ethnicity or Race/Multi-Cultural" category comprises more than 12% of individuals served statewide, the third largest population in California, and they face the same significant disparities as Hispanics.** We have no idea who these individuals are and which race/ethnicities are included in this "Other" category. If we assume that most of these individuals also belong to ethnic/language minority groups, and likely that many of them are at least partially Hispanic, then the current classification scheme is likely to paint an incomplete, and potentially misleading, portrait of the extent of racial and ethnical disparities across the regional center system.
- **Regional centers often bury their disparity data on their website and make no effort to present the data in a clear or understandable format**. The information, usually tucked under the headings "Transparency" or "Governance," is not provided in plain language and is very difficult to understand for many self-advocates and their families. The data is aggregated and in tables, and none of the documents are in searchable or machine-readable formats. DDS does not freely allow data queries so that services can be searched by race/ethnicity, regional center, location, etc.

ROOT CAUSES OF DISPARITIESARE STILL NOT BEING ADDRESSED

Hispanic, African American, Asian, and multi-race families face multiple barriers to receiving services. Many regional centers still blame the ethnic cultures of their clients and families rather than committing to self-reflection and exploring the structural culture within their own organizations. Based on our extensive outreach to these communities, we believe that the greatest root cause of these disparities is the culture of "no" that families often experience when trying to get services. Parents tell us that instead of it being <u>their</u> ethnic culture, **it is the culture of regional centers that keep their children from getting the services they need.** They say they feel the Regional Center culture is often an **"us versus them"** mentality, in which the "them" are the very families the regional centers are supposed to serve.

Many in the underserved communities report feeling **intimidated** by the regional center system and staff. They tell us, "The regional center knows that some of us are low-income, don't speak English well, and lack formal education. And then we face people with college degrees who are experts, and they use their position against us." We also hear that parents, even those with education and who speak fluent English, are sometimes **afraid to speak up** in fear of **retaliation against their child**.

While most regional center staff are caring and work very hard for their clients, too many parents report that **they are treated in a condescending or disrespectful way**. One parent told us that the psychologist who came to diagnose her son took only 15 minutes with him, and at one point during that time, posted something on her Facebook page. Another parent said her service coordinator told her that he "can't trust parents because many parents lie."

Most commonly, we hear that **parents don't know what services are available** at their regional centers. They feel grateful when their service coordinator gives them a small amount of services for their children. But, as parent Abner Antunez said at the Senate Human Services hearing on disparities in 2017, "It's like we are starving, and they give us a little piece of candy, and we think we are being helped. But we haven't been given the whole menu. We have to find out about things ourselves. Nothing is provided unless we ask. Even then it is a battle." Regional Centers are required to provide a list of vendored service providers on their websites, but our analysis shows that these lists are often difficult to find, disorganized, and littered with inaccuracies. The service coordinators become gatekeepers, since they have built relationships with preferred vendors, and their options of services providers is often the only information that families get.

We also consistently hear that a common tactic at regional centers is to **not respond to families' requests**. "Mostly, they don't call us back or return our emails. Or they say they are 'working on it.'

We don't usually get denied a service. And if we finally do get denied, the regional centers know that we can't afford to go to due process or understand what that means."

For many families from non-white ethnic groups, with cultures that don't encourage the challenging of authority figures, the answer "no" is final. Though families are told of their rights to appeal (in legalese), many families are not able to fill out the confusing paperwork and are not supported in the intimidating process of facing a judge. These **barriers to due process** mean that those who have the resources, education, and ability to hire a lawyer (typically white families), are those who are able to fight to obtain services.

The 2009 funding cuts that eliminated social/recreational programs and put a cap on respite have also contributed to disparities. Many underserved families relied on these services, such as swimming, horseback riding, and summer camp – all programs that low income families can't afford on their own. But, last year, the legislature lifted the cap on respite specifically to target those affected by disparities. We are concerned, based on reports from families, that access to additional respite remains difficult and that caps basically still exist – in practice, if not in words. Since **regional centers do not regularly track, and make public, funding of a specific service by race/ethnicity, it is very unclear if families are benefitting from increased respite at every regional center.**

RECOMMENDATIONS: LACK OF PROGRESS IS UNACCEPTABLE

Ultimately, we need to ask whether, with all of the legislative hearings, select committees, news articles, and $33 million, we have made any progress in breaking down the barriers to an equitable system. If we don't address the root causes of the disparities, any progress we make could be erased over time. **Our clear goal should be the eradication of racial, ethnic, and geographic disparities and creation of a statewide equitable system.** With that in mind, we urge the legislature to consider the following recommendations:

1. **Require more rigorous, evidence-based, data-informed processes for selecting grants, while also ensuring inclusion of grassroots groups with deep community connections**
- DDS should proportionately target grants to regional center catchment areas and ethnic groups that are experiencing the greatest levels of disparities.
- DDS should bring in outside independent experts to assist in the screening and selection of grants as well as in determining evaluation standards.
- DDS should provide information on evidence-based practices and require utilization of those practices as a condition of grants to regional centers and community-based organizations.
- At the same time, special consideration should be given to grassroots, regional center unaffiliated, parent-led groups who have a reach deep into the community.

2. **Independent (third party) evaluation research must be conducted as to whether current projects are actually working**
- Future projects must be tied to outcomes of disparity reduction and outcomes of improvements to individuals' lives.
- The legislature should require spending accountability to ensure the funds went directly to projects that will reduce disparities.

3. **Erase the "culture of NO" and nurture a culture of respect and compassion**
- DDS must provide more oversight and accountability concerning the treatment of individuals and families.
- DDS should create an office dedicated to the elimination of disparities, sharing of best practices, development of plain language information. The office should include an ombudsman with direct phone numbers and email to communicate with concerned families.
- A statewide ongoing survey should be conducted on satisfaction and perceived treatment of those served by the regional centers, focusing on equity and disparity (well beyond the National Core Index survey), and should be reported annually to disseminate widely.

- The legislature should enact a statewide policy that any client or family contact (phone, email, etc.) should be returned promptly and professionally within 48 hours, with the ability for families to report concerns.
- Independent mediators should be provided for parents who express concerns about intimidation or fear of retaliation from their regional centers.

4. **Require deep and meaningful community involvement and leadership of families and self-advocates affected by disparities**

- Community engagement should not be a once-a-year exercise but an ongoing practice. Regional centers should be required to establish ongoing relationships with unaffiliated and conflict-free family and consumer-led groups.
- DDS should be required to evaluate and report on how and to what extent community involvement influenced the provision, implementation, and evaluation of grants.

5. **Eliminate additional barriers by dropping legislative restrictions on funding**

- The legislature should restore funding for social/recreational programs and non-medical therapies that was cut a decade ago.
- The legislature and DDS should monitor whether regional centers are actually providing more respite hours to families since the cap was lifted on January 1, 2018.

6. **Focus on "geographic disparities" in addition to ethnic disparities**

- Ask regional centers to provide justification for the widely disparate methods they use to determine service policies and delivery.
- DDS should be required to create and implement a comprehensive and long-term plan that focuses on creating a more equitable statewide system.

7. **Require more data reporting and more public access to data to improve transparency**

- The legislature should require that POS data is made more freely accessible and in usable formats in which each variable is searchable. Tables should be made with each data point by race/ethnicity or region. Similarly, data should be made available so that each service can be searched by race/ethnicity, regional center, location, etc.
- DDS should clarify their "other/multi-cultural" race/ethnicity data field and conform it to other federal and state requirements for race/ethnicity data.
- The legislature or DDS should require that data on regional centers websites be easily found under titles that are descriptive and contain information written in plain language.

8. **Consider disparities in the context of the future of the developmental disabilities system**

- As the Self-Determination Program (SDP) moves closer to implementation this year, it is important that this new option doesn't perpetuate disparities. Since SDP participants' budgets are developed based on previous spending, unless adjustments are made, Hispanics, African-Americans, and Asians will continue to be underserved.
- DDS and regional centers need to ensure that Hispanic, African-American, and Asian families, particularly those who speak languages other than English, are provided timely information and training about the new federal Home and Community-Based Services (HCBS) rules that require regional center-funded services to be delivered in inclusive settings. Unless special attention is paid to these communities, they may be faced with additional disparities with no compliant services available.

This report was researched and written by the volunteer board of directors and interns of Disability Voices United, including Judy Mark, Isis Piccillo, Paul Smith, Tyler Morad, Allen Erenbaum, Alison Morantz, Fernando Gomez, Kelly Kulzer-Reyes, and Nina Spiegelman. Disability Voices United is a statewide advocacy organization directed by and for individuals with developmental disabilities and their families. We advocate for: choice and control over our lives; meaningful outcomes that matter to us; and, systems that are equitable and accountable to us.