

Addressing Funding Disparities in Services for Children with Developmental Disabilities





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EXECUTIVE SUMMARY

California provides specialized supports and services to persons with developmental disabilities through a network of 21 regional center agencies charged with promoting the most independent and productive lives possible for these individuals, referred to as “consumers” or “clients.” Regional center services are intended to be available to all consumers without regard to race, ethnicity, language, income level, or geographic location. For more than 25 years, however, research studies and consumer advocates have raised concerns about disparities in service access. Now with the availability of published data, inequities within the regional center system are no longer in dispute.

The California Department of Developmental Services (DDS) and the 21 regional centers with which it contracts are required to collect and publish data on purchase of services (POS) authorization, expenditure and utilization, broken down by consumers’ age, race/ethnicity language, and other factors. Analysis of this data found:

- Most regional centers that authorize the lowest amounts for POS are those with larger Hispanic and Black/African-American populations. In 2017-2018, eight out of the ten regional centers with *higher*-than average percentages of Hispanic and Black/African-American consumers had *lower*-than-average per capita authorizations. Conversely, eight of out of the eleven regional centers with *lower*-than average percentages of Hispanic and Black/African-American consumers had *higher*-than-average per capita authorizations.
- DDS’ method of allocating funding to the regional centers perpetuates these POS disparities. Regional centers that historically have authorized more POS generally continue to outpace the others, while regional centers that historically have authorized fewer POS do not appear to be narrowing this gap. Inequitable funding allocations persist because regional centers’ budgets are based upon their past year’s expenditures, and there is little variation in each regional centers’ funding patterns. The contracts between DDS and the regional centers discourage increased budgeting to enable lower funding regional centers to meaningfully address these disparities.
- A significant percentage of clients do not receive any services during a reporting year. For example, in Fiscal Year 2017-2018, almost 32% of consumers ages 3-21 did not receive any POS statewide, with 44% of children going without any services at one regional center.
- At each of the 21 regional centers in the state, Hispanic children average significantly less funding than White children. In 2017-2018, White children receiving services had at least \$5,000 more in per capita expenditures than Hispanic children receiving services in four regional centers and in another eleven regional centers, the gap was at least \$3,000 more.

Even at the most equitable regional center under this analysis, White children still averaged over \$1,000 more in expenditures than Hispanic children. Hispanic children at one regional center received only 47% of what White children received.

- There are also significant gaps in authorized services between English-speaking and Spanish-speaking children within nearly every regional center. In 2017-2018, nineteen out of the 21 regional centers had higher per capita authorizations for their English-speaking consumers, with the largest funding gap being \$3,856 higher. Eleven regional centers had at least a \$1,000 difference between English and Spanish speaking consumers.
- DDS and the regional centers are not in compliance with the statutory data reporting requirements. The data still is not being compiled in a uniform manner and many of the regional centers' data reports are incomplete, inaccurate, and inaccessible to the public.

To effectively address these substantial systemic inadequacies, we recommend the following:

- Replace the current funding formula, which DDS previously has admitted is flawed, and resume development of DDS' abandoned client-needs-based funding model, which would be based on objective criteria to adequately meet each client's needs
- Restore critical suspended services and repeal other services restrictions that were imposed during the budget crisis ten years ago to the detriment of minorities
- Require each regional center to develop, maintain, and publish language access service plans to identify its language capacities and needs for ensuring non-discriminatory processes in the provision of intake, assessment, and purchase and provision of services
- Commission an independent study to thoroughly examine the efficacy of recent disparity reduction efforts funded over the past three years and redirect efforts accordingly based on the study's findings
- Convene another legislative hearing to revisit the dozens of proposals, never acted upon, that were made by the 2012 Equity Taskforce for potential remedial legislation
- Enforce the regional centers' compliance with data reporting and other public disclosures requirements by tying compliance to the regional centers' performance contracts
- Require regional centers, as part of their contractual obligations, to review all cases where consumers are receiving no purchase of services, classify the reasons for their deprivation, and report their findings to DDS for public dissemination

INTRODUCTION

California's Lanterman Developmental Disabilities Services Act of 1969 (Lanterman Act), was designed to ensure that persons with developmental disabilities get services that enable them to live more independent and productive lives in the community, and imposes an obligation on the state to provide services. The Act created a network of 21 regional centers to help individuals get services and supports. Services are intended to be available and accessible to all persons with developmental disabilities, without regard to race, ethnicity, or language. But for more than 25 years, researchers and advocates have raised concerns about disparities in service access.

These concerns eventually prompted legislation, enacted in 2012, requiring the California Department of Developmental Services (DDS) to collect and analyze data on purchase of services (POS) authorizations, expenditures, and utilizations from the regional centers, broken down by consumers' age, race/ethnicity, and language, among other factors.

This report analyzes POS expenditures and authorizations data for Fiscal Years 2017-2018 and 2016-2017 by race, ethnicity and language for children and youth ages 3-21 and finds stark racial and language disparities in the funding of regional center services. The report discusses root causes for the observed disparities and makes recommendations for addressing them. Information describing the methodologies used to create this report is provided in Appendix A.¹

BACKGROUND

California's Developmental Disability Service System

Under the Lanterman Act, California Welfare & Institutions Code (WIC) § 4500 et seq., the state must provide services and supports for individuals with developmental disabilities, such as autism, epilepsy, cerebral palsy, and other intellectual disabilities. Further, under the California Early Intervention Services Act, California Government Code § 95000 et seq., the state must also provide services to infants and toddlers who have, or who are at risk of having, developmental disabilities.

These services are provided through 21 regional centers, which are independent, private, non-profit corporations that each contract with DDS to determine program eligibility, provide case management, and purchase or secure specialized services and supports for persons with developmental disabilities and developmentally delayed or at-risk infants and toddlers. Services include intensive behavioral intervention, family supports such as respite care, specialized medical

¹A full copy of this report, including appendices, endnote references, and a glossary is available on Public Counsel's website at: <http://www.publiccounsel.org/tools/assets/files/1173.pdf>. The appendices supplementing the full report provide detailed explanations of the specific data analyzed and the methods used during the analytical process. All references to this report's appendices contained herein may be viewed in the above-linked document.

and dental care services, adaptive equipment and supplies, early intervention services such as infant development programs, and daily living and social skills training programs.

California's Legal Framework on Equal Access to State-Funded Programs and Services

DDS allocates federal and state funds to the regional centers and must monitor them to ensure they operate in compliance with federal and state law and regulation. Statutory provisions have given DDS the authority and the duty to ensure regional centers comply with laws prohibiting discrimination on the basis of race, ethnic group identification, national origin, and other protected characteristics. California Government Code § 11135 provides:

No person in the State of California shall, on the basis of race, national origin, ethnic group identification, religion, age, sex, sexual orientation, color, genetic information, or disability, be unlawfully denied full and equal access to the benefits of, or be unlawfully subjected to discrimination under, any program or activity that is conducted, operated, or administered by the state or by any state agency, *is funded directly by the state, or receives any financial assistance from the state.* (emphasis added)

The law historically required state agencies to promulgate regulations to prevent discrimination in provision of services. Former California Government Code § 11138 stated:

Each state agency that administers a program or activity that is funded directly by the state or receives any financial assistance from the state and that enters into contracts for the performance of services to be provided to the public in an aggregate amount in excess of one hundred thousand dollars (\$100,000) per year *shall . . . adopt such rules and regulations* as are necessary to carry out the purpose and provisions of this article. (emphasis added)

Thus, as early as 1979, DDS was obligated to promulgate and enforce regulations to prevent discrimination on the basis of race, national origin, and ethnic group identification in the programs of the regional centers. However, DDS never promulgated such regulations.

In 2016, Senate Bill (SB) 1442 transferred responsibility of enforcing these civil rights laws from the Secretary of Health and Human Services, which DDS falls under, to the Department of Fair Employment and Housing (DFEH). DFEH now has the authority to investigate, mediate and prosecute Section 11135 complaints in the same manner it handles other discrimination claims.

Legislative Oversight Hearings on Purchase of Services (POS) Disparities

Regional centers perform some of their obligations to eligible individuals by authorizing and purchasing specialized services and supports to help enable these individuals to live successfully

in the community. Disparities in POS authorizations and expenditures were first brought to public attention by an article in the Los Angeles Times in December 2011. That article reported significant disparities in access to regional center services based on race and ethnicity, income level and socio-economic community. The article found, among other things, that children diagnosed with autism served by one regional center in a predominantly Hispanic and Black/African American community received an average of only \$1,991 per child for services, while at the highest funded regional center with a predominantly White population, \$18,356 was spent on services for each child with autism. The article prompted the Senate Select Committee on Autism & Related Disorders to hold an oversight hearing on this issue on April 30, 2012. As a result of the information and testimony presented at this hearing, Senator Darrell Steinberg convened an Equity Taskforce, which published a report to the Senate Select Committee in 2013 listing dozens of recommendations, most of which have not been implemented.

Five years later, on March 14, 2017, the Senate Human Services Committee (Committee) held another oversight hearing on disparities among regional centers' POS activities. The Committee determined that POS disparities based on race, ethnicity and language persisted and that very little improvement had been made in reducing these disparities since the prior legislative committee hearing in 2012. The Committee asked both DDS and the Association of Regional Centers Agencies (ARCA), which represents the statewide network of 21 regional centers, to submit to the Committee within 60 days of the hearing their separate disparity reduction plans including timetables for achieving outcomes to "help move the needle." The Committee made clear that it did not want to wait another five years only to see the disparities remaining essentially unchanged. In its response, ARCA proposed four action items: 1) increase funding for lower uniform caseload ratios, 2) divert previously earmarked funding for community resource development projects, 3) reinstate camping, social recreational, and respite services, and 4) fund for a comprehensive independent study of the POS data to investigate the root causes of the "variances."

The Role of DDS' Budget and Allocation Methodology in Perpetuating POS Disparities

Two decades earlier, in April 1998, the California Bureau of State Audits (BSA) issued a report concluding that DDS was not budgeting and allocating funds based on the needs of consumers within each regional center's catchment area. Thus, DDS was unable to ensure that all consumers throughout the state had equal access to regional center services. The BSA proposed that DDS develop and pilot a master plan based on a matrix of services, which listed each type of disability and severity level, the services diagnosed for each type of and degree of disability, the maximum service level for each service diagnosed, and the anticipated cost. This matrix would be a guide in determining services in individual cases and in estimating each regional center's annual budget. DDS dismissed BSA's findings and matrix proposal at that time.

Fourteen years later, during the first legislative oversight hearing on April 30, 2012, former DDS director Terri Delgadillo testified at length about DDS' budget and allocation methodology.

Director Delgadillo explained that regional centers' POS budgets are based on what the regional centers spent the prior year, and any additional money is distributed based on caseload ratios and growth in service utilization. Director Delgadillo acknowledged that DDS' budget and allocation methodology was inequitable and that DDS planned to put in place a "bridge" methodology as a step towards a client-needs-based budget and allocation methodology that "would be blind to ethnicity" and serve as a "starting point" in addressing POS disparities. As reported by the Los Angeles Times, Director Delgadillo testified that regional center budgets eventually would be set so that similar amounts of funding would be available to clients with similar needs.

Consequent to this hearing, Senator Steinberg convened an Equity Taskforce to provide recommendations to combat the regional centers' funding disparities. Among its many recommendations, the Equity Taskforce recommended legislation requiring DDS to report to the Legislature a process for developing a new budget and allocation methodology that would be transparent and provide opportunities for consumer and public input. This Taskforce recommendation, along with many others, was not pursued by the Legislature.

During the second legislative oversight hearing on March 14, 2017, DDS' budget and allocation methodology was again identified as a contributing factor to the POS disparities. Areva Martin, executive director of Special Needs Network, who co-chaired the 2012 Equity Taskforce along with Dr. Sergio Aguilar-Gaxiola of UC Davis' Center for Reducing Health Disparities, stated that the families her agency serves are among the thousands of consumers each year that suffer from a state-funded program that consistently spends less on Children of Color than on White children. Ms. Martin stated DDS' presumably neutral funding scheme in fact is discriminatory in its application and effect and has been so for decades.

The Committee then asked ARCA's director, Amy Westling, to respond to Ms. Martin's concerns about DDS' budget and allocation methodology and to account for the apparently self-perpetuating disparities of funding among regional centers. Ms. Westling stated that there were efforts a few years ago to move some funding around. Presumably, Ms. Westling was referring to the "bridge" formula that former DDS Director Delgadillo testified to during the April 2012 hearing as the interim scheme until the client-needs-based model would be implemented. In her opinion though, Ms. Westling stated, the issue has to do more with what services people are seeking in a particular community, developing relationships and working with communities to figure out how to best meet their needs. Ms. Westling reminded the Committee earlier in this hearing that services disparities exist not just in the regional center system, but throughout health and human services' programs, including special education, in-home supportive services, Medi-Cal, SSI and mental health. But Ms. Westling then suggested some of the disparities seen in regional center services may be attributable to consumers having their needs met elsewhere by these other agencies.

Current DDS Director Nancy Bargmann also testified at the March 14, 2017, oversight hearing but she did not provide a response to the Committee’s budget and allocation methodology question. DDS still has not created a POS budget and allocation methodology like the one planned by former DDS Director Delgadillo, and it is unclear if DDS, under its current administration, will ever do so.

Unrestored Legislative Budget Cuts to Services Have Further Disadvantaged Minority Groups

During the budget crisis of 2009, DDS proposed to generate cost savings by suspending certain services including social/recreational activities, such as swimming, martial arts and gymnastics programs, camping programs, non-medical therapies, such as art, music, and dance therapies, and educational services such as tutoring services for children. DDS also proposed to implement a new service budgeting method called the Individual Choice Budget. DDS stated that the above service suspensions would only be temporary until the Individual Choice Budget was developed, implemented, and certified by the director of DDS to yield cost-savings sufficient to restore the suspended services. Legislation was then enacted to adopt these and several other cost savings proposals that over time have been shown to have had an adverse effect on minority populations.

Ten years have passed, and though the “temporarily” suspended services remain in force, the Individual Choice Budget was never developed. Echoing one of the causes of POS disparities previously identified in research, the suspension of services has disproportionately affected minority families, who are more likely to use and thus potentially benefit from these services. The Senate Human Services Committee’s review of expenditure data for social/recreational services from 2008-2009 before the cuts were made found that the per capita expenditures on these services were nearly double for Hispanic consumers compared to White consumers.

In its May 15, 2017, response to the Senate Human Services Committee’s request for its disparity reduction plan, ARCA confirmed that the Individual Choice Budget was no longer being pursued by DDS, and ARCA proposed reinstatement of the suspended services as a step to enhance ongoing efforts towards equitable spending across ethnic lines.

PRIOR RESEARCH ON SERVICE DISPARITIES

A previous report published in May 2017 included a list of research studies which had analyzed services disparities within the developmental services system. The studies identified several root causes of funding disparities, including lack of access to information about available services and in some cases lack of needed services, lack of cultural and linguistic competence among regional center staff and associated service providers, and families feeling intimidated by the system, staff and providers. Importantly, one study noted that regional center funding allocations do not take into account the predisposing characteristics of the clients being served (such as race, age, and gender) or the availability or absence of enabling factors (such as income, insurance, and

education). Risk-adjusted, client-needs-based funding of regional centers would enable greater equity to services across regional centers.

METHODS

This report analyzed POS data from the online reports of each of the 21 regional centers. See Appendix A for more details about the specific data and methodologies used for this report.

The main sets of analyses included in this report are:

- Racial/ethnic per capita POS authorizations for all age groups for Fiscal Years 2017-2018 and 2016-2017
- Total per capita POS authorizations for all age groups for all Fiscal Years 2011-2012 to 2017-2018
- Difference in per capita POS expenditures between White and Hispanic children ages 3-21, as reported and only for children who received services for Fiscal Years 2017-2018 and 2016-2017
- Per capita POS authorizations for English-speaking and Spanish-speaking children ages 3-21 living in their home, for Fiscal Years 2017-2018 and 2016-2017

We focused primarily on per capita authorizations data as the outcome variable as it represents the extent to which each regional center is willing to offer services and supports to its families through its individualized service planning process. Service authorizations reflect existing policy differences among the regional centers and directly impact which services are received. Also, because expenditures help determine future budget allocations, we analyzed these data to determine if spending differences increased when expenditures were attributed only to consumers who actually received services. For more methodological details, see Appendix A.

SUMMARY OF FINDINGS

Based on an analysis of the most recent POS data, we found that large differences persist in the distribution of authorized services among the regional centers, and regional centers providing the lowest per capita authorized amount of POS tend to be those with larger Hispanic and Black/African-American populations. This report also confirms that there are significant POS expenditures disparities among children ages 3-21 in the regional center system based on race within individual regional centers. When reported data on per capita POS expenditures is analyzed to only assess for children who actually received services, differences between White and Hispanic children within individual regional centers become even more pronounced. There are also significant gaps in per capita authorized services between English-speaking and Spanish-speaking

children within nearly every regional center. Additionally, the regional centers and DDS itself are in violation of the statutory data reporting requirements; the data reports from many regional centers' are incomplete, inaccurate, and inaccessible to the public. (See Appendix B).

RESULTS

1. There continues to be a strong association between low POS authorizations and high minority populations

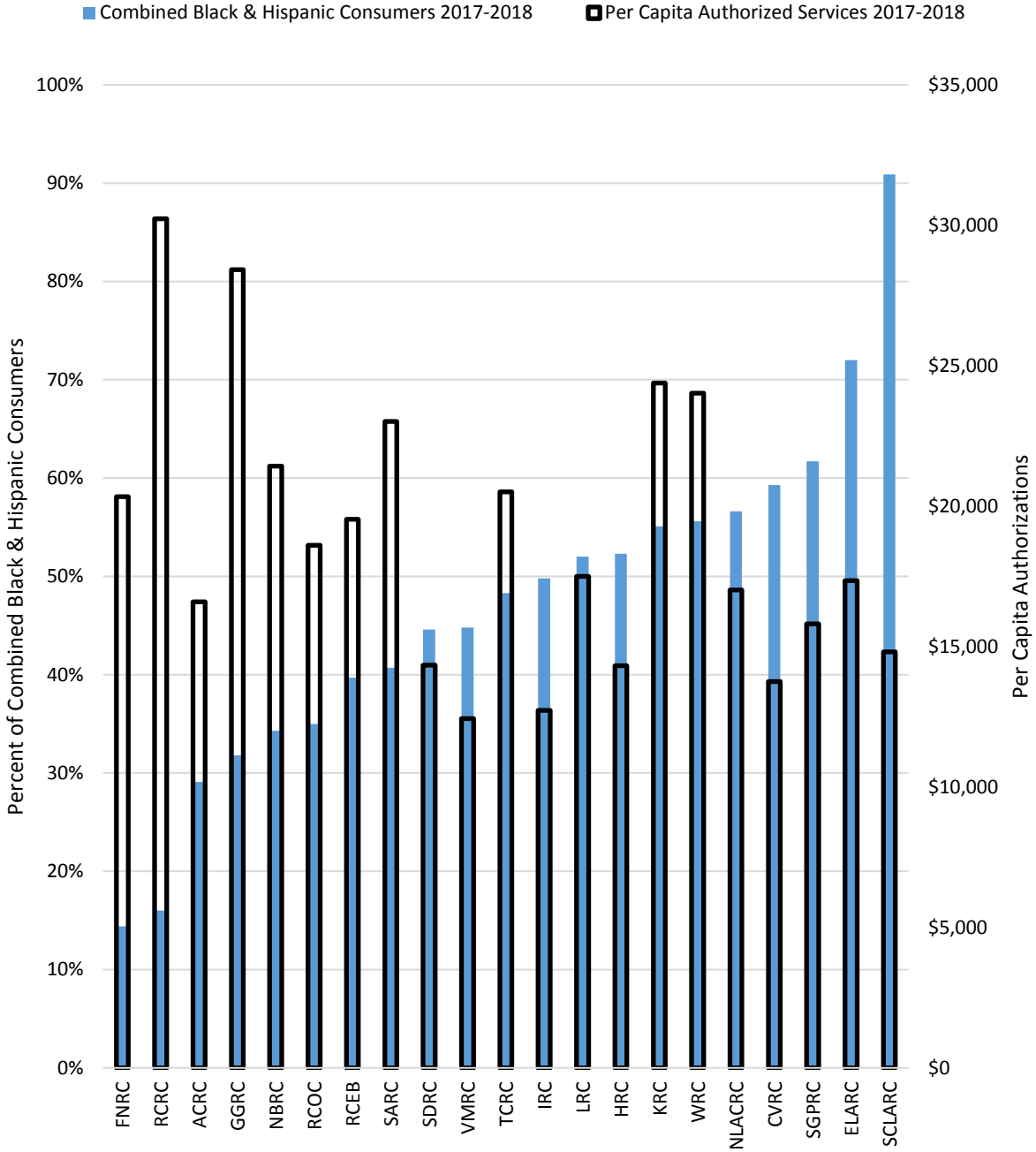
POS data for the past two fiscal years continue to show vast differences and racial/ethnic disparities in the distribution of authorized services among regional centers.

For 2017-2018, the population of Black/African-American and Hispanic consumers of all ages combined made up 48.8% of the total population among the 21 regional centers. Additionally, the average of per capita authorizations for each consumer in the regional center system was \$17,545. From these baselines, our analysis found that eight out of the ten regional centers with *higher*-than average percentages of Black/African-American and Hispanic consumers had *lower*-than-average per capita authorizations. Conversely, eight of out of the eleven regional centers with *lower*-than average percentages of Black/African-American and Hispanic consumers had *higher*-than-average per capita authorizations. (See Figure 1 and Appendix C). Results were similar for Fiscal Year 2016-2017. (See Appendix C for full details of our analysis).

Conclusion

There is a direct association between regional centers' authorization amounts and the proportion of their Black/African-American and Hispanic clients. Regional centers that authorize lower amounts of POS are mainly those with larger Hispanic and Black/African-American client populations.

Figure 1: Per Capita Authorizations Compared with Percentage of Black/African American and Hispanic Consumers (All Regional Centers, Fiscal Year 2017-2018)



Statewide Percentage of Combined Black/African American and Hispanic Consumers: **48.8%**
 Statewide Average Per Capita Authorizations: **\$17,545**

2. DDS' budget and allocation process perpetuates inequitable funding of regional centers

Since 2012, when the data first became publicly available, there has been little evidence of remedial outcomes in the current efforts to rectify inequities in funding of regional centers as reflected in per capita authorizations of services for clients. Regional centers that historically have authorized more POS generally continue to outpace the others, while regional centers that historically have authorized fewer POS do not appear to be narrowing this gap (Figure 2 and Appendix D). The flawed budget and allocation methodology described by former DDS Director Delgadillo during the first legislative oversight hearing accounts for this cycle of inequity.

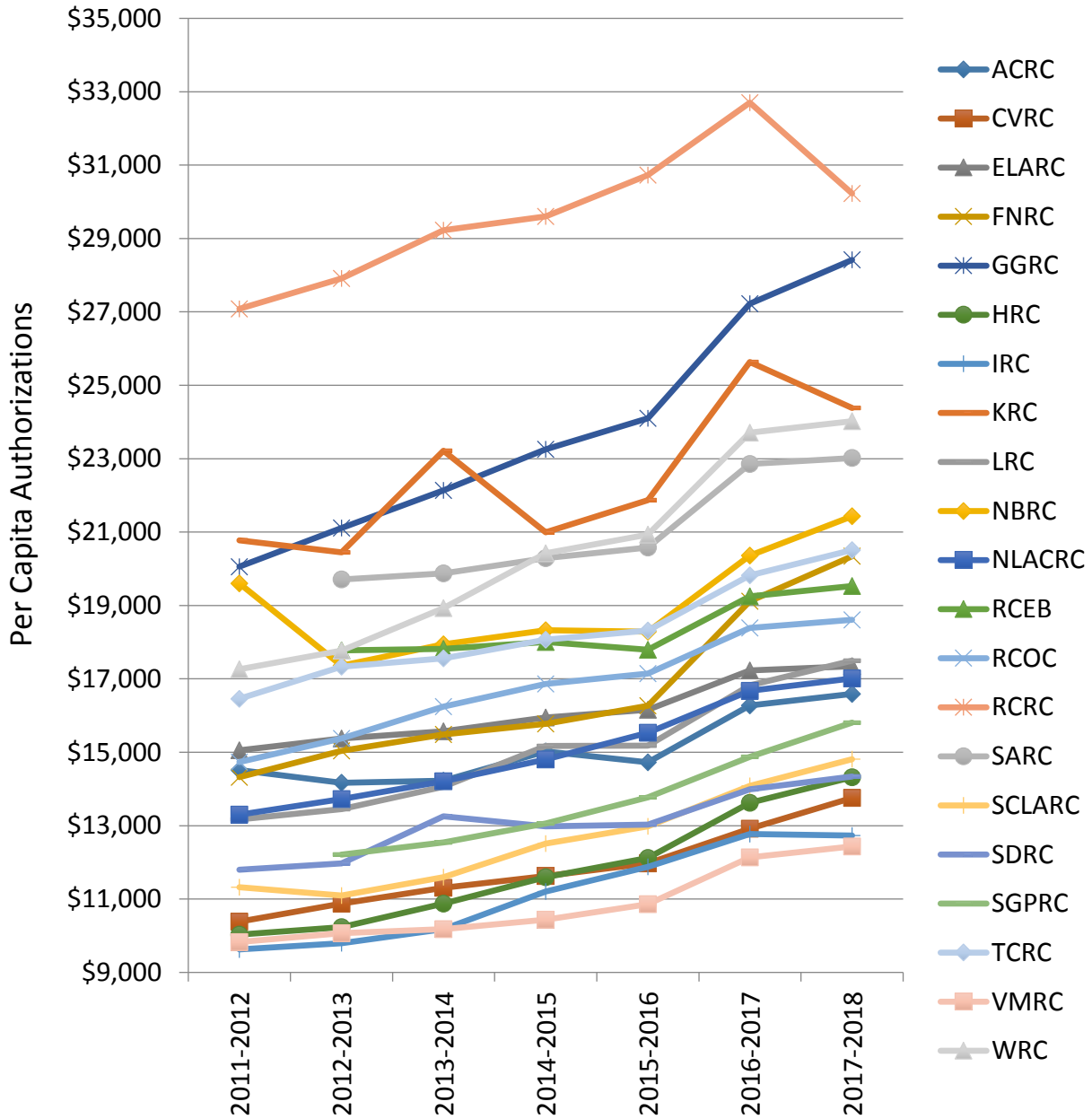
The seven regional centers which constituted the bottom third of all regional centers in terms of lowest averages of per capita authorizations in 2012 still remain in this bottom tier as of 2017-2018. Likewise, the seven highest-funding regional centers have occupied the top tier of per capita authorizations throughout the entire data collection period. Inequities in the distribution of funding among the twenty-one regional centers are constant and likely not to change without serious restructuring of DDS' budget and allocation methodology.

Regional centers enter into five-year contracts with DDS which specify the terms by which regional centers and DDS prepare the regional center's budget and allocations. One mandatory performance contract compliance measure requires regional centers to accurately project their future year's allocations, and consequently, regional centers typically budget conservatively based on their historical expenditure and utilization trends to avoid spending beyond the range of their projections and risk facing contract noncompliance.

Conclusion

DDS' budgeting and allocation funding protocols for regional centers are in large part responsible for the continuing inequities in POS disparities. The existing historical expenditure-based funding formula and restrictive budgeting process tied to performance contract measures should be replaced with a client-need-based model, which would use objective data to determine funding amounts based on the severity of the clients' needs living in the community served by the regional center.

Figure 2: Regional Centers' Per Capita Authorizations for All Consumers, 2011-2012 through 2017-2018



3. Analyzing Per Capita Expenditures According to Actual Receipt of Services Exposes Starker Inequities

Regional centers are required to publish data on per capita expenditures, which are calculated by dividing the center's total client population within each reported group by the total expenditures made for that group's total client population by the regional center. However, a significant percentage of clients do not receive any services during a reporting year. For example, in Fiscal Year 2017-2018, among all 21 regional centers, almost 32% of consumers ages 3-21 did not receive any POS; this ranged from over 44% without services at Regional Center of the East Bay (RCEB) to almost 20% at Tri-Counties Regional Center (TCRC). In other words, only about 68% of this consumer population received services while nearly 32% received none.

By excluding the number of consumers who did not receive any services from the numerator amount and only dividing the total expenditures amount by the number of consumers who actually did receive services, the per capita expenditures increase, but so too does the difference in amounts between the White and Hispanic populations. Thus, the current regional centers' data reports substantially underrepresent the extent of the disparities in expenditures for purchase of services.

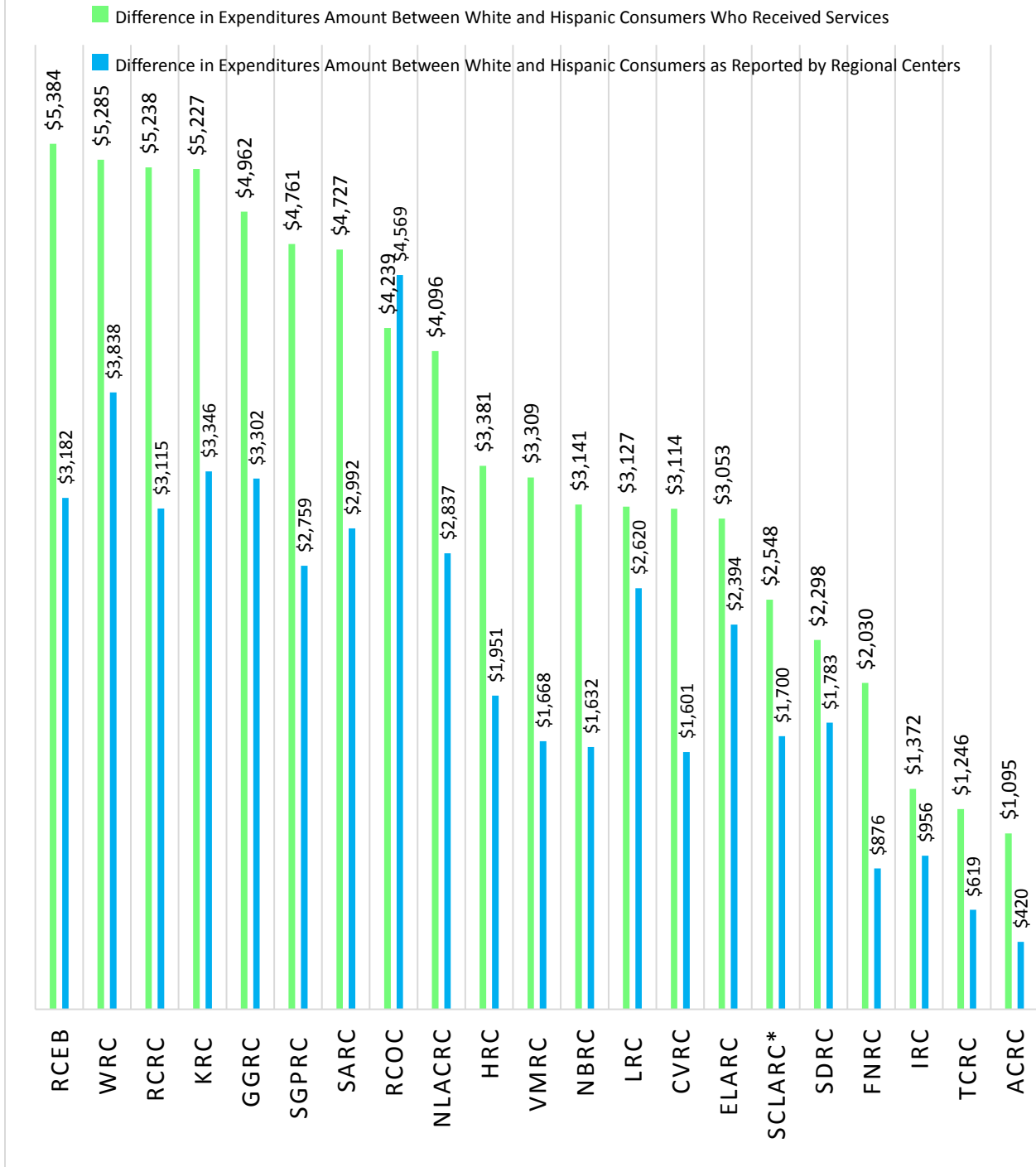
Under this adjusted analysis, for Fiscal Year 2017-2018, we found that Hispanic children ages 3-21 averaged significantly less funding than White children ages 3-21 at every regional center in the state. White consumers receiving services had at least \$5,000 more in per capita expenditures than Hispanic consumers receiving services in four regional centers and in another eleven regional centers, the gap was at least \$3,000 more. (Figure 3 and Appendix E). Similar results were found with the 2016-2017 data, also contained in Appendix E.

Conclusion

By excluding the roughly 32% percent of the pediatric consumer population that do not receive services in a given year when calculating per capita expenditures, a more accurate and starker picture of existing disparities become visible. These hidden disparities especially impact Hispanic children. DDS speculates that disparities in POS expenditures between White and Hispanic children are "likely" because Hispanic children, as a larger population, receive many services through the school system rather than through POS, thus reducing their average POS as a group.

Because DDS's current budget and allocation methodology is based on the regional centers' prior year's expenditures, its formula assumes over 3 out of 10 children will not be served and therefore, provides another example as to why DDS' budgeting system is flawed and should be replaced with an objective client-needs-based model.

Figure 3: Comparing Differences in the Amount of Per Capita Expenditures Between White And Hispanic Consumers Ages 3-21: Consumers Who Received Services vs. Reported Consumers, 2017-2018*



*For SCLARC, we compared Black/African-American and Hispanic consumers because SCLARC's White consumer population, for purposes of this report, is too small (less than 1%) to make a meaningful comparison.

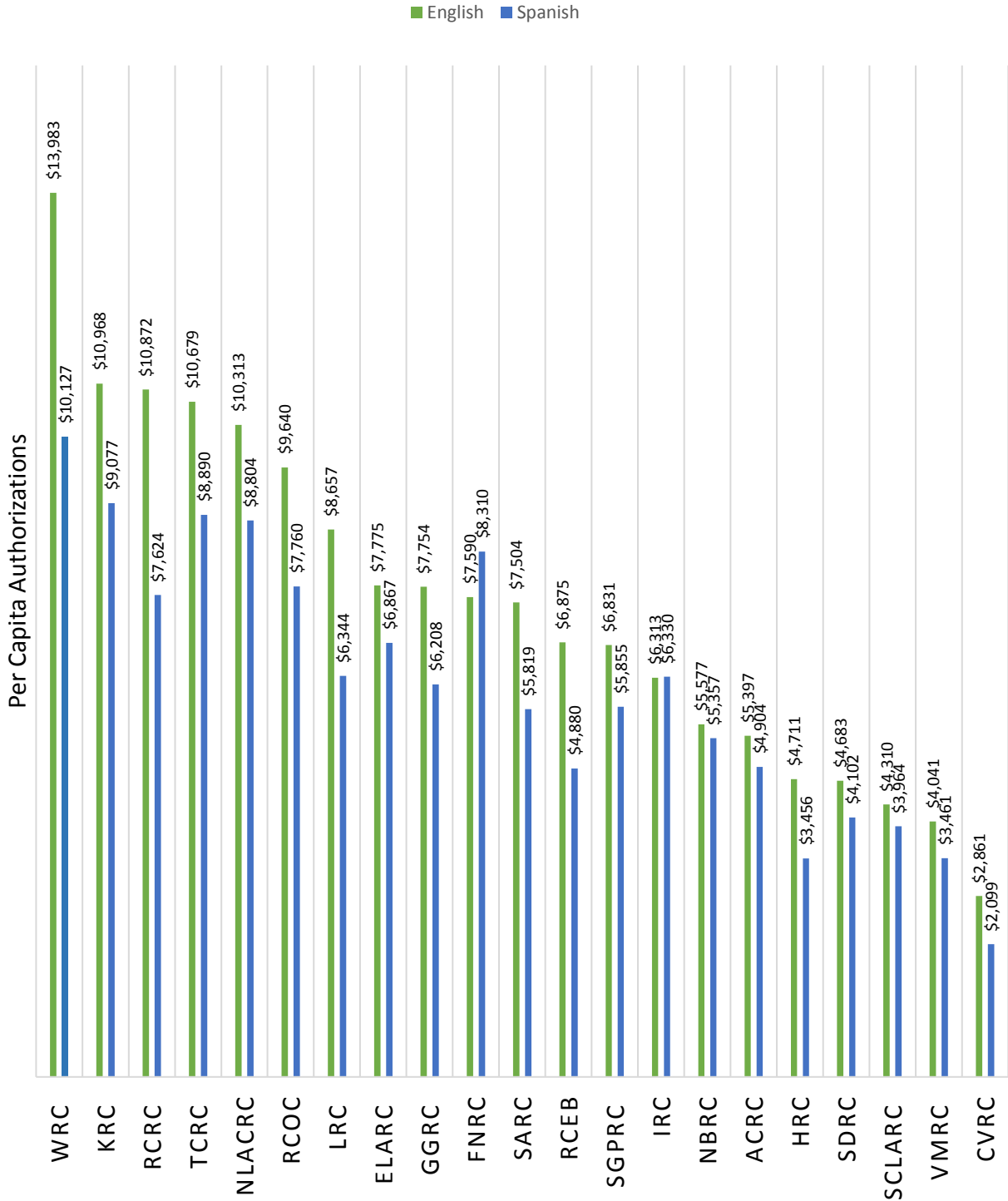
4. Disparities in Amounts of POS Authorized for Children within Each Regional Center are Related to the Languages Spoken in their Home

For consumers ages 3-21 living at home in 2017-2018, there were large discrepancies in POS authorizations among the regional centers between English-speaking and Spanish-speaking clients. Nineteen out of the 21 regional centers had higher per capita authorizations for their English-speaking consumers, with the largest funding gap being \$3,856 higher for English-speaking families at Westside Regional Center (WRC). Eleven regional centers had at least a \$1,000 difference between English and Spanish speaking consumers, and the average disparity amount among all regional centers was \$1,290. (Figure 5 and Appendix F.) Similar results were found with the 2016-2017 data, which is contained in Appendix F.

Conclusion

Health literacy is likely contributing to funding disparities related to client families' primary language. However, despite passage of AB 959 in 2017 requiring regional centers to provide information to consumers and their families in a culturally and linguistically appropriate manner consistent with California Government Code § 11135 and its implementing regulations under the Lanterman Act, there appears to be little compliance with existing law. The persistence of POS disparities between English and Spanish-speaking consumers represents a failure on the part of the regional centers to operationalize current law. More profoundly, it reflects the historical failure of DDS not to have established regulations applicable to the regional centers on language access in the first place.

Figure 4: Comparing Per Capita Authorizations Between English-Speaking and Spanish-Speaking Consumers Ages 3-21, 2017-2018



5. DDS and Most Regional Centers Have Consistently Failed to Meet Their Obligations Under the Data Reporting Requirements

DDS and the regional centers are required to annually compile and post specific data on their respective websites relating to the regional centers' POS authorizations, utilizations and expenditures. Regional centers must post this data by the end of the year each year and maintain all previous years' data on its Internet Web site. DDS has a similar obligation.

A recent review of all 21 regional centers' current and prior data reports indicates that they, and thus DDS, are noncompliant with the law (WIC § 4519.5); many reports are missing, incomplete, inaccurate and inaccessible. Although this failure was also reported in May 2017, much remains the same. Erroneous data is suspected in some reports, some data reports contain only partial information, not all of the Fiscal Years are being reported online and there still is significant lack of uniformity and accessibility to many of the reports that have been posted. (Full analysis of current compliance with the data reporting requirements is provided in Appendix B.)

Conclusion

Statutory data reporting requirements are not being met by most regional centers. Incomplete and inaccurate data obscure evidence of disparities in funding and service authorization.

RECOMMENDATIONS

The Legislature Should Enact Legislation that Requires DDS to Work with Stakeholders to revise DDS' Budget and Allocation Methodology to a Client-Needs-Based Model

The Legislature should enact legislation to impanel a legislative task force, comprised of the department and stakeholders, to develop a client-needs-based POS budget and allocation methodology, as was previously initiated by DDS under prior leadership. The process should be transparent and provide opportunities for consumer and public input.

The Legislature Should Fully Restore the Suspended Services and Repeal Other Services Restrictions that were Enacted in Response to the 2009 Budget Crisis

The suspended services are still in suspense from 2009, despite assurances made by the state then that the suspensions would only be temporary. The legislature should repeal the Individual Choice Budget statute, de-linking restoration of the suspended services from the development and implementation of the since abandoned Individual Choice Budget program.

Current proposed legislation for this year's legislative session proposes to finally restore camping and social recreation services, which should help to improve upon POS equity. However, non-medical therapies, such as specialized recreation, and art, music and dance therapies, and education

services, such as tutoring and supplemental therapies such as occupational and physical therapies, which are especially needed when school is not in session, are other critical suspended services that the legislature and Governor should also restore through this year's annual budget process.

Respite services, which provides families a break from caring for the child and allows them to do other things, were also cut in 2009 for infants and toddlers participating in the Early Start program. While respite services have been restored under the Lanterman Act for consumers over three, they remain unavailable to children under three. Respite services are very important family support services and should be restored for the Early Start program. Their value for many overwhelmed newcomers to the regional center system caring for developmentally delayed and at-risk infants and toddlers, especially families facing added cultural and linguistic barriers, cannot be overstated.

In 2009, the state imposed strict rules requiring consumers to first pursue other sources for medical and dental services and provide documentation of the service denial and efforts to appeal the denial before seeking the service from regional centers. Families are now required to pursue complex appeal processes if denied by the generic agency before the regional center will pay for these services. These rules have burdened low-income, minority and non-English-speaking families who are often less able to navigate appeal processes. The law should be revised for regional centers to fund for these services without families having to undertake an appeal as a prerequisite when a generic agency denies a service.

The Legislature should Enact Legislation Requiring Regional Centers to Develop, Maintain and Publish Specific Language Access Services Plans

AB 959 passed in 2017 requiring regional centers to provide information to consumers and their families in a manner that is culturally and linguistically appropriate, including through the provision of alternative communication services, pursuant to state law prohibiting discrimination on the basis of national origin. But the regional centers still have not developed specific language access services plans on their own in response to this Lanterman Act provision.

The regional centers should be required through legislation to develop language access services plans, utilizing census data to identify languages spoken in their catchment areas to identify the regional center's language capacities and needs for ensuring non-discriminatory processes in the provision of intake, assessment, purchase and provision of services. The language access service plans should also include a specific complaint process for persons who believe their rights to meaningful language access have not been met by the regional center. The regional centers should be required to consult with DFEH for technical assistance and final approval in developing comprehensive language access services plans that comport with the basic tenets of state and federal anti-discrimination law. In turn, these language access service plans should be posted online as part of the regional centers' public disclosures requirements under WIC § 4629.5.

The Legislature should Commission an Independent Study to Review the Effectiveness of the Disparity Reduction Efforts Funded by AB 2X1 over the Past Three Years

On February 29, 2016, the Legislature passed through special session a managed care organization tax, thereby generating approximately \$1.35 billion dollars to the state. With this additional revenue, the Legislature concurrently passed another bill, AB 2X1, that brought in \$400 million additional funds into the regional center system, including annual allocations of \$11 million specifically to have regional centers address POS disparities. In 2017, under AB 107, DDS became authorized to disburse some of the \$11 million to community-based organizations (CBOs) to help promote equity and reduce POS disparities.

After three years of DDS' funding of various disparity reduction projects, it is unclear whether any of these efforts have had any significant impact. Although grantees are required to issue periodic updates describing qualitative and quantitative outcomes accomplished, DDS' program evaluation process appears to be based largely upon the regional centers' and CBOs' self-reports.

The Legislature should commission an independent study to examine the efficacy of recent disparity reduction initiatives that regional centers and CBOs have undertaken. The commission should be charged with providing recommendations for redirecting funds towards those programs that have proven to have made significant remedial impact, based on the study's findings.

The Legislature should Convene another Oversight Hearing to Further Revisit the Recommendations from the 2012 Equity Taskforce

A legislative hearing should be held to revisit the dozens of un-acted upon proposals made by the 2012 Equity Taskforce with the intent of identifying the need for additional legislation to assure reductions in disparities within the regional center system. According to ARCA, 54 proposals were offered in response to the December 2011 LA Times Article; of those, only fourteen became bills, with just six passing out of the Legislature and going to the Governor, who vetoed one of them.

The Legislature should Enact Legislation to Require Regional Centers' Compliance with the Data Reporting Requirements and other Transparency and Accountability Requirements as Part of its Performance Contracts with DDS

The regional centers' contracts with DDS must maintain annual performance objectives and steps for contract compliance, including incentives for regional centers to meet or exceed performance standards and levels of probationary status for regional centers that do not meet, or at risk of not meeting, performance standards. The Legislature should enact law requiring the regional centers to comply with their data reporting and other public disclosures requirements by tying compliance of these requirements to their performance contracts with DDS under WIC § 4629.

DDS should Thoroughly Review and Enforce the Regional Centers' Compliance with their Data Reporting and Other Public Disclosures Mandates

DDS should thoroughly review and enforce the regional centers' compliance with the data reporting requirements and other public disclosures mandates, particularly those that have an inextricable relation to disparity issues. For instance, all regional centers should now have a link on their websites to the list and description services that DDS developed and posted pursuant to AB 959. The law also requires regional centers to post online their revised respite policies in light of changes in the law and their respite assessment tools and protocols so that families can better understand the eligibility criteria for those services. Regional centers should also have all approved minutes and agendas of their board of directors' meetings and their board's committee meetings contemporaneously posted online. These meetings minutes often have disparity issues and other relevant services access information, and online access may be the only means for some families unable to attend board meetings to review this important information.

DDS Should Require Regional Centers to Assess Cases where Consumers are Receiving No Purchases of Services to Determine the Cause of the Deprivation and Report to DDS on their Findings as Part of their Performance Contract Obligations; DDS, in turn, should Make these Findings Publicly Available

DDS and the regional centers have a duty to account for the needs of all their consumers. Suggesting that disconcerting data reflecting large percentages of consumers without any services is perhaps due to the consumers' service needs being met elsewhere, or is perhaps because the consumers have declined POS and only want case management services from the regional center is insufficient, without evidence to substantiate those assertions.

Regional centers are contractually obligated to measure progress in reducing disparities and improving equity in purchase of service expenditures. As part of this mandate, DDS should require regional centers to assess all their cases with no POS to determine the cause for the lack of POS receipt and report their findings to DDS for public dissemination. In the course of this assessment, categories should be created to help clarify the cause of the consumer not receiving any services, including:

- the consumer's needs have been overlooked or neglected by the regional center;
- the consumer has a pending appeal with a generic agency over a service that the regional center may also fund but is not funding;
- the consumer does not meet or has not fulfilled the regional center's criteria under its purchase of services guidelines, protocols and/or assessment tools used to determine service needs;

- barriers to the consumer’s utilization of authorized services exist, such as conflicts in schedules of availability, transportation needs, or lack of bilingual and/or culturally appropriate providers;
- no services have been offered to the consumer by the regional center;
- significant amount of tracked time has lapsed between the consumer’s request for the service to the provision of the service;
- all of the consumer’s needs are being met elsewhere by generic agencies;
- consumer has declined services and wishes to retain case management services only.

These assessment reports should be done at least quarterly to measure progress towards alleviating cases where lack of POS receipt was avoidable and to better identify barriers attributable to lack of resources. DDS should make these reports publicly available.

CONCLUSION AND NEXT STEPS

POS disparities among and within the regional centers continue to be prevalent. We acknowledge that DDS and the regional centers now have a greater awareness of the POS disparities issues and have taken some steps to reduce these disparities. However, this issue calls for a deeper and broader approach, including legislation that will meaningfully provide equal access to services irrespective of the language spoken by the consumer and his or her family, and offer systemic relief to communities that have been especially harmed by the draconian 2009 service cuts. Moreover, in order to truly realize equality in children’s access to regional center services, irrespective of race, ethnicity or language spoken, DDS’ POS budget and allocation methodology needs to be overhauled and replaced with an objective client-needs-based model that does not perpetuate historic inequities.

We strongly urge the state’s legislative and executive administration leadership to pursue the recommendations contained within this report.