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### **Executive Summary**

Inequitable access to developmental services through California's regional center system continues to plague communities of color. Despite California investing \$66 million in the past six years on programs intended to reduce disparities between racial and ethnic groups, significant gaps in funding between children of different racial and ethnic groups persist. Our report found:

- Disparity in service expenditures between Hispanic and White children ages 3 through 21 decreased statewide, but inequitable funding remains deeply rooted and is worsening between these two groups at most regional centers
- Disparity in service expenditures between English-Speaking and Spanish-Speaking children ages
   3 through 21 decreased statewide, but inequitable funding remains deep-rooted and is worsening
   between these two groups at a majority of the regional centers
- Disparity in service expenditures between Asian and White children ages 3 through 21 slightly decreased statewide, but Asian children still receive far less than White children
- Disparity in service expenditures between children of "other ethnicity" and White children ages 3 through 21 is the most profound among all race/ethnicity groups and is worsening
- The Department of Developmental Services' disparity measures do not track improvement for Asian children and children of "other ethnicity"
- Spending now favors Black children ages 3 through 21 compared to White children of the same age
- Disparity in service expenditures is worsening for children of "other ethnicity" ages 0 through 2 compared to White children of the same age
- The rapid population growth of children of "other ethnicity" presents a new cause for concern given this group's worsening plight with disparities
- More children ages 3 through 21 are being left unserved now than at any time since FY 2015-2016
- The rate at which children ages 3 through 21 are able to access services is lower now than at any time since FY 2015-2016
- Children ages 0 through 2 are being left unserved more now than at any time since FY 2015-2016 and the rate at which they can access services is lower than at any time since 2015-2016

<sup>1</sup> According to the Department of Developmental Services, the race/ethnicity category "other" includes all consumers who do not self-report as African-American, Asian, Hispanic, or White. Regional centers have also utilized this category to refer to the following classifications: Other, Russian, Unknown, or Multi-Cultural.

- DDS' flawed methodology for allocating funds to the regional centers requires revision to enable underserved and unserved groups to achieve greater equity
- Parents express concern that they have experienced discrimination by regional centers due to their race or due to the language that they speak

California Department of Developmental Services (DDS), the state agency with oversight over the regional center system, has developed a set of measures containing targets to monitor the regional centers' improvement in reducing disparities. These disparity measures do not track for improvement for Asian children and children of "other ethnicity" and DDS has not provided any explanation for their exclusion.

Our analysis of public data indicates that DDS' measures are inadequate and largely have not been met. Disparities in services between racial and ethnic groups continue to fester.

To effectively address service funding disparities in the regional center system, we recommend that the legislature undertake the following actions:

- Convene a joint legislative oversight hearing on regional center funding disparities to thoroughly examine the issue
- Appoint a legislative taskforce to explore replacing DDS' current funding formula with a new model that targets underfunded and unserved populations within each regional center
- Require DDS to investigate and remedy defects in the regional centers' collection of demographic information and to ensure that a uniform system for gathering demographic information is established and implemented statewide going forward
- Restore respite and other critical family support services to Early Start families that were cut
  during the 2009 budget crisis because they were "nonrequired"
- Repeal the stringent 2009 law that requires families to apply for and appeal denials of services through other agencies before the regional center will consider funding services
- Repeal restrictive parent/caregiver participation requirements for behavioral health treatment services enacted in 2009 which now conflict with Medicaid law
- Amend the law to require additional data reporting that will enable the public to have access to the same data that DDS is using to assess for improvement under its disparity measures
- Require regional centers to comply with the data reporting obligations and other public disclosures requirements by tying compliance to their performance contracts with DDS
- Require regional centers, as part of their contractual obligations with DDS, to review all cases
  where consumers are receiving no purchase of services, to classify the reasons for why this is
  occurring, and to report these findings to the public

#### This is a voluntary system. If you don't like it, you can leave.

An old program manager once told me: "This is a voluntary system. If you don't like it, you can leave." It's true that regional center services are not compulsory like the school, but what other choice do we have? This a state system. There are no other options. We have no family in this country to help. The regional center is necessary for us.

We are 14% of the population, but we are fractionalized. Our cultures are very different and discrimination is nuanced and unique to each of our groups. Yet, we are combined into one "Asian" category or we are put into the "other" category. There is less focus on Asians. We more than contribute our share to society and yet we do not get the same in return.

At a meeting on disparities at IRC, a White man spoke, then me. I have an accent so I came across as angry, like I wanted to fight. I didn't say anything different or more forcefully than the man before me. But their reactions seemed as if his comments were accepted and mine were dismissed.

— Asian parent at Inland Regional Center



### Introduction

California provides specialized supports and services to persons with developmental disabilities through a network of 21 regional centers. Regional centers are independent, private, non-profit corporations that contract with the California Department of Developmental Services (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. Regional centers are charged with supporting eligible individuals, referred to as "consumers," to have the most independent and productive lives possible.

Regional center services are intended to be available to all consumers without regard to race, ethnicity, language, income level, or geographic location. Services include respite care, personal assistance services, behavioral health treatment services, adaptive equipment such as wheelchairs, nursing care, and adaptive skills and social skills training programs. "Purchase of service" (POS) is the method used by the regional centers to pay for services and supports that have been mutually agreed upon by the regional center and the consumer through the individual program plan (IPP) process. Only services and supports for which the regional centers pay are counted as POS funds.

DDS and the 21 regional centers are required to collect and publish data on POS authorizations, expenditures, and utilization, broken down by consumer age, race/ ethnicity, language, residence type, and other factors. Authorizations represent the extent to which the regional center is willing to purchase services for its consumers through the IPP process. Expenditures reflect the extent to which consumers are successful in receiving the authorized services. The regional centers report POS authorizations and expenditures on a "per capita" basis, which divides total amounts the regional center authorized or spent by the total number of consumers eligible to receive services, and not by the number of consumers who actually were authorized services or in fact received services from the regional center. Utilization rates reflect services authorized by the regional center, successfully accessed and used by the consumer and, thus, spent by the regional center.



For 30 years, families and advocates, supported by numerous research studies, have raised concerns about disparities in service access. Over the past six years, the state has attempted to address funding inequities through a disparity reduction program established in 2016 that provides \$11 million annually for projects intended to reduce disparities within the developmental services system.<sup>2</sup> The state has invested \$66 million so far through DDS' disparity reduction program.

Our report analyzes POS expenditures data for Fiscal Year (FY) 2020-2021 by race/ethnicity and language for children and compares these data with data from FY 2015-2016, before the disparity reduction funds were appropriated. We acknowledge that some of the data findings reported herein may have been influenced by the pandemic.<sup>3</sup> There should be a thorough investigation by the state into the how the pandemic may have affected the manner in which services were offered, accepted, made available, delivered, and accessed during this time. We undertook a limited review of these pandemic-related issues through phone interviews with several families from communities of color across the state and we provide excerpts herein of their accounts. We also provide testimonials from these families on how they perceive the funding disparities to have affected them.

We find that racial and language disparities in POS expenditures among and within the regional centers continue to persist and, in some cases, are getting worse. Our report details the current disparities found among children served by the developmental services system and makes several recommendations for addressing these inequities. We set forth five sets of findings to show concerns with DDS' published process for monitoring disparities (Finding 1), funding disparities by race/ethnicity (Finding 2), concerns with demographic classifications by the regional centers (Finding 3), concerns with data reporting (Finding 4), and concerns with DDS' flawed allocation methodology (Finding 5).

<sup>2</sup> For more information on DDS' Disparity Funds Program, see: <a href="https://www.dds.ca.gov/rc/disparities/disparity-funds-program/">https://www.dds.ca.gov/rc/disparities/disparity-funds-program/</a>

<sup>3</sup> Many of the regional centers' data reports for FY 2020-2021 contain the following preface: Changes in service delivery and billing in response to the COVID-19 pandemic may have affected individuals and communities differently. Care should be taken in comparing FY 2020-2021 data to data for previous years. In response to the pandemic and varied individual needs and circumstances, billing for some services changed to a monthly rate instead of hourly or daily rates. As a result, this may have reduced differences among individuals in service authorizations, expenditures, and utilization.

### **Background**

#### CALIFORNIA'S DEVELOPMENTAL SERVICES SYSTEM

The Lanterman Act, codified at California Welfare & Institutions Code (WIC) § 4500 et seq., requires the state to provide services and supports for persons with developmental disabilities, such as autism, epilepsy, cerebral palsy, and other intellectual disabilities, to enable these individuals to approximate the pattern of everyday living available to people without disabilities of the same age. Under the California Early Intervention Services Act, California Government Code § 95000 et seq., the state must also provide services to infants and toddlers ages 0 through 2 who have, or who are at risk of having, developmental disabilities. Services are administered through 21 regional centers, which are independent, private, non-profit corporations that contract with DDS to develop, purchase, and manage services and supports for consumers and their families.

#### 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.<sup>5</sup> Statutory provisions have given DDS the authority and the duty to ensure that regional centers comply with laws prohibiting discrimination on the basis of race, ethnic group identification, national origin, and other protected characteristics.<sup>6</sup> 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)

<sup>4</sup> California Welfare and Institutions Code § 4501.

<sup>5</sup> California Welfare and Institutions Code § 4433(a).

<sup>6</sup> Office of the Attorney General of the State of California, Opinion No. 79-107 (May 11, 1979) 62 Ops. Cal. Atty. Gen. 229. In 2016, Senate Bill (SB) 1442 transferred responsibility of enforcing California Government Code § 11135 to the Department of Fair Employment and Housing (DFEH) under California Government Code § 12930(f)(4).

### **Methods**

We analyzed POS data for children ages 3 through 21 and ages 0 through 2 from online reports published from each of the 21 regional centers. For this report, we analyzed POS expenditures to the extent that public data allow in order to approximate comparisons with DDS' disparity measures. We focused on POS expenditures because they ultimately determine the allocation amounts that DDS provides to the regional centers. DDS is also using POS expenditures to measure if certain improvements are being made by the regional centers in reducing disparities.<sup>7</sup>

Our findings are based on data derived from the public reports of children who actually received some POS services and not the per capita data reported by the regional centers, which includes unserved children. Regional centers calculate and report expenditures based on their total consumer populations, whether the consumers received services or not. However, when per capita expenditures are recalculated based on who actually received services, the gaps are often more substantial between groups and further raises the concern of deprivation – who is not being served and why. True equity is achieved when different groups receive funding at 100% relative to one another and their rates of being served are the same.

For example, the data reported by San Andreas Regional Center for children ages 3 through 21 for FY 2020-2021 has White children receiving \$12,298 and Hispanic children receiving \$7,462 in per capita expenditures. Per this data report, Hispanic children, on average, received \$4,386 less than White children and Hispanic children had a disparity ratio of 61% in service expenditures compared to White children. However, these figures are based off the total eligible populations for both race/ethnicity groups, which were 1,579 for White children and 3,566 for Hispanic children in FY 2020-2021.

When recalculating the total expenditures made for children by only those who actually received services during the fiscal year, the population for White children reduces to 936 and the population for Hispanic children reduces to 2,467. Dividing these numbers by each groups' respective total expenditures produces higher averages. White children who received some POS now have an average of \$20,746 and their Hispanic counterparts now have an average of \$10,786. Per this adjusted data for FY 2020-2021, Hispanic children who were actually served received, on average, \$9,960 less than White children who were actually served. Accordingly, Hispanic children had a worse disparity ratio of 52% in service expenditures compared to their White peers. (Figure 1).

<sup>7</sup> Service authorizations are also important as they represent the extent to which regional centers are willing to offer services through the individual program plan process and thus reflect existing policy differences among regional centers which directly affect what services consumers may receive. For the sake of brevity, our current report focuses on per capita expenditures and not on per capita authorizations, but for more discussion on the latter, see: <a href="Confronting Inequities in California's Funding of Services for Children with Developmental Disabilities: A Sobering View of Our Current Standpoint | Lucile Packard Foundation for Children's Health (lpfch.org)</a>

#### FIGURE 1

### Assessing for Improvement in Reducing Disparities in Access to Regional Center Services Example: San Andreas Regional Center POS Expenditures

Comparing reported per capita expenditures data vs. POS expenditures data between White and Hispanic children based on actual distribution FY 2020-2021, All Residences, Ages 3 Through 21

	WHITE		HISPANIC					
	Total Expenditures	Population	POS Expenditures	Total Expenditures	Populattion	POS Expenditures	DISPARITY AMOUNT	DISPARITY RATIO
ALL YOUTH	\$19,417,992	1,579	\$12,298	\$26,607,993	3,566	\$7,462	\$4,836	61
CONSUMERS W/SOME POS	\$19,417,992	936	\$20,746	\$26,607,993	2,467	\$10,786	\$9,960	52

Additionally, we conducted five one-on-one phone interviews with parents from around the state, which ranged from 30 minutes to an hour in their duration. We selected parents of different race/ethnicity backgrounds from different regional centers statewide to establish a diverse representation of the communities served by the regional center system. We obtained information from these parents about the difficulties they faced during the pandemic in having their children served by their regional center and whether they believe their race, culture, and/or primary language may have contributed to these difficulties.



### **Summary of Findings**

#### Our study found the following:

- Significant disparities in POS expenditures based on race/ethnicity and language remain prevalent.
- The improvement targets developed by DDS in its disparity measures are not being met in almost all cases.
- The measures that DDS is using to track progress in reducing disparities are inadequate because they do not account for Asian and "other ethnicity" populations.
- Although the statewide rates of eligible children who did not receive any services vary little by race/ethnicity, there are several regional centers whose rates of children with no services have consistently exceeded the statewide averages.
- Utilization rates for all children have steadily decreased over time since FY 2015-2016, indicating that services authorized by regional centers are no more easily attainable for them now than six years ago before the disparity reduction program began.
- Enhanced funding at one regional center over the past year has resulted in significant improvement among communities of color within that regional center and this example may provide a path forward for the state to replicate on a statewide basis.

#### ... better transparency is needed.

I think better transparency is needed. SARC should walk families through the process. If my child needs something, I am going to pursue it. But I have a Latina friend whose case was closed when her child aged out of Early Start. She had to submit a whole new application. SARC told her that he may be provisionally eligible, but her child is more severe than mine.

— Asian parent at San Andreas Regional Center

### Results

FINDING 1: DDS' disparity measures are flawed and require revision and greater transparency to achieve their intended purpose

In response to a legislative hearing held by the Senate Human Services Committee on March 14, 2017, DDS developed a set of disparity measures to track progress in reducing disparities and to establish short- and long-term improvement targets for the measures. Unfortunately, these measures are inadequate because they do not measure for equity improvement in Asian and "other ethnicity" populations. Further, DDS's measures are lacking in transparency because DDS has chosen criteria for its measures based on data to which only it has access.

Our analysis finds that many of the improvement targets developed by DDS for measuring POS equity in its disparity reduction measures are not being met by the regional centers.

#### **DDS' Disparity Measures Lack Transparency**

Regional centers report per capita expenditures by dividing total expenditures by total consumer count, which results in a lower figure. Assessing for equity in expenditures instead by just consumers who actually received some POS causes an increase in the per capita amounts reported by the regional centers and the increase will vary depending on how many children went unserved within each subgroup.<sup>9</sup>

The publicly available data reported by regional centers does not provide data on expenditures for consumers by race/ethnicity and language living in the family home who received some POS and who went unserved, which is the data that DDS is using for its measures. California Welfare and Institutions

<sup>8</sup> DDS' disparity measures are available for review here: <u>DDS Disparity Measures - CA Department of Developmental Services</u>, specifically: FY15-16 Statewide Disparity Measures (ca.gov)

<sup>9</sup> For example, suppose you had a set of 10 White children and a set of 10 Hispanic children and you were going to distribute \$1,000 each among both sets, but prior to distributing, you selected eight White children and five Hispanic children to be the ultimate recipients of the money. The eight White children would each receive \$125 and the five Hispanic children would each receive \$200, while two White children and five Hispanic children would receive nothing. Yet, the way per capita expenditures are reported by regional centers suggests that all 20 children received \$100 each.

Code § 4519.5 should be amended so that the data DDS is using to track progress through its disparity measures is also publicly available so that the public can independently assess the outcomes in the same manner as DDS.<sup>10</sup>

In replicating DDS' disparity measures as close as possible given these limitations, we used the public data that pertained to consumers of all residence types and not the subclass of consumers living at home. However, this substitution should have a minor effect because over 98% of children ages 3 through 21 live at home and nearly 100% of children ages 0 through 2 live at home.

#### DDS' Measures are Inadequate

In measuring POS equity for children ages 3 through 21, DDS did not assign improvement targets for Asians and children of "other ethnicity."

In FY 2016-2017, race/ethnicity data reporting fundamentally changed to incorporate Filipino into the Asian category, whereas in prior years, Filipino consumers were reported separately. This change

caused the statewide Asian population for consumers ages 3 through 21 to jump from just over 7% to almost 10% of the overall population. Given this significant change, it raises the question as to whether DDS developed its measures for Asians to include Filipinos in establishing its baselines, which uses the FY 2015-2016 data. If not, DDS should clarify what impact the inclusion of Filipino consumers has had on data relating to Asian consumers. DDS should develop improvement targets for the Asian population for its measures using data that includes the Filipino population.

DDS' disparity measures state that the race/ethnicity category "other ethnicity" includes active consumers who do not self-report as African-American, Asian, Hispanic, or White. This further begs the question as to whether Filipinos were classified as "other" or Asian when DDS developed its

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<sup>10</sup> DDS is also measuring improvement in equity according to specific services received by race/ethnicity, such as respite, personal assistance, adaptive skills training, supported living and independent living services, and supported employment program services. California Welfare and Institutions Code § 4519.5 should also be amended to require regional centers to report data on these services by race/ethnicity and language so that the public may follow along with DDS' measuring process.

measurement baseline for Asians using FY 2015-2016 data and if this has since been reconciled. According to an ethnicity coding sheet utilized by the regional centers, "other" can refer to the following classifications: Other, Russian, Unknown, or Multi-Cultural.<sup>11</sup>

DDS' disparity measures do not include any improvement targets for children classified as "other ethnicity" despite that group's significant increase in population in recent years. More discussion about the population growth of children of "other ethnicity" and the stark disparities that they are currently enduring is detailed below.

Given the high population rates of "other ethnicity" children within the regional center system, DDS should be separately accounting for them in its disparity measures to ensure that the inequities they too are facing are not obscured behind the other main race/ethnicity groups.

#### Summary

DDS' stated goal in developing its disparity measures was to identify a relatively small number of key indicators that may serve as bellwethers for system change. 12 However, these measures are flawed, particularly in their omission of improvement target goals for Asians and children of "other ethnicity." Corrections and additional clarifying information are needed from DDS in order for these measures to be more inclusive and achieve their intended purpose.



<sup>11</sup> See, for example, Alta California Regional Center's Purchase of Service Expenditure and Demographic Data, FY 2020-2021 (p.9): <a href="mailto:fy\_20-21\_pos\_exp\_data\_-english\_1.pdf">fy\_20-21\_pos\_exp\_data\_-english\_1.pdf</a> (altaregional.org)

<sup>12</sup> See DDS' Background and Process for Developing Disparity Measures, p.1, available for review here: <u>Background and Process</u> for Developing Disparity Measures (ca.gov)

## FINDING 2: Disparities in POS expenditures by race and language are worsening for most children of color

Disparity in service expenditures between Hispanic and White children ages 3 through 21 decreased statewide, but inequitable funding remains deeply rooted and is worsening between these two groups at most regional centers

Hispanic children received 80% of the service expenditures that White children received during fiscal year (FY) 2020-2021. This is up from 66% in FY 2018-2019 and up from 72% from the baseline year of FY 2015-2016.

However, this still falls short of DDS' baseline for its Measure #5 of 85% for FY 2015-2016 and comes nowhere close to meeting DDS' upcoming improvement target goal of 97% for FY 2021-2022 or even DDS' prior improvement goal of 90% for FY 2018-2019.<sup>13</sup>

Interestingly, one regional center contributed to most of the statewide improvement in reducing this disparity. In FY 2020-2021, South Central Los Angeles Regional Center (SCLARC) more than doubled its POS expenditures for children ages 3 through 21 from the prior fiscal year, resulting in substantial increases to the per capita expenditures for their Hispanic children. Taking into consideration this outlier, the improvement in the statewide average becomes more modest, reducing from 80% to 75% when data from SCLARC are not included.<sup>14</sup> (Figure 2).



<sup>13</sup> See DDS' Disparity Measures, Measure #5 (p. 7) here: FY15-16 Statewide Disparity Measures (ca.gov)

<sup>14</sup> For sake of brevity, we will hereinafter refer to the regional centers by their official acronyms, but their full names are listed in the Glossary at the end of this report.

#### FIGURE 2

#### Approximating DDS' Approach for Measure #5

Comparison of Average POS bewteen White Children and Hispanic Children, Ages 3 through 21 (All Residence Types)

DDS MEASURE: POS EQUITY TARGET						
W	WHITE: HISPANIC					
<b>BASELINE</b> 2015/2016						
0.85	0.90	0.95				

PUBLIC DATA FINDINGS							
W	WHITE: HISPANIC						
2018/2019	2018/2019 2019/2020 2020/2021						
0.66	0.68	0.80*					

<sup>\*</sup> Note that when South Central Los Angeles Regional Center is not factored in, the statewide average of POS expenditures that Hispanic children received in FY 2020-2021 compared to what White children received reduces from 80% to 75%

Despite what the current statewide average suggests, improvement in disparities between White and Hispanic children is not being realized among each of the regional centers statewide. In fact, SCLARC and three other regional centers (ELARC, LRC, and RCRC) are primarily responsible for reducing the gap statewide.

Comparing data from FY 2020-2021 with data from FY 2015-2016, disparities in service expenditures between White children and Hispanic children improved in only four regional centers while worsening in the other seventeen regional centers. ELARC comes the closest to achieving equity, with Hispanic children receiving about \$200 less than their White counterparts. (Figure 3).

<sup>15</sup> We are mindful that our findings here relate to changes in disparity amounts and not to disparity ratios, which may yield different findings if assessed. However, we believe such an analysis is premature because it would not produce reliable results due to the effects of the pandemic over the past year. In FY 2020-2021, COVID resulted in the unserved rate for all children increasing by around five percentage points, from 31% to 36%. This resulted in more money going to fewer children, which, in turn, has artificially inflated all children's POS expenditures and has thus created some odd results when looking at improvement in the disparity ratios among the regional centers. For instance, in FY 2015-2016, SGPRC had a \$2,809 funding disparity in favor of White children over Hispanic children (\$10,062 vs. \$7,523), which is a 72% ratio. In FY 2020-2021, SGPRC had a considerably worse funding disparity of \$4,523 between these groups (\$16,883 vs. \$12,360). Yet, because both groups' per capita expenditures significantly increased due to fewer children overall being unserved, the disparity ratio paradoxically "improved" one percent point to 73% between Whites and Hispanic children at SGPRC. Improvement in disparity ratios by regional center should be examined in the future, when the effects of the pandemic are less present in the data.

FIGURE 3
Change in Disparity in POS Expenditures Within Regional Centers
Disparity between White and Hispanic Children, Ages 3 through 21 (All Residence Types)
Goal of Disparty Amount = \$0

Regional Center	Disparity Amount <b>2015-2016</b>	Disparity Amount <b>2020-2021</b>	Change in Disparity Amount	Worse	Better	Favors Hispanic	Nearly Equal
ACRC	\$1,073	\$1,790	(\$717)	•			
CVRC	\$3,168	\$4,299	(\$1,131)	•			
ELARC	\$4,044	\$202	\$3,843				•
FNRC	\$1,427	\$1,586	(\$159)	•			
GGRC	\$3,845	\$7,066	(\$3,222)	•			
HRC	\$2,404	\$2,474	(\$70)	•			
IRC	\$1,323	\$1,563	(\$240)	•			
KRC	\$3,803	\$5,619	(\$1,816)	•			
LRC	\$3,669	\$3,044	\$625		•		
NBRC	\$2,911	\$8,711	(\$5,799)	•			
NLACRC	\$2,866	\$6,042	(\$3,175)	•			
RCEB	\$4,016	\$7,928	(\$3,912)	•			
RCOC	\$2,696	\$6,979	(\$4,283)	•			
RCRC	\$7,094	\$4,412	\$2,682		•		
SARC	\$3,259	\$9,960	(\$6,701)	•			
SCLARC*	\$12,710	\$865	\$11,845		•		
SDRC	\$1,565	\$1,923	(\$358)	•			
SGPRC	\$2,809	\$4,523	(\$1,714)	•			
TCRC	\$1,768	\$1,896	(\$128)	•			
VMRC	\$2,927	\$3,665	(\$738)	•			
WRC	\$3,009	\$4,468	(\$1,459)	•			
				17	3	0	1

\*SCLARC's White population is 1%: 2015/2016 n = 102 (1%); 2020/2021 n = 107 (1%)

The general statewide average for POS expenditures among children ages 3 through 21 of all races who received some POS in FY 2020-2021 is \$11,072. Yet, seven regional centers currently have spending disparities exceeding \$5,000 in favor of White children over Hispanic children: SARC (\$9,960), NBRC (\$8,711), RCEB (\$7,928), GGRC (\$7,066), RCOC (\$6,979), NLACRC (\$6,042), and KRC (\$5,619). By contrast, in FY 2015-2016, only two regional centers (SCLARC and RCRC) had disparities exceeding \$5,000 between White and Hispanic children. SCLARC has dramatically reduced disparity since that time due to its increased spending, from \$12,710 in FY 2015-2016 down to just \$865 in 2020-2021.

There are still profound inequities in POS expenditures between White and Hispanic children at most regional centers, which have only exacerbated since FY 2015-2016.

Disparity in service expenditures between English-Speaking and Spanish-Speaking children ages 3 through 21 decreased statewide, but inequitable funding remains deeply rooted and is worsening between these two groups at a majority of the regional centers

Spanish-speaking children received 91% of the service expenditures that English-speaking children received during FY 2020-2021. This is up from 72% in FY 2018-2019 and up from 77% from the baseline year of FY 2015-2016.

### I've had translators at meetings, but they always take the side of the regional center.

I am the one who always has to reach out. My regional center worker never makes contact. My older child was getting respite, but not my younger one, and they had the same worker. I asked for a new worker but she is new and does not know too much. Language is definitely a barrier. I've had translators at meetings, but they always take the side of the regional center.

— Hispanic parent at Redwood Coast Regional Center

Ostensibly, this gain appears to meet DDS' improvement target goal for its Measure #9a for FY 2018-2019, which is also 91%. However, this statewide average reduces down from 91% to 83% when data from SCLARC is not included, and still falls well short of DDS's upcoming improvement target goal for FY 2021-2022 of 98%. (Figure 4).

## FIGURE 4 Approximating DDS' Approach for Measure #9a

Comparison of Average POS between English-Speaking Children and Spanish-Speaking Children, Ages 3 through 21 (All Residence Types)

DDS MEASURE: EQUITY TARGET FOR LANGUAGE DIVERSITY							
EN	ENGLISH: SPANISH						
<b>BASELINE</b> 2015/2016							
0.87	0.91	0.98					

PUBLIC DATA FINDINGS							
EN	ENGLISH : SPANISH						
2018/2019 2019/2020 2020/2021							
0.72	0.76	0.91*					

<sup>\*</sup>Note that when South Central Los Angeles Regional Center is not factored in, the statewide average of POS expenditures that Spanish-speaking children received in FY 2020-2021 compared to what English-speaking children received reduces from 91% to 83%.

Comparing data from FY 2020-2021 with data from FY 2015-2016, disparities in service expenditures between English-speaking children and Spanish-speaking children have improved in eight regional centers but have worsened in the other thirteen regional centers. Funding favors Spanish-speaking children over English-speaking children in three regional centers, with IRC coming the closest to achieving equity with Spanish-speaking children receiving \$142 more than their English-speaking counterparts. (Figure 5).

<sup>16</sup> See DDS' Disparity Measures, Measure #9a (p. 12) here: FY15-16 Statewide Disparity Measures (ca.gov)

<sup>17</sup> Our findings here relate to changes in disparity amounts and not to disparity ratios. As explained above, improvement in funding ratios by regional center should be examined in the future, when the effects of the pandemic are less present in the data.

FIGURE 5

#### Change in Disparity in POS Expenditures Within Regional Centers

Disparity between English-Speaking and Spanish-Speaking Children, Ages 3 through 21
(All Residence Types)
Goal of Disparty Amount = \$0

Regional Center	Disparity Amount <b>2015-2016</b>	Disparity Amount <b>2020-202</b> 1	Change in Disparity Amount	Worse	Better	Favors Spanish- Speaking	Nearly Equal
ACRC	\$1,553	\$2,222	(\$669)	•			
CVRC	\$3,133	\$2,779	\$354		•		
ELARC	\$1,400	(\$288)	\$1,688				•
FNRC	\$1,870	\$1,980	(\$110)	•			
GGRC	\$3,115	\$4,572	(\$1,457)	•			
HRC	\$2,047	\$1,051	\$996		•		
IRC	(\$9)	(\$142)	\$133				•
KRC	\$2,924	\$3,358	(\$434)	•			
LRC	\$2,171	\$2,224	(\$52)	•			
NBRC	\$2,660	\$5,902	(\$3,242)	•			
NLACRC	\$1,068	\$2,189	(\$1,122)	•			
RCEB	\$3,542	\$7,489	(\$3,947)	•			
RCOC	\$1,189	\$4,522	(\$3,333)	•			
RCRC	\$5,686	\$6,933	(\$1,247)	•			
SARC	\$3,060	\$6,909	(\$3,849)	•			
SCLARC	\$1,394	(\$2,046)	\$3,440			•	
SDRC	\$898	\$1,322	(\$425)	•			
SGPRC	\$2,355	\$1,920	\$435		•		
TCRC	\$1,221	\$1,382	(\$162)	•			
VMRC	\$2,532	\$2,506	\$26		•		
WRC	\$2,250	\$1,763	\$487		•		
				13	5	1	2

The general statewide average for children ages 3 through 21 who received some POS in FY 2020-2021 is \$11,072. However, four regional centers currently have disparities exceeding \$5,000 in favor of English-speaking children over Spanish-speaking children: RCEB (\$7,489), RCRC (\$6,933), SARC (\$6,909), and NBRC (\$5,902). By contrast, in FY 2015-2016, only one regional center, RCRC, had disparities between these two groups that exceeded \$5,000.

There are still profound inequities in POS expenditures between English-speaking and Spanish-speaking children at many regional centers which have continued to worsen since FY 2015-2016.

# Disparity in service expenditures between Asian and White children ages 3 through 21 slightly decreased statewide, but Asian children still receive far less funding than White children

Asian children received 86% of the service expenditures that White children received during FY 2020-2021. This is up from 82% in FY 2019-2020, but still significantly down from FY 2015-2016, when Asian children received 95% of what White children received. Additionally, among all race/ethnicity groups in FY 2020-2021, Asian children experienced the highest rate for those that went unserved at nearly 39%. Fewer Asian children received services, causing an increase in the statewide average of their per capita expenditures and making it appear as though the disparity gap between them and White children has improved more so than it actually has. (Figure 6).



<sup>18</sup> In our 2020 report, we assessed POS expenditures for White and Asian children ages 3 through 21 and concluded, based on the public data available then, that Asian children had received slightly more (101%) than Whites in FY 2015-2016. However, the public data at that time had Filipino children being reported separately. For our current report, we corrected these data by combining the data for Asians and Filipinos for FY 2015-2016 to ensure consistency in group comparisons across years, which reduced the statewide average of POS expenditure amounts for Asian children (including Filipino children) with some POS to 95% compared to White children for that fiscal year.

#### FIGURE 6

#### Approximating DDS' Approach for Measure #5

Comparison of Average POS between White Children and Asian Children, Ages 3 through 21 (All Residence Types)

DDS MEASURE: POS EQUITY TARGET						
	WHITE : ASIAN					
BASELINE 2015/2016						
1.02	None	None				

PUBLIC DATA FINDINGS						
WHITE : ASIAN						
2018/2019	2018/2019 2019/2020 2020/2021					
0.88	0.82	0.86				

DDS' Measure #5 does not contain improvement targets for Asian children relative to White children, presumably, as explained above, because DDS incorrectly considered Asians' FY 2015-2016 baseline to be above Whites and therefore unnecessary.<sup>19</sup> This is troubling given the inequitable trajectory that Asians have since faced. DDS' disparity measures were finalized in March 2019, which has given DDS ample time since then to establish targets to evaluate for improvement in equity for Asians in comparison to Whites. Yet, DDS has not done so.<sup>20</sup>

## Spending now favors Black children ages 3 through 21 compared to White children of the same age

Black/African-American children ages 3 through 21 received 113% of the service expenditures that White children of the same age group received during FY 2020-2021. This is up significantly from FY 2015-2016, when Black/African-American children received 92% of what White children received. This is one instance where considerable progress has been made in supporting a historically underserved population. (Figure 7).

<sup>19</sup> Similar to the findings of our 2020 Report, where Filipinos were not factored into our analysis for Asians, DDS had Asians receiving 1.02 (102%) compared to White children for FY 2015-2016. This figure suggests that DDS also did not include Filipinos when it established a measurement baseline for Asians using FY 2015-2016 data. As such, we presume that DDS, in turn, did not create improvement targets for Asians because it erroneously believed Asian children were receiving more than White children, which has never been the case since FY 2015-2016. According to DDS' Background and Process for Developing Disparity Measures, p.5: "For some measures that show little or no disparity at the state level, the Department has not established improvement targets." Background and Process for Developing Disparity Measures (ca.gov)

<sup>20</sup> DDS is certainly capable of revising its disparity measures. In July 2021, DDS updated its disparity measures to correct a calculation relating to Measure #4, which tracks Early Start Utilization rates. That update resulted in an adjusted baseline and target ratios for that measure.

# FIGURE 7 Approximating DDS' Approach for Measure #5

Comparison of Average POS between White Children and Black Children, Ages 3 through 21 (All Residence Types)

DDS MEASURE: POS EQUITY TARGET						
	WHITE: BLACK					
<b>BASELINE</b> 2015/2016						
0.94	0.90	0.97				

PUBLIC DATA FINDINGS						
WHITE: BLACK						
2018/2019	2018/2019 2019/2020 2020/2021					
1.00	1.02	1.13				

DDS' target improvement goal for Black/African-American children under Measure #5 for FY 2018-2019 is 90% (.90), but this appears to be a drafting error by DDS, given that the FY 2015-2016 baseline was 94% (.94). The improvement target goal for DDS now should be revised to achieve equity (1.00), instead of the upcoming target goal of 97% (.97) for FY 2021-2022.

Disparities between children of "other ethnicity" and White children are the most profound among all race/ethnicity groups and are worsening

Children identified as "other ethnicity" received 68% of the service expenditures that White children received during FY 2020-2021, the lowest disparity ratio among all race/ethnicity groups. This rate is down from 70% in FY 2018-2019, and significantly down from FY 2015-2016, when children of "other ethnicity" received 77% of what White children received.<sup>21</sup> Children of "other ethnicity" have seen disparities worsen in relation to White children since FY 2015-2016. (Figure 8).

<sup>21</sup> DDS' Disparity Measure #5 purports that children of "other ethnicity" received 95% (.95) of what White children received in FY 2015-2016. Our analysis indicates otherwise. In FY 2015-2016, "other ethnicity" children ages 3 through 21 with some POS (all residences) received an average \$7,170 while White children ages 3 through 21 with some POS (all residences) received an average of \$9,350. The ratio for those averages is 77%.



### FIGURE 8 Approximating DDS' Approach for Measure #5

Comparison of Average POS between White Children and Children of Other Ethnicity, Ages 3 through 21 (All Residence Types)

DDS MEASURE: POS EQUITY TARGET			
WHITE : OTHER			
BASELINE 2015/2016	<b>TARGET #1</b> 2018/2019	TARGET #2 2021/2022	
0.95	None	None	

PUBLIC DATA FINDINGS			
WHITE : OTHER			
2018/2019	2019/2020	2020/2021	
0.70	0.68	0.68	

As with Asian children, DDS Measure #5 does not contain any improvement targets for children with "other ethnicity" relative to White children.

Children with "other ethnicity" are the fastest growing race/ethnicity group, and, in addition to having the lowest disparity ratio of POS expenditures in relation to Whites among all race/ethnicity groups, they

have the lowest utilization rates of authorized services received among communities of color in FY 2020-2021. Further, they are ranked second behind Asian children for the highest percentage of children unserved in FY 2020-2021. These points are discussed more thoroughly below.

A presentation provided by DDS in July 2021 indicated that 336 disparity reduction programs had been implemented since 2016 and that for FY 2020-2021, there were 108 active grants with monthly check-ins, collaborations, and quarterly reporting. Yet, of these 108 grants, only seven (6%) were awarded to address disparities relating to children with "other ethnicity."<sup>22</sup>

Given the abysmal position children with "other ethnicity" now occupy, DDS should develop improvement goals in its disparity measures for them and monitor their equity status more closely.



<sup>22</sup> See DDS' presentation "How Data Supports Equity Efforts to be More Transparent, Responsive, and Client-Centered" (July 2021), available for review here: ARCA Web Academies | Cal Collab (cal-collab.net)

# Disparities are worsening for children of "other ethnicity" ages 0 through 2 compared to White children of the same age

Although there are some disparities found among children ages 0 through 2, overall, disparities are less significant than those found in children ages 3 through 21. One notable exception that warrants special attention is the growing inequity found with very young children of "other ethnicity." In FY 2020-2021, children ages 0 through 2 received funding at 81% of what their White counterparts received. This rate is down from 85% in FY 2018-2019, and significantly down from 90% in FY 2015-2016.

As discussed below, given the emerging trends in the population growth of children in the regional center system, DDS should be actively monitoring and vigorously seeking to narrow the disparity gaps between White children and children of "other ethnicity" for both age groups. DDS should consider adding measures with improvement target goals for children of "other ethnicity" for both ages 3 through 21 and ages 0 through 2.

#### **Summary**

Disparities in POS expenditures are still evident for most children and worsening for many. Despite the state's significant investment of \$66 million so far to address disparities through DDS' disparity reduction program, regional centers have been largely unsuccessful in reaching targets and reducing inequities among children for most of the communities they serve.



<sup>23</sup> Black/African American children ages 0 through 2 are also experiencing disparities relative to their White peers. In FY 2020-2021, Black/African American children received 89% of what White children received, which is up from 85% in FY 2015-2016, but down from 92% in FY 2017-2018. This is another group that DDS should be targeting.

# FINDING 3: Service access is worsening generally for children and the state's efforts in reducing inequities is further complicated by demographic anomalies

# The rapid population growth of children of "other ethnicity" presents a new cause for concern given this group's worsening plight with disparities

From FY 2015-2016 to FY 2020-2021, the general population of children in the developmental services system statewide increased by 28% among ages 0 through 2 and by 22% among ages 3 through 21. However, the "other ethnicity" population has increased statewide by over 66% for children ages 0 through 2 and by over 52% for children ages 3 through 21.

The US Census Bureau's July 2021 statistics estimates that just 4% of the statewide population for children ages 0 through 17 have two or more races.<sup>24</sup> Yet, in FY 2020-2021, children identified as "other" made up 29% of the statewide population of children in the developmental services system ages 0 through 2 and 14% of children ages 3 through 21.

Children of "other ethnicity" have now overtaken White children as the second largest percentage of children ages 0 through 2 in the state, after Hispanic (41%). Children of "other ethnicity" now constitute the third largest percentage of consumers ages 3 through 21 statewide, after Hispanic (46%) and White (22%). Currently, nine regional centers have population rates of children ages 3 through 21 identified as "other ethnicity" that exceed the statewide average of 14% for this group.

At IRC in FY 2020-2021, children with "other ethnicity" made up an astounding 90% of its ages 0 through 2 population (7,958 out of 8,855 children) and were over 23% of its ages 3 through 21 population (4,665 out of 19,950 children). In contrast, the populations of "other ethnicity" at LRC were only 5% for children ages 0 through 2 and just 2% for children ages 3 through 21. Meanwhile, IRC's ages over 22 population for "other ethnicity" was 4% (602 out of 16,431 adults over age 22), consistent with the July 2021 census data for San Bernardino and Riverside counties, which form IRC's catchment area.<sup>25</sup>

Such high numbers of "other ethnicity" children in comparison to related census data information and even the regional centers' own adult population call into question the credibility of the regional centers' general consumer demographic information and the validity of their POS data when assessing

<sup>24</sup> U.S. Census Bureau QuickFacts: California

<sup>25</sup> The percent of two or more races in the general population for both San Bernardino and Riverside counties according to the July 2021 US Census Data was 3.6%. See: <u>U.S. Census Bureau QuickFacts: San Bernardino County, California; U.S. Census Bureau QuickFacts: Riverside County, California</u>

comparisons by race/ethnicity. For FY 2020-2021 at IRC, there were 543 Hispanic children ages 0 through 2, but 836 Spanish-speaking children of the same age.<sup>26</sup> This suggests that some children may have been misclassified into "other ethnicity" when they should have been classified instead as Hispanic.

The legislature should require DDS to review each regional center's demographic classification system to determine why IRC and many others have such large numbers of "other ethnicity" children, and require DDS to work with the regional centers to correct any over-

Percent of Inland Regional Center's General Population that Consists of "Other Ethnicity" in FY 2020-2021

- Ages 0 through 2: 90%
- Ages 3 through 21: 23%
- Ages 22 & older: 4%

US Census data for region: 4%



categorizations of this race/ethnicity group accordingly.<sup>27</sup> DDS should also be required to establish uniform procedures for demographic data collection among the regional centers.

### More children ages 3 through 21 are being left unserved now than at any time since FY 2015-2016

In FY 2020-2021, 36% of children ages 3 through 21 of all race/ethnicity groups statewide did not receive any services whatsoever. This rate is up from almost 31% from FY 2015-2016 and just over 31% from FY 2019-2020, although the recent increase of children unserved could be at least in part due to the pandemic.

Although the statewide rates of eligible children who did not receive any services vary little by race/ ethnicity, there are several regional centers whose rates of children with no services have consistently exceeded the statewide averages.

<sup>26</sup> See Inland Regional Center's POS Data Report for FY 2020-2021: <a href="IRC-POS-Disparity-Data-Reports-2020-2021-2.pdf">IRC-POS-Disparity-Data-Reports-2020-2021-2.pdf</a> (inlandrc.org)

<sup>27</sup> SDRC has previously worked with DDS to re-classify its consumers away from the "other ethnicity" category. In its FY 2016-2016 disparity report to DDS, SDRC states: "An artifact of the categorization process of racial or ethnic identification of SDRC's clients has resulted in a disproportionate number of clients (33%) who were identified as "other ethnicity or race". This larger number of clients in this category prompts questions about the validity of the ethnicity and racial assignment of the clients." See SDRC's June 13, 2017 letter to DDS reporting on its FY 2015-2016 data: fff0ca\_d25cf8b28b864788ae114537ef6e69d0.pdf (sdrc.org)

In FY 2020-2021, six regional centers had rates of unserved children exceeding 40% of their total eligible populations: RCEB (52%), CVRC (48%), KRC (46%), SDRC (45%), RCOC (43%), and FNRC (42%). For FY 2020-2021, the rate of deprivation among the regional centers for all consumers ages 3 through 21 ranged from almost 23% (SCLARC) to nearly 52% (RCEB). Only one regional center (SCLARC) has maintained a lower deprivation rate across all six years, including during the pandemic, compared to its deprivation rate status in FY 2015-2016.

Some regional centers also have troubling racial disparity rates for their unserved children. For instance, at RCOC in FY 2020-2021, 50% of Hispanic children were not served compared to 36% of White children.<sup>28</sup>

In its background material for its disparity measures, DDS has attempted to justify differences seen in per capita expenditures between Hispanic and White children under the following premise: Comparison of Children Ages 3 through 21 at Regional Center of Orange County with No Services in FY 2020-2021.

• White: 36%

Hispanic: 50%

Statewide Average: 36%



"A larger share of Hispanic consumers are age 3 through 21 years than is true for White consumers, for example; those younger consumers *likely* receive many services through the school system rather than through POS, reducing average POS for Hispanic consumers as a group." (emphasis added).<sup>29</sup>

The regional centers have attempted to similarly explain disparities between White consumers and consumers from communities of color.<sup>30</sup> However, suggesting that disconcerting data reflecting large

<sup>28</sup> Since 2015-2016, Regional Center of Orange County has consistently reflected stark disproportionalities in receiving no services between Hispanic children and White children. Currently, the ratio between unserved Hispanic and White children at Regional Center of Orange County is 14 percentage points greater for Hispanic children, which remarkably, is still down from a 21 percentage point difference in 2019-2020, when 47% of Hispanic children went unserved versus 26% of White children at that regional center.

<sup>29</sup> See page 1 of DDS' Background and Process for Developing Disparity Measures here: <a href="https://www.dds.ca.gov/wp-content/uploads/2019/03/Disparities\_BgProcessDevelopingDisparityMeasures\_20190329.pdf">https://www.dds.ca.gov/wp-content/uploads/2019/03/Disparities\_BgProcessDevelopingDisparityMeasures\_20190329.pdf</a>

<sup>30</sup> During a legislative hearing before the Senate Human Services Committee on March 14, 2017, the executive director of the Association of Regional Center Agencies (ARCA) testified that some of the disparities seen in regional center services may be attributable to consumers having their needs met elsewhere by these other agencies. This testimony occurred at approximately 25:30–30:00 minutes into the hearing, which can be viewed or heard on the California State

percentages of children of color without any services or lower per capita expenditures is due to their service needs being met elsewhere is speculative and insufficient without any evidence to substantiate those unfounded assertions.

## The rate to which children ages 3 through 21 are able to access services is lower now than at any time since FY 2015-2016

In FY 2020-2021, children statewide were only able to utilize 60% of the services authorized by regional centers, down from 67% in FY 2015-2016 and 63% from FY 2019-2020. Utilization rates for all children ages 3 through 21 have steadily decreased over time since FY 2015-2016, indicating that services authorized by regional centers are no more easily attainable now than six years ago before the disparity reduction program began. Only one regional center (VMRC) has maintained a higher utilization rate across all six years, including during the pandemic, compared to its utilization rate status in FY 2015-2016.

# Children ages 0 through 2 are being left unserved more now than at any time since FY 2015-2016 and the rate to which they can access services is lower than at any time since 2015-2016

The overall population for children ages 0 through 2 served by the regional centers is down 4% from its FY 2018-2019 level. DDS is proposing additional support for these children in the current 2022 budget by having lower caseload ratios, establishing procedures intended to make transitioning out of the Early Start program run smoother, and lowering the eligibility criteria to increase overall participation.

For children ages 0 through 2, the rate of unserved children more than doubled in the past year to over 6% in FY 2020-2021, up from 3% in FY 2019-2020 and up from 4% in FY 2015-2016.

Additionally, utilization rates for children ages 0 through 2 have also fallen each year, now at 58% in FY 2020-2021 compared to 62% in FY 2015-2016.

To help meaningfully incentivize Early Start participation, the state should also consider restoring the regional centers' ability to purchase nonrequired services, which were cut during the budget crisis in 2009. Such services then included: child care, diapers, dentistry, interpreters, translators, genetic counseling, music therapy, and respite services not related to the developmental delay.

Senate's website at: <a href="http://senate.ca.gov/media-archive">http://senate.ca.gov/media-archive</a>.

#### **Summary**

Erroneous demographic classifications have had the effect of masking discrete disparities that have grown detrimentally for Hispanic, Asian, Spanish-speaking, and "other ethnicity" children over the past six years. Additionally, large rates of unserved children create hidden disparities and especially impact communities of color because "per capita" expenditure inequities reflected in the data reported by regional centers are muted and do not tell the whole story. Meanwhile, despite the considerable money invested to help promote service access, utilization rates have been consistently lowering among all children each year. These findings suggest that DDS' service access and equity efforts are failing for many children served by the regional center system.

#### They don't understand the impact that all of this has had on us.

The Self-Determination Program pilot started, but CVRC made it hard to apply. A lot of misinformation, runaround, barriers, and bureaucracy. Still, I wanted to transition. I applied directly with DDS and I got in. When COVID hit, everything was put on hold. People started getting sick. His therapy center was still doing in-person sessions, but I was worried. Our safety was non-negotiable. We are now on a waiting list to return to the center.

After my budget plan was approved, my spending plan got audited. Everything paused again. My son's emergency response system was supposed to arrive in February and I still haven't received it. He elopes.

I've sent so many emails. I should be focusing on this year for my son but instead I'm having to deal with last year. I'm traumatized. I'm trying to get my sleep back. I've gotten so ill. They don't understand the impact that all of this has had on us.

— Hispanic parent at Central Valley Regional Center

#### FINDING 4: Regional center data reporting is not fully compliant

DDS and the regional centers are required to annually compile and post their POS data in a uniform manner and maintain all of their previous years' POS data on their respective websites.<sup>31</sup> Unfortunately, VMRC's FY 2020-2021 report reverts to reporting data for its Filipino population separate from its Asian population. This old reporting classification model has not been used by any regional center since FY 2015-2016. Thus, anyone seeking to evaluate the FY 2020-2021 data for VMRC must take the additional step of combining the data for its Filipino and Asian populations to compare its data with other regional centers' reports and its own data from prior fiscal years. VMRC should make this correction and resubmit its FY 2020-2021 data report online to ensure accuracy and uniformity with the other regional centers' reports.<sup>32</sup>

#### **Summary**

Statutory data reporting requirements are still not fully being met by all regional centers. Inaccurate and inaccessible data obscure evidence of funding disparities.



<sup>31</sup> California Welfare and Institutions Code § 4519.5

<sup>32</sup> Additionally, with the exception of its report for FY 2020-2021, VMRC's prior reports contain erroneous classifications for its "For ages 22 years and older" and "For All Ages" categories in its sub-reports for race/ethnicity and language. The columns for the per capita expenditures and per capita authorizations data appear to have been reversed, with the per capita expenditures amounts being greater than the per capita authorizations amounts, thus producing utilization rates exceeding 100% for the over 22 years old and for the "all ages" groups. VMRC should make these corrections and resubmit its prior years' reports online to ensure accuracy and uniformity with the other regional centers' reports.

FINDING 5: DDS' flawed methodology for allocating funds to the regional centers requires revision to enable underserved and unserved groups to achieve greater equity

DDS' current budgeting formula allocates funding to regional centers not according to their consumers' needs but on what the regional centers have previously spent. Under prior leadership, DDS acknowledged that such a formula is flawed and DDS previously initiated a process, since abandoned, to reform the methodology that would be more equitable, based on client characteristics.<sup>33</sup>

To better inform decision-makers reviewing the findings of this report, we attempted to obtain through a California Public Records Act request documents associated with the initial development and ultimate disbandment of DDS' client characteristics-based allocation model that it had once considered. Our intent was to provide a summary of those documents for inclusion into this report for the legislature's consideration. However, DDS has claimed these documents exempt from public disclosure, citing "preliminary drafts and deliberative process privilege." Should the legislature wish to investigate the client characteristics-based allocation model formerly contemplated by DDS, including how much taxpayer dollars were spent towards its development only for it to be discarded, the legislature may want to do so soon. DDS has informed us that it has a document retention policy for only a limited number of years before such documents may be purged.

The legislature should impanel a task force to explore developing and implementing an alternative allocation methodology to the regional centers. The process for creating a new allocation methodology should be transparent and provide opportunities for consumer and public input.<sup>35</sup>

One model to consider is to create a targeted funding plan that provides specified earmarked funding for underserved and unserved race/ethnicity and language groups at each regional center.

<sup>33</sup> At the Senate Select Committee on Autism and Related Disorders hearing on April 30, 2012, former DDS Director Terri Delgadillo testified that regional centers' POS budgets are based on what the regional centers spent the prior year, and that 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 allocation methodology that "would be blind to ethnicity" and serve as a "starting point" in addressing POS disparities. The transcript and ability to view this hearing is available on the California Senate Select Committee on Autism and Related Disorders' website at: <a href="http://autism.senate.ca.gov/informationalhearings">http://autism.senate.ca.gov/informationalhearings</a>; also available here: <a href="Media Archive">Media Archive</a> | California State Senate.

<sup>34</sup> Final Response to Public Records Act Request Dated February 8, 2022, dated April 11, 2022 from DDS' Office of Legal Affairs (on file with authors).

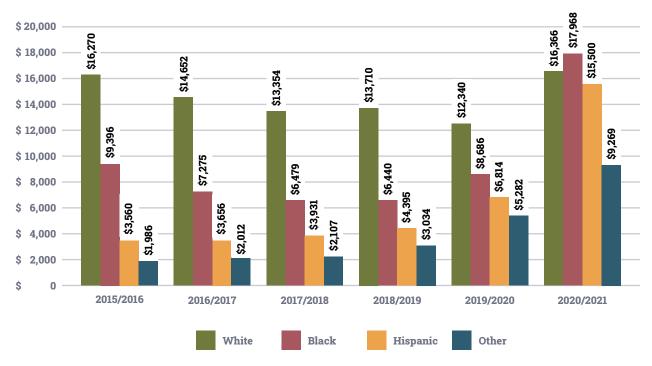
<sup>35</sup> Similar recommendations were made nine years ago. See "A Preliminary Report by the Taskforce on Equity and Diversity for Regional Center Autism Services" (2013), pages 25-26 available for review here: <a href="1542-S Autism & related Disorders for the web.pdf">1542-S Autism & related Disorders for the web.pdf</a> (ca.gov)

In developing such a model, the spending trends of SCLARC for FY 2020-2021 may serve as a potential example to replicate.

As stated above, SCLARC is single-handedly responsible for causing a five percentage point increase in disparity reduction improvement to the statewide aggregate data for Hispanic children and an eight percentage point increase in disparity reduction improvement to the statewide aggregate data for Spanish-speaking children in FY 2020-2021.

SCLARC achieved this by more than doubling its total expenditures in the past year for its children ages 3 through 21, from \$64,641,991 to \$136,771,935. This huge influx of money mostly went to its Hispanic and Black/African-American populations. This substantial infusion of money led to all main race/ethnicity groups, with the exception of children of "other ethnicity", either surpassing or nearly equaling their funding comparison ratios to Whites.<sup>36</sup> (Figure 9).

FIGURE 9
Distribution of POS Expenditures at SCLARC by Race/Ethnicity
Children Ages 3 through 21 (All Residence Types)



\*Asian children at SCLARC received more than White chidren in FY 2015-2016 and FY 2020-2021, but are less than 1% of the general population and thus not included here

<sup>36</sup> Funding for Spanish-speaking children also surpassed that for English-speaking children at SCLARC in FY 2020-2021 as a result of this enhanced spending.

Assessments should first be done to identify the underserved and unserved groups for each regional center, then a targeted spending plan should be implemented for those groups to effectuate equitable outcomes much like what occurred at SCLARC in the past year. Regional centers could apply reduced caseload ratios, utilize navigator programs, and work with community-based organizations through disparity reduction projects to help ensure that targeted funds to these underserved and unserved groups are spent on regional center services as allocated. The state may wish to consider this proposal in addition to the disparity reduction projects that it has been funding now for six years with varying success.

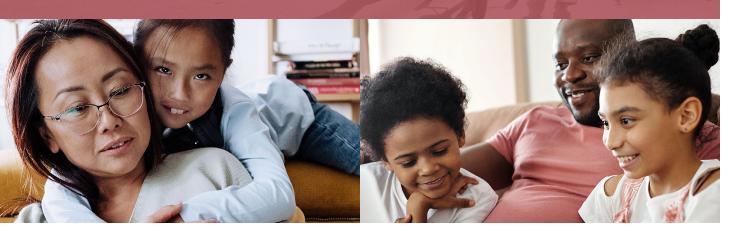
#### **Summary**

As previously acknowledged by DDS, its allocation methodology to the regional centers is partially responsible for the continuing inequities in POS disparities. DDS' historical expenditures-based formula should be replaced with a model designed to help reduce disparities perpetuating among the regional centers.

#### My coordinator said: "don't worry – I can always reinstate you."

I received a notice saying they were are cutting my self-assigned respite. I responded, but services still stopped. I was calling because I needed to know what to do. No one was responding because no one was in the office. My coordinator said: "don't worry – I can always reinstate you." I just got a letter from ACRC this week stating my respite was reactivated, but it is dated December 2020! I try to stay above the fray. I definitely got lost in the system, but I don't feel it was because of race. Sometimes, it just seems easier to walk away from a benefit to avoid feeling like this.

— African-American parent at Alta California Regional Center



### Recommendations

A joint legislative oversight hearing should be convened to thoroughly examine the current status of regional center funding disparities

There have been just two legislative hearings dedicated exclusively to examining funding inequities in the developmental services system: one before the Senate Select Committee on Autism and Related Disorders on April 30, 2012, and one before the Senate Human Services Committee on March 14, 2017. Neither hearing consisted of a fully impaneled set of legislators from both the Senate and Assembly. Given that \$66 million has thus far been invested in disparity reduction efforts with few gains made, the legislature should jointly and comprehensively revisit the issue now to assess what more can be done to address this problem.

The legislature should assemble a task force to explore developing and implementing an alternative allocation methodology to the regional centers

Funding projections for allocations by DDS to the regional centers are based on actual expenditures already made and include consideration of caseload growths and utilization in services.<sup>37</sup> Given the problematic issues described above relating to inequitable expenditure trends among race/ethnicity and language, concerns arising from demographic shifts in the population, and stagnant rates in general service access over the past six years, it is long overdue for the state to consider implementing an alternative allocation model that does not serve to perpetuate and exacerbate existing disparities. One potential model could be a targeted spending plan that effectuates more equitable results similar to those recently achieved by SCLARC during the 2020-2021 fiscal year. A legislative taskforce should be assembled to thoroughly review DDS' funding formula and report back to the legislature on the matter.

<sup>37</sup> Testimony of former DDS Director Terri Delgadillo before the Senate Select Committee on Autism and Related Services, April 30, 2012, available for review here: <a href="http://autism.senate.ca.gov/informationalhearings">http://autism.senate.ca.gov/informationalhearings</a>; also available here: <a href="Media">Media</a> Archive | California State Senate.

The legislature should require DDS to conduct an assessment of regional centers' demographic information collection systems, fix any over-categorizations, and establish and apply a uniform information-gathering system that regional centers must follow

As noted above, there is an uncharacteristic abundance of children designated as "other ethnicity" in the developmental services system relative to comparable census data in the general population. Children of "other ethnicity" receive the lowest amounts of POS expenditures in both relevant age race/ethnicity groups and have the highest rates of being unserved among communities of color. Meanwhile, their population continues to grow in both age categories at an alarming rate while nearly all other race/ethnicity groups see their populations shrinking. The legislature should require DDS to investigate and remedy defects in the regional centers' collection of demographic information and ensure that a uniform system for gathering demographic information is established and implemented statewide going forward.<sup>38</sup>

The legislature should restore the availability of regional center funded nonrequired services to Early Start participants

To help meaningfully incentivize Early Start participation, the state should restore the regional centers' ability to purchase nonrequired services, which were cut during the budget crisis in 2009. Such services then included: child care, diapers, dentistry, interpreters, translators, genetic counseling, music therapy, and respite services not related to the developmental delay. For sixteen years, from 1993 to 2009, these family support services were available to provide critical support to Early Start children and their families.<sup>39</sup> However, these services were cut because they were not federally mandated and the state perceived a savings then from their elimination.

<sup>38</sup> California Welfare and Institutions Code § 4750.5 states: "In order to gather data that is relevant to ensuring the safety and well-being of persons with developmental disabilities, the department shall ensure that the client master fie entry for any person with developmental disabilities placed by a regional center will be updated within 30 days after the change in residence." This statute should be amended to provide that client master file data gathering by regional centers on race/ethnicity and primary language spoken is reviewed by DDS for accuracy and consistency in furtherance of ensuring greater equity among all populations served by the regional centers.

<sup>39</sup> SB 1085 (1993) enacting California Government Code § 95020; 17 California Code of Regulations § 52000(b)(13).



If the premise behind DDS' recent budget initiatives of providing enhanced case management and enhanced case transfer procedures is to address Early Start families' expressed challenges with understanding and navigating the multiple service delivery systems, then the additional reinstatement of these critical family support services too would go a long way in furthering that cause.

The legislature should repeal the requirement of families to pursue certain generic agency services through appeals

During the budget crisis in 2009, the state imposed rules requiring consumers and their families to first pursue other agencies for medical and dental services and to appeal denials if the regional center deems an appeal has merit.<sup>40</sup> Families since have been required to pursue complex appeal processes if denied by a generic agency before the regional center will pay for these services. These rules have burdened low-income and non-English-speaking families who are often less able to navigate appeals. A recent report has exposed how the regional center fair hearing system itself disadvantages communities of color.<sup>41</sup> Families should not be forced into intimidating adversarial situations as part of a standard process for accessing services. They are caregivers, not appeals specialists.

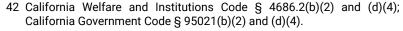
<sup>40</sup> ABX4-9 (2009) codified this restriction by adding California Welfare and Institutions Code § 4659(d)(1).

<sup>41</sup> See "Unfair Hearings: How People with Intellectual and Developmental Disabilities Lack Access to Justice in California" (2021), Disability Voices United, et al., available for review here: Unfair Hearing Report (disabilityvoicesunited.org)

# The legislature should repeal parent participation requirements that serve as barriers to accessing behavioral health treatment services

The 2009 service restrictions imposed parent participation requirements for children to access intensive behavioral intervention services. 42 Regional centers have interpreted this law to require parents or caregivers to first participate in group training classes before their children may receive behavioral health treatment. Families of color face numerous barriers to participation in group classes, including language barriers, inflexible work schedules, and lack of transportation. In its written testimony to the Senate Select Committee on Autism and Related Disorders in April 2012, the Association of Regional Center Agencies acknowledged that that the 2009 legislative mandates related to parent training and participation "may be insurmountable barriers for many."43

Behavioral health treatment (BHT) services are now a covered Medi-Cal benefit.<sup>44</sup> Although BHT services are now largely administered through county Medi-Cal managed care plans, regional centers still maintain responsibility for delivering BHT services for fee-for-service (FFS) Medi-Cal children and obtain reimbursement through Medi-Cal after providing these services.<sup>45</sup> Children who continue to be served with BHT services from regional centers primarily consist of current and former dependents of the child welfare system or children whose conditions are so severe that they have been granted a medical exemption from managed care. The Department of Health Care Services (DHCS) has clarified that a child enrolled in FFS Medi-Cal cannot be denied BHT services for lack of parent participation.<sup>46</sup>



<sup>43</sup> The Association of Regional Center Agencies' written testimony for the April 30, 2012 Senate Select Committee's hearing can be found here: <a href="http://autism.senate.ca.gov/sites/autism.senate.ca.gov/files/Association%20of%20Regional%20Center%20Agencies.pdf">http://autism.senate.ca.gov/sites/autism.senate.ca.gov/files/Association%20of%20Regional%20Center%20Agencies.pdf</a>.



<sup>44</sup> California Welfare and Institutions Code § 14132.56

<sup>45</sup> See Department of Health Care Services' Behavioral Health Treatment Frequently Asked Questions for Fee-For-Services Beneficiaries (December 2018), available for review here: bht faq (ca.gov)

<sup>46</sup> See Id., page 2 here: bht faq (ca.gov)

Given DHCS' clarification, regional centers must not be permitted to deny or delay the benefits of behavioral services due to lack of parent or caregiver participation.<sup>47</sup> Yet, regional centers continue to impose parent participation requirements and make group classes a mandatory prerequisite to receive BHT services for FFS Medi-Cal recipients.<sup>48</sup> Accordingly, the legislature should repeal the parent participation requirements in the Lanterman Act that now conflict with Medicaid law.

The legislature should amend the law to allow the public access to the data that DDS is using to track progress through its disparity measures

In developing its POS expenditure measures, DDS has chosen criteria based on data to which only it has access. The data reported by regional centers does not provide the data on expenditures for consumers by race/ethnicity and language living in the family home who received some POS and who went unserved, which is the data that DDS is using for its measures. DDS is also measuring improvement in equity according to certain services received by race/ethnicity, which are also not available to the public. California Welfare and Institutions Code § 4519.5 should also be amended to require regional centers to report data on these services by race/ethnicity and language so that the public may follow along with DDS' disparity monitoring process.

The legislature should enact law requiring DDS to enforce the regional centers' compliance with data reporting and other public disclosures mandates

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. In turn, DDS should be required to 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.

<sup>47</sup> The California Health Benefits Review Program (CHBRP), in analyzing SB 1034 (2016), concluded that behavioral health treatment improves outcomes regardless of the extent of parent involvement. CHBRP's analysis of SB 1034 can be found here: http://chbrp.ucop.edu/index.php?action=read&bill\_id=207&doc\_type=3.

<sup>48</sup> For example, see North Los Angeles County Regional Center's Flow Chart for Behavioral Services: 637206325953100000 (nlacrc.org); many other regional centers' online policies for behavioral services are woefully outdated and therefore do not even account for DHCS' December 2018 clarification on this issue.

For instance, all regional centers should now have a link on their websites to the list and description of services that DDS developed. Regional centers are also required to post online their respite assessment tools and any policies, guidelines, or regional center-developed assessment tools used to determine the transportation, personal assistant, or independent or supported living service needs of a consumer 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 boards' committee meetings contemporaneously posted online. These meetings' minutes often have disparity issues and other relevant service access information, and online access may be the only means for some families unable to attend board meetings to review this important information.



The legislature should enact law requiring regional centers to assess and report on cases where consumers have no POS

DDS and the regional centers have a duty to account for the needs of all their consumers.<sup>49</sup> Regional centers are contractually obligated to measure progress in reducing disparities and improving equity in purchase of service expenditures.<sup>50</sup> The legislature should enact law requiring the regional centers to assess all of their cases with no POS to determine the cause for the lack of POS receipt and report their findings to the legislature and the public through the regional centers' and DDS' website. These assessment reports should be done quarterly to measure progress towards alleviating cases where lack of POS receipt was avoidable and to better identify barriers attributable to lack of resources.

<sup>49</sup> California Welfare and Institutions Code § 4501.

<sup>50</sup> California Welfare and Institutions Code § 4629(c)(1)(A)(iv).

### **Conclusion & Next Steps**

DDS has stated it anticipates the regional centers, working within existing resources, will substantially reduce disparities.<sup>51</sup> Our findings indicate that the opposite has happened, as many disparities and other service access issues have only gotten worse over time.

Having spent \$66 million in the past six years on disparity reduction programs with very little to show regarding improvement, it is past due for the state to adopt more fundamental changes to address funding inequities that only seem to be increasing as the developmental services population continues to diversify. The state now faces the additional challenge of addressing disparities for the burgeoning population of children of "other ethnicity" who currently suffer from these inequities in relative anonymity. We strongly urge the state's legislative and executive administration leadership to pursue the recommendations provided in this report.

#### We are treated as foreigners, like we are trying to abuse the system.

There are preconceived expectations and stereotypes with Asians. There is now more cultural awareness for other groups, but still cultural misappropriation with us. We are treated as foreigners, like we are trying to abuse the system.

There is a perception of Asians that makes others think: "you look like you are financially well off enough, why don't you just do it yourself?" I know some Asians that don't want to deal with this scrutiny and bias. Dealing with disabilities themselves is already traumatic enough.

— Asian parent at Inland Regional Center

<sup>51</sup> See page 2 of DDS' Background and Process for Developing Disparity Measures here: <a href="https://www.dds.ca.gov/wp-content/uploads/2019/03/Disparities\_BqProcessDevelopingDisparityMeasures\_20190329.pdf">https://www.dds.ca.gov/wp-content/uploads/2019/03/Disparities\_BqProcessDevelopingDisparityMeasures\_20190329.pdf</a>.

# Glossary of Acronyms

DDS	Department of Developmental Services
DHCS	Department of Health Care Services
ARCA	Association of Regional Center Agencies
POS	Purchase of Services
IPP	Individual Program Plan
ACRC	Alta California Regional Center
CVRC	Central Valley Regional Center
ELARC	Eastern Los Angeles Regional Center
FNRC	Far Northern Regional Center
GGRC	Golden Gate Regional Center
HRC	Harbor Regional Center
IRC	Inland Regional Center
KRC	Kern Regional Center
LRC	Frank D. Lanterman Regional Center
NBRC	North Bay Regional Center
NLACRC	North Los Angeles County Regional Center
RCEB	Regional Center of the East Bay
RCOC	Regional Center of Orange County
RCRC	Redwood Coast Regional Center
SARC	San Andreas Regional Center
SDRC	San Diego Regional Center
SCLARC	South Central Los Angeles Regional Center
SGPRC	San Gabriel Pomona Regional Center
TCRC	Tri-Counties Regional Center
VMRC	Valley Mountain Regional Center
WRC	Westside Regional Center